‘STILL WAITING’

A Rights Based Review of Mental Health Services and Support for Children and Young People in Northern Ireland

September 2018

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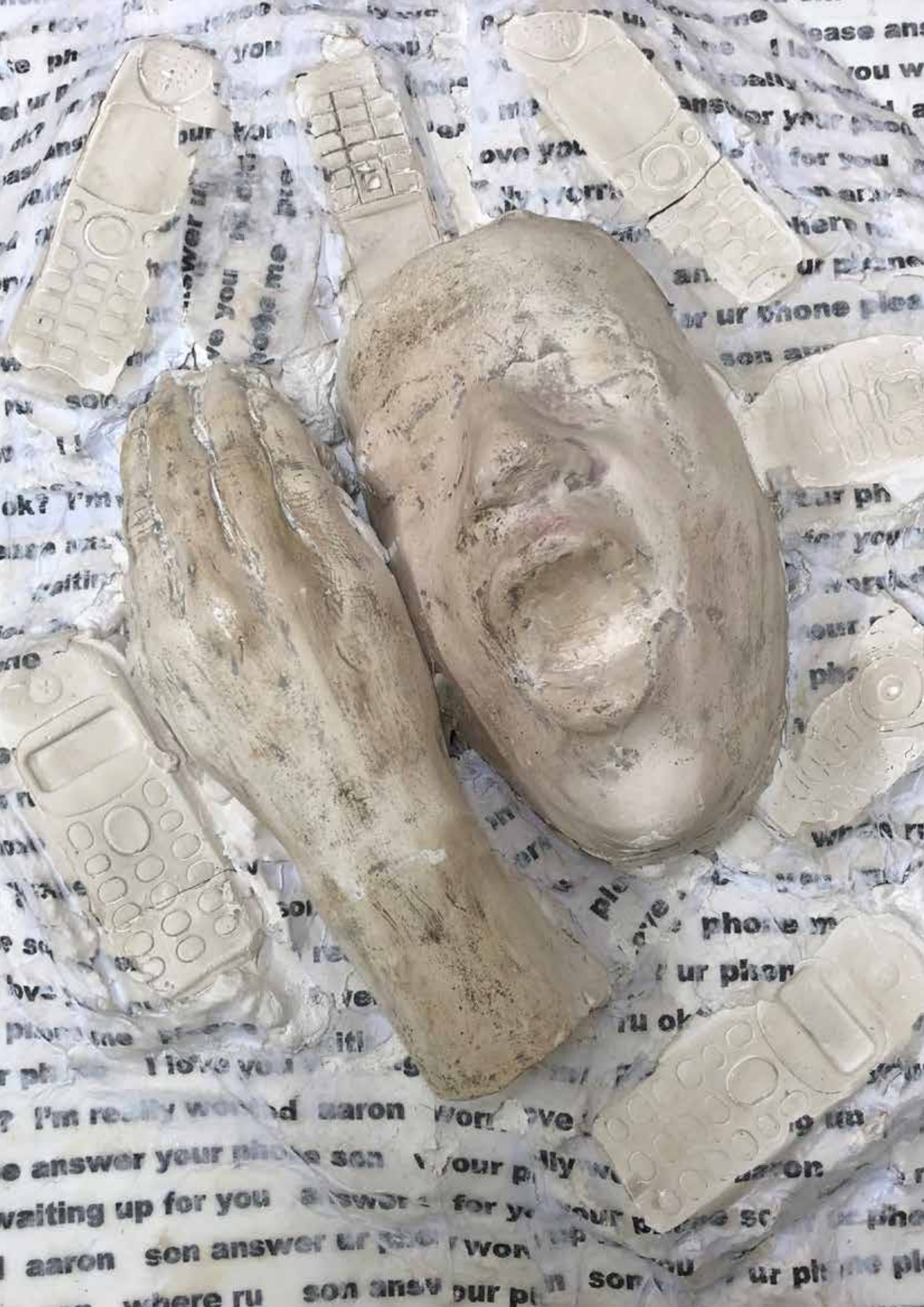
PROMOTING THE RIGHTS OF CHILDREN & YOUNG PEOPLE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Acknowledgments

We would like to thank the following people, without their support this report would not have been possible.

The Mental Health Professional Advisory Group and the Young Person Mental Health Advisory Group, both of which provided important input at key points as the Review was being undertaken.

All of the young people who gave up their time to share their experiences through the online survey or interviews.

Staff from the HSCB, PHA, HSCTs, RQIA and EA for providing information to support the data collection and budgeting information referred to in the report.

The wide range of professionals and practitioners working in mental health services or supporting young people to access services that provided a valuable and complementary perspective to what we were hearing from young people.

Artwork

We thank the children and young people from the Upper Springfield Youth Team in West Belfast who kindly allowed us to use their artwork as part of this report. It was created with support from local youth Worker David McComb and artist Fra Maher, as part of a project in which they explored the issues impacting on local young people's mental health (Front cover, contents, back inside cover and sections 2, 3, 4, 5, 7, 8, 9 artwork).

We thank Aaron Fox's parents, Paul and Sarah, who kindly allowed us to use Aaron's artwork as part of this report. Aaron created this as part of his GCSE Art and Design in 2016 (Front inside cover artwork).

We thank the children and young people from the Extern Pathways Project in Nelson Street Site who created this artwork, with support from local artist Claire McComish, in which they explored themes around identity and belonging within their community and concepts which were important in their lives (Background section artwork).

We thank the young people from Bloomfield Youth Safety Partnership in east Belfast who created their art with support from Bloomfield Community Association, East Belfast Alternatives, Artist Clinton Kirkpatrick, Connswater Community Greenway, Belfast City Council Parks & Leisure, The Youth Safety Network and Big Lottery Fund NI. The project's aim was to raise awareness and reduce the stigma of mental health for young people and to signpost those affected by mental health issues to direct services that are available in the community (Back cover and section 6 artwork).

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Foreword

I became Northern Ireland Commissioner for Children and Young People in March 2015, and at that time I announced priorities that my office would focus on during my term in office. One of those priorities was the emotional well-being and mental health of children and young people. At that time I under-estimated how important an issue it would be, I do not under-estimate it any longer.

The United Nations Convention on the Rights of the Child (UNCRC) is the framework that guides the delivery of law, policy and services for all children and young people. The Convention is not an aspirational set of ideas, but a set of basic minimum standards which should be upheld for the promotion, protection and realisation of the rights of all our children. This Review is underpinned by the UNCRC and based on the experiences of children and young people, services and the system. We hope we have demonstrated how child and adolescent mental health services (CAMHS) can be 'rights compliant'.

In 2016, the Committee on the Rights of the Child published General comment No. 20, on the implementation of the Rights of the Child during Adolescence:

> *"States should adopt an approach based on public health and psychosocial support rather than over medicalization and institutionalization. A comprehensive multi-sectoral response is needed, through integrated systems of adolescent mental health care that involve parents, peers, the wider family and schools and the provision of support and assistance through trained staff"* (UN 2016, Para 58).

A children's rights compliant mental health system, is one which is responsive to children and young people as their needs arise. It is integrated and takes a whole-system, end-to-end approach, extending from prevention through to inpatient services.

A lot of work has already been done in reviewing and reforming the child and adolescent mental health system in Northern Ireland, which I commend. However, the pace of reform has been glacial, which is only partly due to insufficient resources. My office spent a considerable amount of time in the course of this Review talking to young people, their parents/carers, and professionals from across all sectors. It became apparent some issues still require further scrutiny, namely understanding children and young people's access to services, particularly within statutory CAMHS. We heard from parents and practitioners that young people with learning disabilities, and those with drug and/or alcohol problems, were not receiving the services they required.

As Commissioner for Children and Young people, I have a range of duties and powers in relation to statutory authorities, and for this reason we concentrated on the statutory system's services. However, it is clear from the findings of the Review that this system cannot function without the vital input of the voluntary and community sectors. Children and young people were very clear that the services provided by voluntary and community sector organisations, were just as essential in

meeting their mental health needs as those provided by the statutory system. Reform and developments cannot focus on one aspect of the system alone.

On reading this report you will quickly discover why *"Still Waiting"* can be its only title. Young people wait to seek help, and they wait to access the help they need. Despite the plethora of reports recommending reform, Northern Ireland still waits to see the necessary legislative, policy and system changes being fully implemented.

My intention is that the recommendations we have made will be helpful to a system that is still in development. It will be clear as you read *"Still Waiting"* that an enormous amount of work has gone into it, however that is only part of the process. We now have a greater understanding of children's experiences of services, of the data collected and held by the system, and some of the resources expended. We have assessed this information against the UNCRC and other human rights standards, and have found the system wanting in particular areas, and have made recommendations to address these.

"Still Waiting" shines a light on the positive changes that have been made to date, as well as changes urgently needed. NICCY's work in the coming period will be to ensure that the entire children's mental health system responds to my calls, and makes the changes necessary.

We were determined that this work would be undertaken by the NICCY team, so that we could engage with the system and with children and young people directly throughout the process. This decision was the right one and we have learnt a lot from this approach.

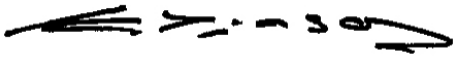
We are deeply grateful to two Advisory Groups – firstly the professional group who were incredibly generous with their time, knowledge and expertise. Their support was invaluable. Secondly, the NICCY Youth Panel who advised throughout the process and were amazing when it came to the survey development, the publicity materials and of course the final reports.

This Review contains a significant amount of data and financial information, and we thank our colleagues in the relevant statutory authorities for their assistance.

The partnership with Mencap, Start 360 and Dunlewey Addiction Services ensured that the young people with whom NICCY engaged in the course of the Review, were prepared and supported to share their experiences through interviews.

The NICCY team have been remarkable and very resourceful. They have not only risen to, but exceeded the challenge. I am in awe of their professionalism and commitment to this work.

To the hundreds of young people who participated in this Review, by sharing your experiences, completing the survey or participating in interviews, I am honoured that you trusted us with your stories and experiences. We are mindful this is a privilege and we will not let you down. My office will work to ensure that the next generation of young people will not have to wait for their rights to be met, in the way some of you did. Therefore it is with enormous pride and determination that I present *"Still Waiting"*.



Koulla Yiasouma
Northern Ireland Commissioner for Children and Young People
September 2018

Executive Summary and Recommendations

This Report is the culmination of a Rights Based Review of Mental Health Services and Support for Children and Young People in Northern Ireland, carried out by the Northern Ireland Commissioner for Children and Young People (NICCY), in accordance with its functions under Article 7(2) and 7(3) of The Commissioner for Children and Young People (Northern Ireland) Order 2003. The aim of the Review was to assess the adequacy of mental health services and support for children and young people, using a children's rights framework. A central focus of the Review was to enable children and young people (and their parents and carers) to share their direct experiences of accessing, or trying to access, mental health services or support; identify barriers preventing children and young people accessing adequate support; highlight good practice and make recommendations for improving services. In doing so we also wanted to increase public awareness of the rights of all children and young people to good quality mental healthcare.

The Stepped Care Service Model for Child and Adolescent Mental Health Services (CAMHS) is the preferred regional model for the organisation and delivery of mental health services and support for children and young people in Northern Ireland (DHSSPS, 2012). The Model applies a broad 'whole system' approach to services, and contains 5 Steps of support which includes: prevention, early intervention, specialist intervention services, crisis intervention and inpatient and regional specialist services. This Review examined children and young people's experiences of mental health services and support, using the Stepped Care Model as the service framework. It also examined available operational and budgeting data relating to mental health services in Northern Ireland. The Review has given a particular focus on Steps 3 – 5 of the Stepped Care Service Model for CAMHS, which includes statutory community out-patient, crisis intervention and inpatient care. **(Main report: Section 1)**

A mixed methods approach was adopted in carrying out the Review, which included gathering the views and experiences of children and young people who had accessed or tried to access mental health services and support. This involved carrying out a survey with 11-21 year olds- 604 young people started the survey, however, not all young people had experience of every service covered, for this reason the sample size varies for each service. The survey gathered experiences of seven key services across all steps of the Stepped Care Model, from GP services (n=246), through to inpatient provision (n=28). In addition, face-to-face interviews were carried out with two groups of young people at higher risk of developing mental health problems - young people with a learning disability (n=15), and young people with drug and/or alcohol problems (n=17). **(Main report: Sections 3 & 4)**

A mapping and analysis exercise of available operational and budgetary data on mental health services and support available to children and young people was carried out. NICCY also engaged with a range of professionals in the course of the Review on an ongoing basis, and carried out two practitioner focus group workshops in Derry/Londonderry and Belfast which engaged with 68 professionals. **(Main report: Sections 3 & 7)**

The Review found a system under significant pressure, finding it difficult to respond to the scale of need, and the complexity of issues children and young people are presenting. It is clear that the core budget for children and young people's mental health services has not changed significantly enough to meet its ambitions for system reform. It also found chronic under-investment, historical patterns of funding allocations which are not based on known mental health needs, and a very mixed experience from young people on the availability, accessibility and quality of services provided. **(Main report: Sections 4–6 & 8)**.

Alarming gaps were found in the collation of vital disaggregated, basic operational data required to efficiently plan, commission and deliver CAMHS. We acknowledge that during the period of this Review important steps were being taken to fill gaps in service level data through the implementation of the CAMHS Dataset, and the commissioning of the first population wide prevalence survey on children and young people's mental health which will provide essential information on the extent of mental ill health of children and young people. Comprehensive information monitoring systems must be established and maintained. **(Main report: Sections 3.7 & 7)**

The Review Team engaged with many practitioners committed to improving the mental health and well-being of children and young people. It spoke to Voluntary and Community Sector (VCS) organisations who were supporting young people with mental health needs of a much more serious nature than they should be working with, because of waiting times or other problems young people have with accessing specialist statutory services. We heard from Health and Social Care Trust (HSCT) CAMHS teams who are developing innovative practices in order to try and meet the challenge of increasing need, without an increase in the core budget. A range of stakeholders also talked about the benefits and opportunities of statutory and VCS service providers working closely together to support young people. **(Main report: Sections 9.4 & 9.6)**

We were fortunate to have such a large number of courageous and resilient young people who shared their experiences of accessing, or tying to access, support for their mental health. Overall there were very mixed views of the availability, accessibly and quality of support, but one consistent message was the hope that their experiences would help to improve the system for other young people. **(Main report: Sections 4–6)**

The Review found a lack of recognition of the Stepped Care Model for CAMHS among non-mental health professionals, as being a relevant, overarching policy in their area of work. This disconnect was particularly apparent as Accident and Emergency (A&E) does not have a clear strategic position within the Stepped Care Model, even though it is a key service which comes into contact with young people with mental health problems. The Review found delays in the implementation of the Managed Care Network (MCN), which has been designed to ensure better integration and co-ordination of acute CAMHS. It also found the inclusion of only health and social care CAMHS providers within the MCN. **(Main report: Section 9.3)**

Mental Health Pathways and Thresholds for Accessing Services. **During the professional workshops**, both VCS and statutory practitioners described children being 'referred on' from service to service within the Stepped Care Model, due to a lack of capacity within services. Within the survey and during the interviews, young people themselves talked about having to speak to multiple professionals, across a range of services before getting access to appropriate support, a situation which is contrary to one of the main aims of the Stepped Care Model, which is to 'simplify patient pathways'. The Review found young people having to wait too long to access services, and the perception that in practice, if not in policy, thresholds to access Step 3 CAMHS had increased. Single point of entry and triage systems aim to ensure that children and young people are directed to the most appropriate support as quickly as possible, however they also rely on sufficient capacity in the services or support identified. The evidence NICCY has gathered shows that services across the Mental Healthcare System are struggling to meet demand. **(Main report: Sections 4–6 & 9)**

In practice, it appears that a significant proportion of referrals to Step 3 CAMHS come from GPs, this is despite a number of other 'accepted referral agents' being included in the regional referral guidelines for Step 2 and 3

CAMHS.[1] GPs expressed a need for training in children and young people's mental health, resources to allow them access to a greater range of self-help supports to offer young people, better communication between primary care and statutory CAMHS, clarity on referral criteria and pathways, stronger links between mental health experts and GP surgeries, and more robust and efficient feedback mechanisms where statutory CAMHS referrals are not accepted. **(Main report: Section 9.4)**

During the Review a range of stakeholders including GPs, VCS representatives and children and young people, said they would like referral pathways to be opened up to allow a greater range of professionals to make referrals to statutory CAMHS, and to ensure 'accepted referral agents' knew they could do so. This was particularly the case where young people had already been engaging with a VCS organisation, school counselling service or Self Harm Intervention Programme (SHIP). **(Main report: Sections 4.7 & 9.4)**

A key part of this Review has been about gathering a detailed understanding from young people themselves, about the stages or events between the first symptoms of their mental health problems emerging, and accessing professional support. It has become apparent that for many young people this process can an unacceptably long time. It is concerning that, on average, just under half (49%) of the young people who had experience of services covered in the online survey, said they were able to access help when they needed it. Many young people are also delaying seeking help, only asking for help when they can no longer cope. This makes it vitally important that they are enabled to seek help earlier, and that when they do seek help, the pathways to access support are straightforward, responsive and effective. **(Main report: Sections 4, 4.2, 5.8, 6.4, 9.4 & 9.6)**

In terms of Step 3 CAMHS, the Review found that between 2013/14 and 2015/16 the percentage of referrals not accepted ranged between 33% and 42%. There is no regional monitoring of the reasons for referrals not being accepted, and the review has raised concerns about how adequately young people, not accepted for Step 3 CAMHS, are supported to find other more appropriate help. The 9 week waiting time target for Step 3 CAMHS is calculated from the date of acceptance of the referral to the time the patient is seen, and assessed at their first appointment. There is policy and clinical guidelines but no monitoring of the waiting times at critical points of young people's care – between first appointment and review appointments, the waiting time between the referral being made to Step 3 CAMHS, and the decision being made about whether they are accepted. Nor is there monitoring of waiting time targets relating to access to psychological therapies for children, despite the existence of statutory 13 week waiting times, which apply to children and adults. Very vulnerable young people talked about their mental health deteriorating, for some to a crisis point, as a direct result of the delay in being able to access services, and being dissuaded from seeking services in future due to a lack of timely interventions. **(Main report: Sections 4, 5.8, 6.4, 7.1 & 7.2)**

There are a range of extremely concerning findings relating to **access to crisis mental health support**. The development of Crisis Assessment and Intervention Teams (CAIT) are a very welcome addition to the support and services available to young people, who require urgent intensive community intervention, to meet their needs and prevent hospitalisation. The introduction of CAIT services may have contributed to the overall reduction in the numbers of young people admitted to adult mental health wards, reported between 2014/15 (n=21) and 2017/18 (n=6). However, the Review also found

1 Accepted referral agents include: GP, Child and Family Social Services, Paediatric Services, Child Health Services, Education Welfare Services including the Independent Counselling Service for Schools (ICSS), voluntary agencies within the Stepped Care Model and Family Support Hubs (HSCB, 2018:2).

considerable variances in the service coverage across HSCTs, which means that not all young people have access to the same level of support. Crises for a lot of young people happen outside of normal 9am-5pm working hours of services **(Main report: Sections 7.5 & 9.5)**

Accident and Emergency (A&E) is a regional medical emergency service available 24 hours a day, 7 days a week. When specialist crisis mental health services are not available or easily accessible to young people, or when medical intervention is required, young people are likely to present to A&E. A quarter (23%) of young people surveyed, and three quarters (75%) of young people interviewed with alcohol and/or drug problems, had experience of using A&E during a mental health crisis. The experiences shared by young people have highlighted significant problems with the support that is available for young people who are suicidal, and also with the aftercare support for those who have attempted suicide. 60% described the help they received in A&E as unhelpful. Young people did not think staff in A&E were adequately trained to support them or help them to access appropriate support. Over half (54%) reported feeling uncomfortable and unsafe when accessing A&E for their mental health issues, and many described a lack of follow-up support in the hours and days following presentation to A&E. Suicidal young people described leaving A&E without seeing a mental health professional, which in some cases led to an escalation in their crisis situation, due to the delay in being able to access appropriate and timely help. This Review has found no evidence of a central monitoring system to track young people who attend A&E with mental health problems as a presenting need. Nor is there any systematic regular review of A&E facilities, regarding how they respond to children with mental health needs. The pathways from A&E to other more appropriate support need to be quicker, clearer and more robust. **(Main report: Sections 4.12, 6.4 & 9.5)**

A recurrent issue raised by young people was that they would have liked more **support at different stages of accessing Step 3 services**. Young people were more positive about their experience of Step 3 CAMHS when they could access 'wrap around support', often from a VCS organisation, between clinical appointments. Young people and practitioners agreed that a collaborative approach, which included support from both statutory (clinical) and VCS organisations (practical) was effective in aiding young people's journey through the mental health system, and in achieving better mental health and well-being outcomes. It was noted however, that availability of such multi-sectoral collaborative approaches are patchy. Young people also reported that self-help support such as coping strategies or online resources, would be useful while waiting for a Step 3 CAMHS appointment. Practitioners suggested the provision of a statutory CAMHS 'on call' telephone line for young people, parents/carers and health professionals to get advice, whilst waiting for a referral or between appointments. Some young people spoke about not being able to access support while waiting for a Step 3 CAMHS appointment, including schools' counselling (ICSS). Also, young people waiting for Autism/Autism Spectrum Disorder (ASD) assessments reported not being able to access Step 3 CAMHS. **(Main report: Sections 4, 5.8, 6.4 & 9.6)**

Many young people talked about difficulties they faced with **making and attending mental health appointments**, many of which related to the symptoms of their mental health problems. In the survey, 42% of young people reported having to cancel or not being able to attend a mental health appointment. The Review also found that substantial and persistent regional rates of Did Not Attend (DNA) or Cannot Attend (CNA) for first appointment and review appointment for Step 3 CAMHS. For the 3 year reporting period provided, rates of DNA and CNA have remained at 15–16% for first appointments, and 24% for review appointments. The reasons for non-attendance are not monitored by the Health

and Social Care Board (HSCB) and there are no plans to. For the purposes of this Review, there was no data available on the number of young people being discharged from the statutory CAMHS system, due to DNA/CNA. Young people and a range of health professionals referred to a lack of follow-up on support being arranged after discharge from mental health services. Nine GPs talked about young people being discharged from Step 3 CAMHS without their knowledge, which indicates a potentially significant issue with compliance with the regional IEAP guidelines, which requires that: *"if a patient / client DNA / CNA their appointment, a review of the risk factors should be undertaken in partnership with the patient / clients General Practitioner (GP) and a second appointment offered, if required. Any decision to discharge should be fully documented and the patient / client informed in writing."* (HSCB, 2010, para 7.6; HSCB, 2018:2) **(Main report: Sections 7.3 & 9.6)**

Young people, particularly those with co-occurring mental health and drug and or alcohol problems, spoke about needing intensive support to make and attend appointments. During the Review, young people identified a range of practical changes that would help with making and attending appointments, this included online booking systems and appointment slots outside of school hours. Young people with anxiety or depression said that being able to attend appointments at home, or closer to home, may have helped them to keep their appointments. **(Main report: Sections 4.15, 6.4 & 9.6)**

Young people reflected on poor **co-ordination and communication between services**, particularly regarding relevant information about their circumstances, needs and support arrangements e.g. school, social services and statutory CAMHS. Young people talked about feeling exhausted and re-traumatised having to repeat their 'story' or circumstances, to a range of different professionals. They also talked about difficulties they faced when a course of treatment ended and no follow-on support was provided. Young people highlighted 'follow on support' as vitally important in helping them to recover. In fact young people, parents/carers and professionals were unanimous in agreeing that more intensive community based mental health support is required for children and young people. They highlighted the practice of professionals 'signposting' young people on to another service without support to navigate through the complexities of the mental health system, as very unhelpful and overwhelming for some. There is currently no system in place to track young people moving between different services or support within the Stepped Care Model for CAMHS, and many young people were identified in the course of the Review who had 'fallen through the gaps'. A lack of handover between services, including challenges with transitioning between statutory CAMHS and Adult Mental Health Services (AMHS), were highlighted as particular problems. **(Main report: Sections 9.6 & 9.12)**

With regard to the **effectiveness of treatment and support**, young people commonly referred to a lack of choice in the support or treatment available or involvement in the decision making. They wanted to have a greater range of psychological therapies or alternative therapies available to them. NICCY was unable to obtain regional information on the range of psychological or alternative therapies 'available', or being 'used' with children and young people in the course of this Review. Many of the young people engaged with through the Review had experience of taking prescribed medication in 2017, 12,765 prescriptions of anti-depressants were given to under 18 year olds in Northern Ireland, a proportion of which were to under 12 year olds, and there has been a year on year increase in prescriptions since 2014. This is a worrying pattern in itself, but, it is extremely concerning that statistics show that some types of anti-depressant medication prescribed to young people are not recommended for children and young people by NICE guidelines. **(Main report: Sections 4.2 & 9.7)**

Young people with co-occurring **drug and/or alcohol and mental health problems** spoke about their frustration at medication being the main form of support available to them, and expressed their reluctance in taking medication because of their problems with substances. Young people wanted to have a greater range of support options available to them. The engagement with young people also raises concerns about the extent to which appropriate supervision and support are available to this group of young people to ensure that prescribed medication is being taken as directed. **(Main report: Sections 6.4 & 9.15)**

Young people were unanimous in the need for the **root cause of poor mental health** to be addressed as part of their overall care. They identified a range of factors as contributing to their poor mental health and many young people, particularly those with drug and/or alcohol and mental health problems, described dealing with multiple adversities and toxic stress. These included child sexual exploitation, neglect, physical abuse, domestic violence, substance abuse in their family and bereavement. It was clear that a failure by the system to deal with these issues when they arose, or since, was compounding the young people's problems. The review found that mental health problems for young people with a learning disability are often caused, or exacerbated by, the barriers and discrimination they face in day to day life. **(Main report: Sections 4.4, 5.8, 6.4 & 9.14)**

The critical **role of a significant adult** was a key theme raised by all the young people engaged with as part of the Review. Young people were clear they confide in adults about their mental health based on who they can trust, and not on mental health competency: the main people being family and friends, GP, CAMHS, A&E, Hospital, School Counsellors, and Teachers. The Review identified a need for a whole population approach to children's mental health needs, in order to respond in a timely and sensitive manner. **(Main report: Sections 4.5, 5.8, 6.4 & 9.8)**

With regard to **participation and feedback**, when young people were asked to rate the quality of their care, on average, across all seven services young people were asked to share their experiences on, 73% agreed they were spoken to in a way they could understand, and 57% felt listened to and respected. Only 42% agreed they felt involved in the decisions being made about their care (ratings for different services varied between 16% and 75%), and 40% agreed they were given a choice of treatment and support, this was lowest for in-patient care (19%) and A&E (23%) as opposed to VCS (67%). **(Main report: Sections 4.2 & 9.9)**

Regarding **outcomes**, the Review found that on average, across all seven services young people were asked to share their experiences on, just under half (49%) of young people did not find the services they accessed helpful. A number of services rated below average – GP (44%), Community CAMHS (45%), In-Patient Care (39%) and A&E (34%). Young people and their parents also expressed a lack of knowledge on how to make a complaint about a mental health service. The information from this Review highlights the absolute necessity of embedding feedback mechanisms into the system, to inform the planning and delivery of services. It is also essential that the outcomes measured are not solely clinical and include those that are defined by, and important to young people. **(Main report: Sections 4.2, 4.17 & 9.10)**

The young people who engaged in the Review gave their views on The **key characteristics of a good mental health service**. They talked about the need for a professional, relaxed, non-judgemental, non-clinical, age-appropriate approach. Clear and consistent boundaries of confidentiality are vitally important to young people. Services should be flexible and operate outside of Monday to Friday 9–5pm hours. The physical environment should be non-clinical and informal, with appointments in places familiar to the young people. Young people want to be able to access clinical and practical support at the same time, which may be why they tended to

be most positive about the mental health support they received when it involved both statutory CAMHS and VCS organisations. **(Main report: Sections 5.8, 6.4 & 9.11)**

Many young people (54%) when speaking about the **transition from CAMHS to AMHS**, highlighted a lack of support in transitioning, which had negatively affected their longer term treatment and recovery. They highlighted the need for more preparation and support before, during, and in the period after moving from child to adult services, and reflected on the importance of better communication between CAMHS and AMHS. Young people also mentioned the value of a bridging service for young people aged 16 to 25, which would allow for a smoother transition from child to adult services. Other issues raises include, long waiting lists for adult mental health services, the loss of relationships with trusted health professionals when moving from CAMHS, and young people not meeting the threshold for adult services on discharge from CAMHS. **(Main report: Sections 4.14 & 9.12)**

The Review found varying levels of **mental health awareness and literacy** across young people. A lack of awareness was particularly apparent among young people with a learning disability. A lack of support exists for young people (and their parents/carers) to develop awareness and literacy around emotional well-being and mental health, and age appropriate and effective ways to address stigma and fear around talking about mental health problems. The adoption of a consistent regional approach to educating children, and normalising conversations about mental health and emotional well-being as vital parts of a system in which prevention and early intervention are prioritised. Strategic oversight and resourcing to ensure this is happening for all young people is essential **(Main report: Sections 4, 5.8, 6.4 & 9.13)**

With regard to **young people with a learning disability**, current models of mental health services available for children and young people with a learning disability vary across Health and Social Care Trusts. There is no regional specialist service model for young people with a learning disability. The Southern Health and Social Care Trust (SHSCT) operate an Intellectual Disability CAMHS (ID-CAMHS) service. In the remaining HSCTs young people with a learning disability are signposted to generic CAMHS, or to learning disability services, and the decision regarding which service young people are directed to, tends to be determined by their IQ level. There is no regional policy on this practice, and therefore each HSCT sets its own IQ cut off point. Generic CAMHS is generally not accessible to children with severe learning disability. However, young people with a mild learning disability or borderline IQ are at risk of having difficulty with accessing either service because they 'sit around' the cut-off point between services. The separation of CAMHS and learning disability services results in a lack of professionals with expertise or experience in working with children who have a learning disability and mental health problems. The IQ based referral system is extremely concerning, reported to be flawed if used on its own to determine the best service for a young person, and potentially discriminatory, if an equivalent service is not available to young people denied access to generic CAMHS. This Review has also found a high proportion of admissions to the Iveagh Centre are on the basis of detention, and highlighting the potentially inappropriate use of detention as a way of permitting staff to use restrictive practice. **(Main report: Sections 5 & 9.14)**

With regard to **young people with alcohol and/or drug problems**, the Review found that drug and alcohol services and mental health services do not always work in an integrated way, nor is there adequate resources to meet the needs of young people requiring different levels of intervention. Gaps in services were particularly apparent for young people with the most complex needs, which would require intensive rehabilitation care in the community, or specialist inpatient care (Step 4 – 5). Many of the young people engaged with through this Review reported that substance misuse was a form of

'self-medication', to cope with the symptoms of their mental health problems. There is a need for a service approach which can support these young people in a holistic way, which includes responding to substance use and mental health problems simultaneously. Detention under existing mental health legislation (the Mental Health (NI) 1986) is not possible when a young person is under the influence of alcohol and/or drugs. Mental State Assessments can't be complete either. This means that some extremely vulnerable young people are unable to access specialist mental healthcare, including inpatient care. A high proportion of the young people interviewed had attended A&E during a mental health crisis, and many described a poor response from the service. **(Main report: Sections 6, 9.5 & 9.15)**

Regarding the **operational data** requested and sourced as part of the Review, NICCY was extremely surprised by the lack of basic operational data collected regionally on children and young people accessing, or trying to access statutory CAMHS services (Step 3 – 5). The Review found alarming gaps in the collation of vital disaggregated, basic operational data required to efficiently plan, commission and deliver CAMHS. Data was not available on the demographic make-up of children in contact with statutory services, their presenting need or diagnosis, the types of treatments received, or the outcomes from these. While some of these data gaps will be addressed through the children's mental health prevalence survey, and through the implementation of the Regional CAMHS dataset, some will not. Very little data is currently in the public domain, the new datasets must be made publicly available. **(Main report: Section 9.16)**

There is general agreement that the **investment in emotional and mental health services for children and young people** is inadequate, however there has been little understanding of the levels of funding for services across different bodies and agencies. This is essential in determining how additional resources should be allocated. One element of the Review was an analysis of how emotional and mental health services for children and young people are resourced, using a fund mapping methodology. NICCY received data sheets from the Public Health Agency (PHA), HSCTs and the Education Authority (EA), providing information on the allocation of more than £31 million on 93 services provided to support children and young people's emotional or mental health and well-being. While statutory agencies delivered all the services from Step 3 to Step 5, many of the early intervention and prevention services in Steps 1 and 2 were delivered by VCS organisations. The Review has identified a need for a renewed focus on the coordination of services, as per the Children's Services Cooperation Act 2015, which places a statutory duty on all 'Children's Authorities' to cooperate in improving children's well-being, and to 'pool resources' for this purpose. The Review has also found that in the case of children's mental health, substantial additional and sustainable funding is required, to ensure the needs of children and young people are being met at the earliest opportunity, and in the most effective way. **(Main report: Section 9.17)**

This Review has concluded that if there is to be a significant and sustainable improvement in the quality and accessibility of mental health support for children and young people, it must become a regional health priority. Further progress can only be achieved if all the partners involved in the Regional Stepped Care Model work together, in a meaningful and genuinely collaborative manner. All services whether statutory or non-statutory, specialist mental health or focused on broader well-being are important parts of a whole system approach. Mental health services and support must be available and responsive to children's needs. Despite the barriers and challenges that young people faced whilst seeking help or receiving services, the vast majority stated that they would advise others to seek help for their mental health if they needed it. But there is significant room for improvement and the contributors to this Review have identified what needs to be done.

Recommendations

A system-wide response is required to the challenges outlined in this Review. All relevant agencies and sectors must engage together, cooperating to improve children and young people's emotional and mental well-being. This is reflected in how the recommendations are articulated; in most cases this report does not specify any one agency or department against individual recommendations.

The Regional Model for the Delivery of CAMHS

1. NICCY recommends the establishment of a high level multi-agency, multi-sectoral project board that is tasked with the development of a comprehensive, adequately resourced action plan for taking these recommendations forward. This work should be embedded into the existing transformation agenda, and should include:

    a) The development of a Children and Young People's Mental Health Transformation Fund to drive the change required. This should be a long term and sustainable 'funding and practice partnership model', which takes account of the investment required across all key services and sectors included in the Stepped Care Model;
    b) The use of the fund mapping methodology and analyses of need, to map increases in spending on emotional and mental health services over time, and to demonstrate how additional resources are being effectively and efficiently allocated to meet the needs of children and young people;
    c) Formalisation of the relationship between Statutory CAMHS and the Voluntary and Community Sector (VCS), through the development and implementation of clear strategic policy direction;
    d) The development of a culture and practice of multi-disciplinary and multi-sectoral team working; and
    e) Full implementation of the Managed Care Network (MCN) as a matter of urgency, and review of its potential as a mechanism for co-ordinating and operationalising a whole system approach to the delivery of human rights compliant mental health services for children and young people.

Pathways and Referral Processes

2. The Department of Health (DoH) should review the implementation of the Regional Referral Criteria for Step 2 and 3 CAMHS to:

    a) Develop a comprehensive training and awareness raising programme, to ensure that all 'referral agents' are aware of the referral process and their role within it;
    b) Develop regional protocols which allow a broader range of VCS organisations working with young people with mental health problems, to make a direct referral to Step 3 CAMHS or with the support of a GP (fast track process via GP); and
    c) Introduce multi-disciplinary and multi-agency decision making processes in individual care planning, to ensure that support pathways for young people are direct and effective.

3. Steps must be taken by the HSCTs and the HSCB to address the reasons why young people referred to Step 3 CAMHS are not having their referrals accepted.

4. Progress the development, implementation and monitoring of service specific integrated care pathways, such as those involving A&E, CAIT and SHIP. These must be informed by the staff and professionals working across the agencies involved.

Professional Support

5. Introduce a mandatory programme of mental health training for all professionals likely to come into contact with young people with mental health problems, this must include GPs. The training needs to develop core professional competencies to respond to young people in a sensitive, competent and age appropriate way. This should include refresher training every 3 years.

6. Designated mental health practitioners, trained to work with young people, should be attached to every GP surgery, and statutory mental health professionals should also be available to every primary and post primary school in Northern Ireland.

7. Introduce Community Mental Health Fora across Northern Ireland, which bring GPs and VCS organisations together to develop local relationships and exchange local knowledge.

Support for Young People at Different Stages of Accessing Step 3 Services

8. Review appointment systems and consider the introduction of:

    a) An online booking system so young people and carers have more control over the appointment time given;
    b) Appointment slots available outside of school hours;
    c) The option of appointments being held in their own home or close to home;
    d) Reminder texts about appointments; and
    e) The option of making remote contact with a trained mental health counsellor between appointments i.e. telephone, text.

9. Introduce a Mental Health Passport Scheme that contains key information on young people, which they want professionals involved in their care to be able to access.

10. Introduce a dedicated telephone advice line for statutory CAMHS, which professionals, parents/carers and young people could use as a way of improving the communication and support offered by services, whilst young people are waiting for an appointment or between appointments.

11. Develop a children and young people specific Regional Integrated Elective Access Protocol (IEAP).

12. A range of community based after care supports must be available to young people discharged from Community CAMHS or inpatient care.

13. Provide resources to GPs to allow them access to a greater range of self-help supports to offer young people.

Care Planning and Treatment

14. The administration of prescription medication for young people must comply with NICE guidelines. Where medication is prescribed to a young person with a history of alcohol and/or drug problems this should be risk assessed and appropriately supervised. HSCB must monitor prescribing data to ensure compliance with NICE guidelines.

15. The complete range of evidence based, effective psychological treatments and alternative therapies should be made available to children and young people. Targets for accessing such treatments should be set in the best interests of children and young people, met, closely monitored and reviewed.

16. Joint care planning processes should be developed and reviewed, to ensure that key services work collaboratively and in a co-ordinated manner to support young people to address the biological, psychological and social factors that are causing or contributing to their poor mental health.

17. The practice of admitting children onto adult mental health wards should end. Children and young people requiring inpatient mental healthcare should receive it separately from adults.

18. Children should receive the most appropriate and effective inpatient care for their mental health. This should be tailored and appropriate to the level of need, and include the provision of inpatient intensive care where necessary.

19. Reasons for the increase in the number of young people being detained in Beechcroft need to be urgently interrogated. Similarly, an examination of the variances in referral rates to Beechcroft by HSCTs should be carried out. A clear policy response and actions should be taken forward as a result, in the best interests of children and young people.

20. The reasons for Extra Contractual Referrals, treatment received and outcomes for children and young people should be closely monitored. Services which are not currently available in Northern Ireland should be provided, so that all young people who require treatment for mental health problems can receive it close to their family and community. This should include secure forensic mental health provision and complex eating disorder treatment.

Access to Crisis Mental Health Support

21. Implement RCPCH 'Minimum Care Standards for Children and Young People in Emergency Care Settings who Present with Mental Health Problems' (RCPCH, 2018).

22. The DoH should enhance the statutory framework, requiring RQIA to routinely inspect A&E Departments against the 'Minimum Care Standards for Children and Young People in Emergency Care Settings who Present with Mental Health Problems' (RCPCH, 2018). This should include appropriate, robust enforcement powers and the provision of sufficient resources to carry out this role.

23. Crisis intervention support for children and young people should be available 24 hours a day, all year round, in all HSCTs.

24. Include a Clinical Decision Unit, or equivalent service model, as part of every A&E Department in Northern Ireland. This would be useful for young people who may require a period of observation, further investigation or other interventions which cannot be completed within the four hour timeframe within A&E Departments.

25. An evaluation of the compliance with, and effectiveness of, the Card Before You Leave scheme (CBYL) for children and young people in A&E should be carried out.

Participation and Feedback from Young People

26. Development of an action plan to strengthen advocacy, enhance peer support, and develop practice standards to evidence the involvement of young people in service development, and in their own care planning.

27. Revise and establish fora in each HSCT to support the active engagement of children young people and their parents/carers, to inform both acute and community care. Views expressed through this engagement should be considered at the practice based meetings, where day to day issues are raised and discussed.

28. Develop user-friendly guidance for young people and parents/carers which explain their right to complain, and sets out the minimum standards of care they should expect.

Transition from CAMHS to AMHS

29. A Regional Transitions Policy and Procedure which is compliant with NICE Transition Guidelines should be developed and implemented, to ensure that all young people transition smoothly between CAMHS and AMHS.

30. Specific attention should to be given to meeting the support needs of children and young people who do not meet the transition criteria for adult mental health services.

31. Develop a mental health 'bridging service' for young people aged 16 to 25 years old, that allows for a smoother, flexible and young person centred transition between services.

Mental Health Awareness and Literacy

32. Comprehensive mental health and wellbeing education for pupils should be provided as a core part of the education curriculum. This should ensure that all young people have sufficient vocabulary to talk about their emotional well-being and mental health, know how to look after their mental health, have an understanding of the help available and how to access it.

33. Education and mental health service providers should develop formal partnerships in order to holistically meet the needs of children in education at all levels, and for those children and young people receiving their education 'other than at school'.

34. Equal emphasis should be placed on the measurement and improvement of the well-being of children and young people in education, as on academic attainment. Schools should be inspected by ETI on their ability to develop the conditions required to nurture young people's well-being.

35. Information, guidance and training should be provided to parents, carers and children at key stages and transition points across childhood.

36. A programme of public awareness and community capacity building on mental health and emotional well-being should be developed, and regionally implemented with a specific focus on geographical areas, and groups with the highest risk factors for poor mental health.

Young People with a Learning Disability

37. A comprehensive and integrated mental health service model across Northern Ireland for children and young people with a learning disability should be agreed and implemented. This model must ensure that young people with a learning disability can access comparable services and support as young people without a disability.

38. Assess how widespread the practice of determining eligibility of access to specialist mental health services (CAMHS) solely or mainly on the basis of IQ is, and take all necessary measures to ensure that access to services is always on the basis of need.

39. A comprehensive review of community based emotional, mental and behavioural support services for young people with a learning disability should be carried out without delay.

40. Immediate steps must be taken to ensure that all detentions of children and young people in the Iveagh Centre under the Mental Health (Northern Ireland) Order 1986 is proportionate and appropriate.

Young People with Alcohol and/or Drug Problems

41. Statutory CAMHS should adopt a 'harm reduction approach' to ensure that young people can access mental health support whilst withdrawing from substances. Appropriate levels of supervision and support for young people withdrawing from substances should be provided.

42. Universal and timely access to Drug and Mental Health Services (DAMHS) should be available across Northern Ireland. DAMHS should be closely aligned to CAMHS, and closely linked to Step 2 commissioned drugs and alcohol services.

43. Step 4 specialist intensive community based support and interventions for young people with drug and/or alcohol and mental health problems should be expediently developed, and provided across Northern Ireland. This should include day treatment programmes and age-appropriate interventions.

44. Inpatient care and treatment should be provided for young people with co-occurring drug and/or alcohol and mental health problems, who cannot be safely and effectively supported within the community. This provision should take a holistic approach to need, provide a range of interventions and be fully integrated into the Stepped Care CAMHS service model.

Data and Monitoring

45. The DoH should develop a universal health information system linked to every individual child, to inform every health professional coming into contact with a child and/or their parents/carers. This should link to other information systems, such as UNOCINI. 'Patient level' data should be integrated into statistical reports as part of a transparent and accountable information reporting system, so that the impact of services on outcomes for children and young people can be tracked.

46. Government should ensure that the first Northern Ireland Prevalence Survey of children and young people's mental health is completed by year end 2019/20, and published soon thereafter. Further prevalence surveys should be repeated every 3–5 years.

47. The CAMHS Dataset should be fully implemented across each HSCT. Adequate resources should be provided to establish and maintain the system. Data should be published on a regular basis, in line with other health statistical reporting. The Dataset should be augmented to include additional basic information and data, required to monitor services and effectively plan CAMHS. These include:

Outpatient

a) Information on young people who are accessing emotional well-being and mental health services through Learning Disability Teams/Disability Teams;
b) The specific reasons for referrals not being accepted to Step 3 CAMHS; and
c) Track young people moving between services within the Stepped Care Model for CAMHS. This would help to monitor the length of time and the pathways required for young people to access support. This must include young people who are not accepted for referral to Step 3 CAMHS.

Waiting Times

d) Collection and monitoring of additional waiting time statistics:

   i) Waiting times for services beyond Generic Step 3 CAMHS, to include key services across Steps 2 – 5 and waiting times for urgent and emergency appointments to Step 3 CAMHS;
   ii) Waiting times between referral being made and referral being accepted or not accepted;
   iii) Waiting times for second appointment to Step 3 CAMHS;
   iv) Waiting times for access to psychological therapies; and

e) Data on the types of psychological therapies and alternative therapies used as part of young people's treatment plan.

Attendance at Appointments

f) The reasons for DNAs/CNAs should be recorded and monitored. Specific attention must be given urgently to addressing the reasons for non-attendance; and
g) Record the numbers of young people who are discharged from CAMHS due to DNA/CNA and monitor compliance with IEAP guidance.

Inpatient

h) Record and monitor referrals not accepted to Beechcroft inpatient unit.

Adult Wards

h) Discharge destinations of young people admitted to adult mental health wards should be recorded and monitored.

Demographics

i) A greater range of demographic information for specific groups of young people should be collected e.g. those with a physical, learning, sensory disability, looked after children; LGBT children; Newcomer and Separated Children.

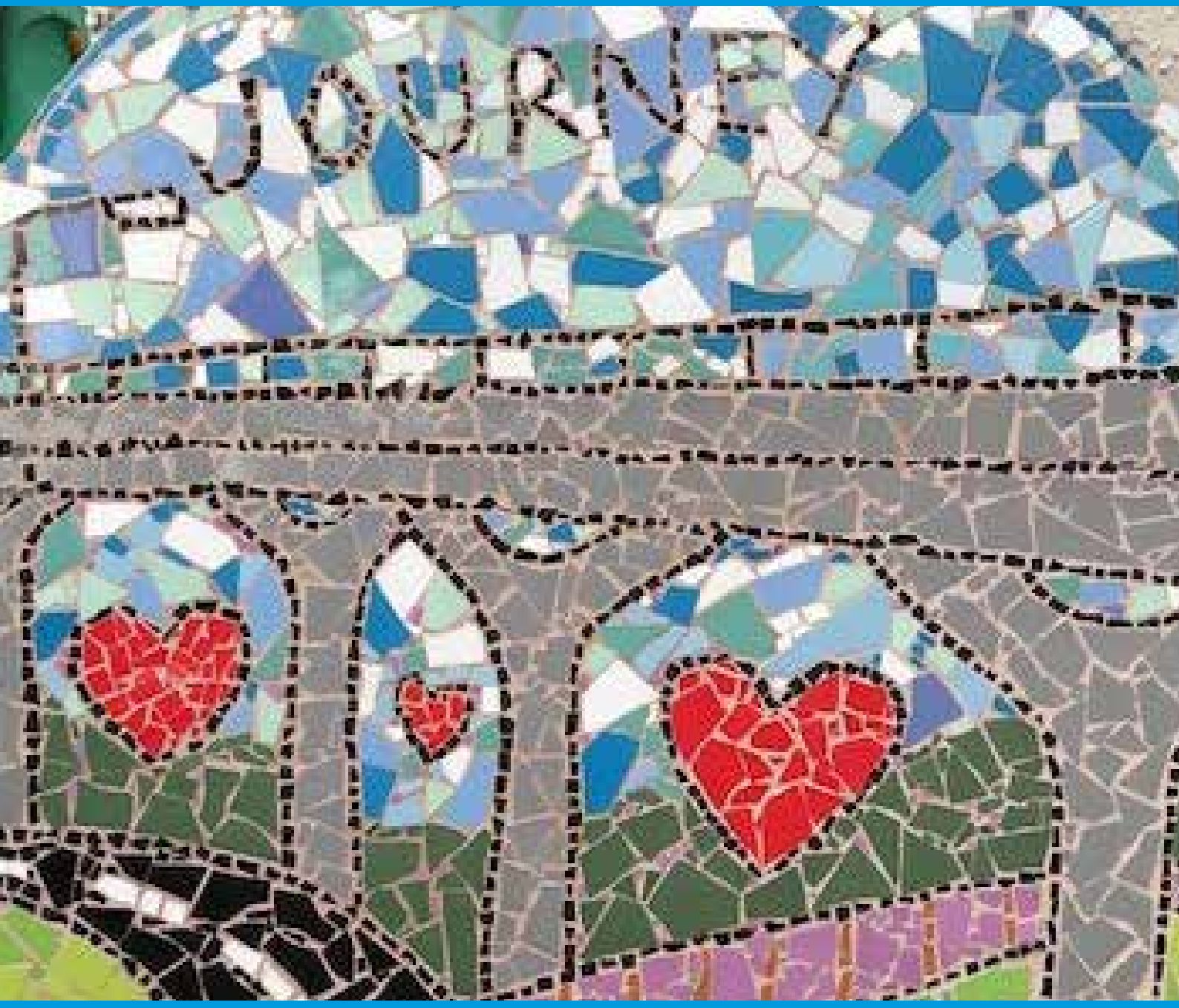
Outcomes

48. A greater depth of information regarding patient experiences and outcomes should be collected and monitored, including outcomes defined by, and important to' young people e.g. improvements in relationships with friends and family - in addition to psychometric scores of mental health.

49. Universal health services, such as GP and A&E, should agree on and implement a set of standardised information system codes, to record and monitor the numbers and profiles of young people with mental health problems and/or drug and alcohol problems accessing their services.

50. When a young person is admitted to a general paediatric bed for mental health treatment or care, the DoH should request that RQIA are notified, and provided with information on what care and treatment is being provided.

The Northern Ireland Commissioner for Children and Young People commits to monitoring the implementation of these recommendations, and will engage with all relevant agencies to ensure improved outcomes for children and young people. NICCY will publish monitoring information on an annual basis.



BACKGROUND

1.1 Background to the Mental Health Review

During 2016, NICCY carried out a scoping exercise to better understand the prevalence and nature of poor mental health within the population of children and young people, and to review the operational aspects of the CAMHS system, such as service usage, need, outcomes, budgetary allocation and expenditure. This scoping process identified a range of issues and concerns, including a significant lack of publicly available information on the prevalence of poor mental health, levels of need or the operational aspects of mental health services such as demographics, presenting need, services / therapies offered, service user experience and outcomes. Some of the other issues it raised included concerns about the equality of availability and accessibility of services, including community based provision, out of hours / crisis support and specialist services.

The scoping exercise also raised issues about the adequacy of the support in schools for young people, this included, the extent to which young people are enabled to participate in their own healthcare planning, and in the development and review of mental health services, gaps in workforce planning and concerns about the quality of the transition between child and adult mental health services (NICCY, 2017:1).

Prevalence of Poor Mental Health in Northern Ireland

There are key predictors for poor mental health, which if identified, and responded to, can eliminate or mitigate against emerging mental health problems. One of the known vulnerabilities to poor mental health is age, and there is a growing body of evidence that adolescence and young adult years are peak years for the first onset of mental illness. Three quarters of adults with a diagnosable mental health problem will have experienced first symptoms of poor mental health by the age of 24 years old (Khan, 2016). High rates of mental health problems in this population, and the risk of a 'long shadow' of mental illness into adulthood if not addressed, highlights the importance of finding the best means of promoting positive well-being, and preventing and addressing mental health problems at the earliest stage possible (Khan, 2016).

There are specific groups of young people at a higher risk of developing mental health problems and they are the same young people that are more likely to face challenges when accessing services and support. These groups of young people include, care experienced children, those living in poverty and in economically deprived areas, children in contact with the criminal justice system or who have a parent in prison, children affected by the conflict (including those exposed to trans-generational trauma), young carers, those with long-term disability or illness, those exposed to parental mental ill health, Roma, Gypsy and Traveller children, children belonging to Ethnic Minority Groups, migrant children and LGBTI children (DoH, 2018; Lundy et al. 2012; Devaney et al. 2012; Khan, 2016).

Access to Mental Health Services

The challenges of providing good quality mental health support to children and young people is not unique to Northern Ireland, other parts of the UK and Ireland face similar problems. For example, a Rapid Review of CAMHS in England, by the Office of the Children's Commissioner in England (OCCE) has identified large numbers of children and young people having problems with getting access to services, including children and young people with life threatening conditions being placed on waiting lists (OCCE, 2017). In recent months the Welsh Government has come under pressure from its Children and Young People's Committee and the judiciary

for not taking the mental health of children and young people seriously (BBC Online 2018:1, Pollock 2018).

However, in Northern Ireland we face a number of specific challenges and opportunities, not least is the fact that Northern Ireland has been without a devolved Government since March 2017. NICCY published its first Statement on Children's Rights in Northern Ireland in 2018, the Statement assessed how Government and their statutory agencies have performed in a number of vital areas of children's lives, including education, poverty and mental health. One of the overarching assessments made within the Statement was that there is a, 'history of slow progress on children's issues in Northern Ireland' but that a lack of a devolved Government was further hampering progress that could be made on children's issues that could result in better outcomes for them (NICCY, 2018:1).

A 2016 survey carried out by the Northern Ireland Statistics and Research Agency (NISRA) with 11–16 year olds found that 35% (n=990) of young people have had concerns or worries about their mental health. Of these, 61% did not seek help from anyone and 39% did. For the young people that did seek help, the most common place / people to seek help from were family (73%) and friends (41%). In terms of professionals, from whom help was sought, the most common people / places were GP (24%), Schools (22%) and CAMHS (13%) (NISRA, 2016). A similar pattern was found for young people who had not already sought help but who were asked who or where they would go to if they were concerned about their mental health. These findings demonstrate that young people are likely to seek out professional help from a range of people and places, and that it is very important that they are equipped to respond to children and young people in a helpful and appropriate way.

A significant percentage of young people who stated that they had been concerned or worried about their mental health, did not seek help. A range of reasons were given for this, including a perception that they could handle things on their own (55%), felt unable to speak to anyone (26%), felt too embarrassed (25%), too busy / didn't have time (14%), didn't know where to go to get help (10%) and that they asked for help before and didn't get any (6%) (NISRA, 2016).

Young people were asked if they had received any therapy or medical treatment for a mental health problem in the last year, 60% had received no such treatment of those that had, the most common treatments / therapies received were counselling (20%), medication (8%), Cognitive Behavioural Therapy (CBT) (4%) and psychotherapy or psychoanalysis (2%) (NISRA, 2016).

We know from other research conducted in Northern Ireland that young people can face a wide range of barriers to both asking for help and in accessing services. These include a lack of knowledge about services or not knowing what help they needed, stigma about asking for help and fear of being told they are too young to have mental health problems (Mind Wise and Youth Action, 2017). Young people often report having a poor perception of or response from services, which include how seriously their mental health concerns are taken, and how suitable the service will be (Orr, 2015).

After completing this scoping work, which included extensive engagement with children and young people and relevant stakeholders, it became clear that further work was required to review mental health provision in Northern Ireland for children and young people, and to use a children's rights perspective to do this.

1.2 The Approach of the Mental Health Review

The Office of the Commissioner for Children and Young People (NICCY) was created in accordance with 'The Commissioner for Children and Young People (Northern Ireland) Order' (2003) to safeguard and promote the rights and best interests of children and young people in Northern Ireland. In carrying out these functions, paramount consideration must be given to the rights of the child or young person, having particular regard to their wishes and feelings and to all relevant provisions of the United Nations Convention on the Rights of the Child (UNCRC). The remit includes children and young people from birth up to 18 years, or 21 years if the young person has a disability or has been/is in the care of social services.

This Review was conducted in accordance with NICCY's functions under Article 7(2) and (3) of the Commissioner for Children and Young People (NI) Order 2003 which includes a duty to 'keep under review the adequacy and effectiveness of law, practice and services provided for children and young people by relevant authorities'. It is also in line with the Commissioner's duties under Article 7(5) (b) and (d) to encourage children and young people to communicate with the Commissioner, and for the views of children and young people, and their parents, to be sought whilst carrying out her functions. Furthermore, under Article 7(4) (b) NICCY has a duty to advise relevant authorities and / or Executive Committees of the Northern Ireland Assembly on issues concerning the rights and best interests of children and young people identified during the Review.

In keeping with the legislative duties and powers of the Office of the Northern Ireland Commissioner for Children and Young People, this Review has been underpinned by child rights. In particular, the Review sought to consider compliance with international children's rights standards and employ processes which themselves comply with international standards on children's rights. It has taken a particular focus on the United Nations Convention on the Rights of the Child, and the United Nations Convention on the Rights of Persons with Disabilities (see Section 2).

NICCY's Vision for the Northern Ireland Mental Healthcare System

A children and young people's mental healthcare system that ensures that all children in Northern Ireland can enjoy the highest attainable standard of mental health, and have equal and unimpeded access to services and facilities for the prevention, early intervention and treatment of mental illness.

Aim and Objectives

The overarching aim of the Review is to **'assess the adequacy of mental health services and support for children and young people using a rights based perspective'** by:

1. Enabling children and young people (and their parents / carers) to share their direct experience of accessing or attempting to access mental health services and support;
2. Identifying barriers which prevent children and young people from getting access to adequate mental health services;
3. Identifying good practice and produce a range of recommendations for improving services; and
4. Increasing public awareness of children and young people's rights to good quality mental healthcare.

Defining 'mental health'

There is no universally agreed definition of mental health. In 2018, the European Network of Ombudspersons for Children (ENOC)[1] chose children and young people's access to mental healthcare as the working theme for the year. Part of the work involved developing a definition of mental health. Guidance provided by the World Health Organisation (WHO) was used as the basis upon which this new definition was drafted (WHO, 2018:1)

ENOC defines child and adolescent mental health as:

"A state of well-being that allows a child to develop and become aware of his or her own unique personality, to build his or her own identity to fulfil his or her own potential, to cope with the challenges of growing up; to feel loved, secure and accepted as a unique individual and to be able to be happy, play, learn and to participate and contribute to family and community." (ENOC, 2018)

The Regional Stepped Care Model for CAMHS was used to establish the scope of the Review in terms of the range of services that it was interested in examining (DHSSPS, 2012).

Throughout this report, the terms 'emotional well-being and mental health services' and 'mental health services and support' have been used to refer to the broad range of services that young people may have accessed and therefore include services that fall across all 5 steps of the Stepped Care Model. The term 'Statutory CAMHS' refers to Steps 3, 4 and 5 services, as defined in the Regional Stepped Care Model for CAMHS.

The Scope of the Review

This Review follows, and complements a significant number of reports, over many years, which wish to inform the transformation of mental health services for children and young people. These have set out a range of recommendations for improving mental health services and support for children and young people in Northern Ireland, and include, but are not limited to:

- Bamford Review (2006) "A Vision of a Comprehensive CAMH Service";
- RQIA (2011) "Independent Review of Child and Adolescent Mental Health Services (CAMHS) in Northern Ireland";
- Rees et. al., (2014) "A Review of Beechcroft and Child and Adolescent Acute Care Pathways"[2];
- HSCB and PHA (2017) "10,000 Voices: Regional Report- Experience of Paediatric Autism and CAMHS Project"[3];
- Leavey et al., (2017) "Improving mental health pathways and care for adolescents during transition to adult services in NI" (IMPACT); and
- DoH (2018) "Review of Regional Facilities for Children and Young People" (publication pending ministerial agreement).

NICCY's Review brings a children's rights based focus to the body of research that exists; Section 2 outlines the child rights framework by which this Review was conducted. Consequently, it places an emphasis on children and young people's experience of accessing, or trying to access, services to support their emotional and mental health. There is a growing body of evidence that shows that children's assessment of their

1 The European Network of Ombudspersons for Children (ENOC) was established in 1997 and is a not-for-profit association of independent children's rights institutions. Its mandate is to facilitate the promotion and protection of the rights of children, as formulated in the UN Convention on the Rights of the Child. They meet annually to discuss an aspect of children's lives from a child rights perspective. http://enoc.eu/?page_id=8

2 Rees Review: the focus was on in-patient experience, 35 respondents, 99% were female and aged between 14 and 17 years old.

3 10,000 Voices: the focus was on Step 3 CAMHS and those using services in the previous 12 months, of the responses returned about CAMHS- 18% (n=27) were from young people and 82% (n=119) were from parents. Overall, 74% of respondents were female.

own mental health and of the services they receive can vary from their parents. Therefore, it is vital that both perspectives are heard and responded to (Patalay and Fitzsimons, 2017).

This Review is also different from existing reports because it has taken a broader view of mental health services, in that it includes Voluntary and Community services, as well as specialist mental health services. It places an equal focus on universal services such as GP and A&E and those that sit outside of Health, such as Education.

In this Review, we have carried out some discrete qualitative work with two groups of particularly marginalised young people, known to be at higher risk of developing mental health problems, and likely to face greater challenges in accessing mental health support. These are children and young people with a learning disability, and children and young people with an alcohol and / or drug problem.

This Review has not focused on the early years or young childhood, however the evidence is clear that mental health is something that needs to be considered across the life course. There are specific predictors or risk factors to poor mental health that are identifiable in the maternal mother or early infanthood. We know that the quality of the attachment with a parent or carer is a significant factor for children and young people's mental health. Babies with insecure or disorganised attachment issues are at greater risk of developing a range of emotional or behavioural problems as they develop, and a subset of these children are more likely to have mental health problems into early adulthood (PHA, 2015).

1.3 Current Data Available on Mental Health of Children and Young People

Data on Prevalence of Mental Ill Health of Children and Young People

In Northern Ireland, population wide data on mental and emotional well-being of children and young people is currently not collected, so it is not possible to determine the scale of mental ill health for this group. To understand the scale and types of mental ill-health experienced by children and young people a population wide prevalence survey including key questions with validated scales would be required. NICCY warmly welcomes the fact that the Department of Health is in the process of commissioning such a survey.[4]

In the absence of current data, there is a range of research and data sources that provide some sense of the scale of mental ill-health of children and young people here, although this can differ quite substantially depending on the source used. It tends to range between 1 in 10, or 1 in 4, depending on the parameters applied such as the age range covered, whether self reported or clinical tools are used, and which target group is included i.e. general population or only those known to services (Khan, 2016; Schubotz and McArdle, 2014; Orr, 2015). There are also specific groups of young people who tend to be excluded from general population surveys due to methodological limitations, for example young people with a learning disability or those for whom English is not a first language.[5]

A range of health data indictors indicate that the prevalence of mental health problems in children is increasing, both in terms of their

4 The HSCB confirmed to NICCY by email in May 2018 that a prevalence survey would be commissioned.

5 Young Person Behaviour and Attitude Survey is a Government Survey of 11–16 years administered through post primary schools which excludes Special Schools- YPBAS Technical Report. https://www.nisra.gov.uk/publications/ypbas-publications

scale and complexity, and mental ill health is presenting in increasingly younger children. These sources include anti-depressant prescription rates for 0–19 year olds, self harm rates for 0–18 year olds, youth suicide rates, self reported poor emotional well-being by children and young people, and referrals to family support services for emotional and behavioural support (NICCY, 2017:1).

Due to a lack of regular and robust mental health prevalence data in Northern Ireland, surveys conducted in other jurisdictions, generally England, tend to be used as a benchmark for the prevalence of mental ill health in children and young people in Northern Ireland. There are considerable problems with using prevalence data from outside Northern Ireland as a benchmark, as they will not take account of the specific epidemiological issues affecting rates of mental ill-health here. This includes the impact that the conflict in Northern Ireland has had on children and young people's mental health. One of the most significant reviews of mental health services in Northern Ireland indicated that rates of mental ill-health are potentially 25% higher here than in other parts of the UK (Bamford, 2006). A more recent report has found that over 40% of children growing up in Northern Ireland are living with parents who have high or moderate experience of the conflict, and therefore are at risk of suffering transgenerational trauma (CVS, 2015).

Data on Emotional and Mental Health Services Provided to Children and Young People

During the 2016 scoping exercise, NICCY was unable to find a central source of official, publicly available mental health data for children and young people. In fact, there was very limited information in the public domain on mental health service usage in Northern Ireland, and the information that was available was generally not broken down by age.

The DoH Hospital Information Branch publishes quarterly statistics on issues such as waiting list and waiting times for emergency care, inpatient and out-patient sessions. However, as these statistics are generally not disaggregated by age, it is impossible to interpret them for children and young people.[6] The information they publish on children and young people's mental health is limited, largely because of inconsistencies in how information is recorded across Trusts.[7]

Standardised statistics are regularly published on specific mental health issues, such the Northern Ireland Self Harm Registry which provides an annual monitoring report of presentations of self harm to Accident and Emergency departments. The Northern Ireland Statistics and Research Agency (NISRA) also publish annual registered suicide death statistics disaggregated by age.

The Children and Young People's Strategic Partnership (CYPSP) brings together a range of agencies, including voluntary and community sector organisations, that aim to improve the lives of children and young people in Northern Ireland. The CYPSP aims to plan and provide services for children and young people more efficiently by making joint decisions about the services needed, and funding these services together. A key role of the CYPSP is to provide a range of regional and local statistical information to inform the coordinated planning of services for children and young people. Information published includes family support hub report cards, Early Intervention Transformation Programme (EITP) report cards and Outcome Monitoring Reports. These latter reports have

6 One of the exceptions would be compulsory admissions of under 18s under the mental health (Northern Ireland) Order 1986 by sex and year (2011/12-2015/16). However, it doesn't include those admitted voluntarily.

7 https://www.health-ni.gov.uk/topics/dhssps-statistics-and-research/hospital-statistics

been produced annually since 2010 and bring together data available from a number of public sources, providing important trend analysis information on some data indicators relevant to children and young people's mental health i.e. suicide rates, rates of self harm, hospital admission due to alcohol or drugs. However, the fact that there is such limited publicly available data on children and young people's mental health means that the information available on the CYPSP website is also limited.

Other parts of the UK, particularly England and Scotland have been making progress in terms of collecting and analysing mental health data.[8] The necessity of making improvements to national CAMHS data collection and monitoring was emphasised by the Children and Young People's Mental Health Taskforce, established in England, to look at ways of improving outcomes for children and young people's mental health and well-being (Department of Health, England, 2015).

There is recognition across the Health and Social Care System in Northern Ireland that there is limited data available on children and young people's mental health and that the information that is available is inconsistent and can be unreliable.[9]

During the data gathering process NICCY was informed that a Northern Ireland CAMHS dataset was in development to provide operational data on key services, using a common framework, and shared definitions for key data variables (HSCB, 2018:1). The dataset, once fully implemented, would include basic data essential for the planning and delivery of mental health services for children and young people. NICCY has been made aware that further investment is required to fully embed the CAMHS dataset across HSCTs and to support analysis.

The need for better CAMHS monitoring data was highlighted in Regulation and Quality Improvement Authority's (RQIA) Review of CAMHS in 2011. At that time the Health and Social Care Board (HSCB) had informed the reviewers that a regional CAMHS dataset was being developed (RQIA, 2011). Unfortunately, the development of a monitoring system has taken many more years than anticipated at the time of the RQIA Review. We have been informed that this has recently been made available from the 'Confidence and Supply' Transformation Fund and it is critically important that progressing this dataset is prioritised without any further delay.[10] Together, the service level data and prevalence data will provide a range and depth of information that Northern Ireland has never had to date, and which is essential to evidence based planning and delivery of mental health services.

Developments in data monitoring and transparency are also necessary in order to fully meet equality of opportunity obligations set out under Section 75 (1) of the Northern Ireland Act 1998. The legislation outlines nine categories / groups against which public authorities are required to monitor for and promote equality of opportunity. This includes between persons of different age and between persons with and without disability.[11] The legislation also requires designated public authorities to take proactive measures to promote equality of opportunity between members of the nine section 75 categories. It also places a statutory obligation

8 http://content.digital.nhs.uk/CAMHS

9 Equity and e-mental health Conference, 28 April 2017.

10 Letter to NICCY from DoH, 24 April 2018.

11 The remaining 9 s75 groups are and persons without religious belief, political opinion, racial group, marital status or sexual orientation; between men and women generally, and between persons with dependants and persons without.

on designated public authorities in Northern Ireland to take action to address enjoyment and equality of opportunity among members of the nine protected groups where inequality has been identified.

1.4 Policy and Legislative Context

The Children's Services Co-operation Act

The Children's Services Co-operation Act (Northern Ireland) 2015 (CSCA) received Royal Assent on the 9th December 2015. The CSCA is a significant legislative development which aims to improve the well-being of children and young people in a manner which realises their rights. The Act places a statutory obligation on Government to co-operate with each other in order to contribute to the improvement of well-being outcomes for children and young people.[12] It also contains an 'enabling power' allowing children's authorities to share resources and pool funds in the carrying out of functions which contribute to the well-being of children.[13] It places further obligations on Departments / Agencies to adopt a Children and Young People's Strategy,[14] in line with the Committee on the Rights of the Child's General Comment No. 5 on the General Measures of Implementation of the UNCRC which obliges State Parties to produce a 'national action plan for children' (UN, 2003).

Eight areas are set out which define the well-being of children and young people. These are:

(a) physical and mental health;
(b) the enjoyment of play and leisure;
(c) learning and achievement;
(d) living in safety and with stability;
(e) economic and environmental well-being;
(f) the making by them of a positive contribution to society;
(g) living in a society which respects their rights; and
(h) living in a society in which equality of opportunity and good relations are promoted between persons who share a relevant characteristic and persons who do not share that characteristic.[15]

It also states that in determining the meaning of well-being for the purposes of this Act, regard is to be had to any relevant provision of the United Nations Convention on the Rights of the Child.[16]

The obligations under the Act should inform all of the work which Government Departments and Agencies undertake to improve the lives of children and young people in Northern Ireland. It presents an opportunity and places a legal obligation on providers of services for children, including mental health services, to work together to achieve better well-being outcomes for children in Northern Ireland. A vital part of ensuring compliance with the obligations under the CSCA will be to ensure that the well-being of our children is measured and responsive services are provided to address areas of concern raised by children to improve well-being outcomes.

12 Section 2(1)

13 Section 4(2)

14 Section 3(1)

15 Section 1(3) states that, "In this section "relevant characteristic" means a characteristic mentioned in any of paragraphs (a) to (d) of section 75(1) of the Northern Ireland Act 1998".

16 Section 1(4)

The impetus for the introduction of the CSCA was the recognition of a lack of co-operation in the delivery of children's services by a range of children's services providers. To effectively address breaches of children's rights in Northern Ireland requires a cross-departmental and cross-agency approach. The ultimate goal for Government Departments and Agencies in the delivery of children's services should be to improve the well-being of children and young people in a manner which ensures the realisation of their rights. This is particularly the case with regard to services provided to children to improve their mental health and emotional well-being.

Mental Health and Mental Capacity Legal Framework

The Mental Capacity Act (Northern Ireland) 2016 (Mental Capacity Act) received Royal Assent in May 2016. It replaces the Mental Health Order (Northern Ireland) 1989 for over 16s and combines mental health and capacity legislation in Northern Ireland. The Act was in development for many years, and at the time of writing, most of the Act is yet to be commenced and the accompanying Code of Practice has not yet been finalised. As only over 16s are included within the scope of the Act, an amended Mental Health (Northern Ireland) Order 1986 will be retained for under 16s.

NICCY has scrutinised developments relating to the introduction of the Mental Capacity Act since the then Department of Health and Social Services and Public Safety (DHSSPS) first introduced its draft policy proposals in 2009. NICCY has consistently expressed concern regarding the application of the Mental Capacity Act only to those aged 16 and over, thus denying young people under 16 access to the protections and safeguards under the Mental Capacity Act. In making alternative provisions for young people under 16, NICCY's primary concern is that they do not experience any disadvantage and are able to access at least equivalent safeguards and protections as will be available to over 16s under the Mental Capacity Act.

A comprehensive review of mental health and learning disability – the Bamford Review of Mental Health and Learning Disability (the Bamford Review) was commenced in Northern Ireland in 2002 and reported on in 2007. There is a recognition that the Mental Health (Northern Ireland) Order 1986 is in places not compliant with the European Convention on Human Rights (ECHR) (Bamford, 2007). The Bamford Review made a number of recommendations regarding necessary reform of the mental health and learning disability system in Northern Ireland in order to render it human rights compliant.

Children Under 16

The rationale for the exclusion of under 16s from the scope of the Mental Capacity Act is the belief that the test of capacity contained in the Mental Capacity Bill cannot be applied to children in the same way as adults because of their developmental stage. This approach is not compliant with Article 12 of the UNCRC which requires the state to actually assess the capacity of each individual child to form an autonomous opinion and emphasises that State Parties cannot begin with the assumption that all children under 16 lack capacity (UN, 2009).

NICCY has a number of concerns with the interim retention of an amended Mental Health (Northern Ireland) Order 1986 for under 16s pending a review of the Children (Northern Ireland) Order 1995. While DHSSPS (now DoH) officials have stated that this is a "temporary measure", NICCY is concerned that the retention of the Mental Health (Northern Ireland) Order 1986 for under 16s will remain in the medium to long term.

Young People Aged 16 and 17

Throughout the development of the Mental Capacity Act the Department of Healthhas been clear that the inclusion of 16 and 17

years olds in the Act would mean that the Act would apply to 16 and 17 year olds in the same way as adults. However, the Children's Chapter in the Draft Code of Practice states that The Age of Majority Act 1969 provides that a person who is 16 or over may consent to surgical, medical or dental treatment without parental consent, it does not remove the right of the parent or guardian to consent on behalf of a 16 or 17 year old. This means that, where a 16 or 17 year old lacks the capacity to consent to an act which requires their consent, responsibility for the provision of consent will transfer to their parents. With the exception of deprivation of liberty, all other acts will require consent.

Therefore, 16 and 17 year olds who come within the scope of the legislation due to their lack of capacity will be unable to access any of the protections and safeguards in the Act unless all persons with parental responsibility for them fail or refuse to give their consent to an act. This is extremely unlikely to happen in many cases, meaning that the vast majority of 16 and 17 years olds will have no access to the protections and safeguards contained in the legislation. Given the introduction of an additional stage before a 16 or 17 year old can have access to the safeguards and protections of the legislation, these young people are at a significant disadvantage to adults.

In the case of children and young people who are in the care of the State, i.e. children who are 'looked after' or detained in the Juvenile Justice Centre, NICCY has serious concerns with regard to power to consent to an act where a 16 or 17 year old lacks capacity passing to the State and the young person being excluded from the protections and safeguards of the Act, unless the state fails or refuses to provide consent to an act being carried out on a young person by the State. NICCY has recommended that this issue should be rectified through non-commencement of the relevant section of the Act[17] and through future legislative amendments. NICCY has received assurances from DoH officials that this issue will be rectified.[18]

1.5 The Planning and Delivery of Emotional and Mental Health Services for Children and Young People in Northern Ireland

The Regional Stepped Care Model

The Stepped Care Service Model for CAMHS is described as 'a comprehensive array of services that addresses the physical, emotional, social and educational needs in order to promote positive mental health.' The description of the model refers to it being about the provision of services to enhance mental and emotional well-being that goes wider than statutory health and social care to include voluntary and community sector services, education and youth justice organisations (DHSSPS, 2012). The Regional Model encompasses a wide range of mental health services that includes primary care, secondary care and non-health specific services, in addition to the specialist services that are generally referred to as CAMHS. Adopting this wider interpretation of mental health services recognises the importance of prevention and early intervention in terms of mental health, as well as the role of specialist intervention, crisis care and inpatient and regional specialist services.

The need to focus on specific groups of children and young people who are vulnerable and marginalised was highlighted as an important aspect of the Regional Model:

17 Section 9(6), Mental Capacity Act (Northern Ireland) 2016.

18 Meeting between NICCY staff and Department of Health senior officials, 26th January 2018.

"The needs of children and young people who are vulnerable and marginalised, in line with Section 75 and UNCRC obligations, need to be prioritised and given targeted support in order to reduce the likelihood of developing lifelong mental health problems" (para 4.6).

The Regional Model contains 5 different stages of support and there are a range of support or services that fall under each of these stages which are outlined in the diagram below.

Step 1	Targeted Prevention	GP, school nursing, maternal care services, school nursing, health visiting, public health education, community / voluntary development, youth services, education, independent sector.
Step 2	Early Intervention	Primary mental health services, paediatric care services, child development services, infant mental health services, family support and social care, LAC Therapeutic services, community led mental health services, youth counselling, children's disability teams.
Step 3	Specialised Intervention Services	Elective CAMHS teams, eating disorder, addiction services, specialist autism service, safeguarding services, Family Trauma Services, Behavioural Support for Learning Disability Services,
Step 4	Integrated Crisis Intervention Child and Family Services	CAMHS resolution and home treatment teams, crisis residential care, intensive day care support services.
Step 5	Inpatient and Regional Specialist Services	Paediatric intensive care unit (PICU), acute inpatient care, Secure care, forensic CAMHS.

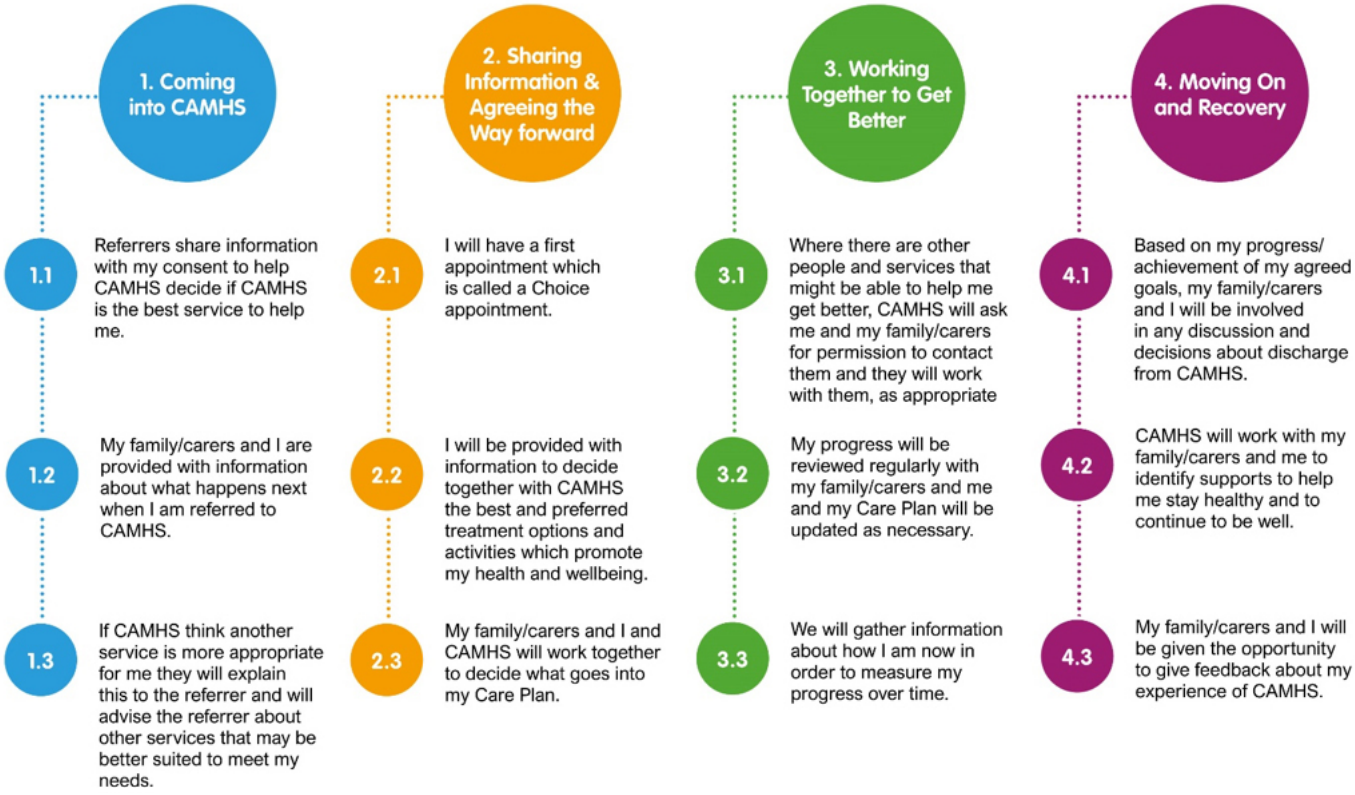
Source: Adapted from DHSSPS, 2012 Stepped Care Service Model for CAMHS.

The regional implementation of the Stepped Care Model of CAMHS continues to be a work in progress. The establishment of core services has not been done in a unified or consistent manner across Northern Ireland, therefore provisions are more developed in some Health and Social Care Trust (HSCT) areas than in others. Although there may be clear locality specific strategic and operational reasons for prioritising the development of some services over others, basic services should be available across the whole region and presently this is not the case, perpetuating the fragmented nature of CAMH services across different Trust areas. The unequal access to regional child and adolescent mental health services, especially for those living furthest away from Belfast, where the regional services are normally located, is also a continuing problem.

The Mental Health Service Pathway for Children and Young People

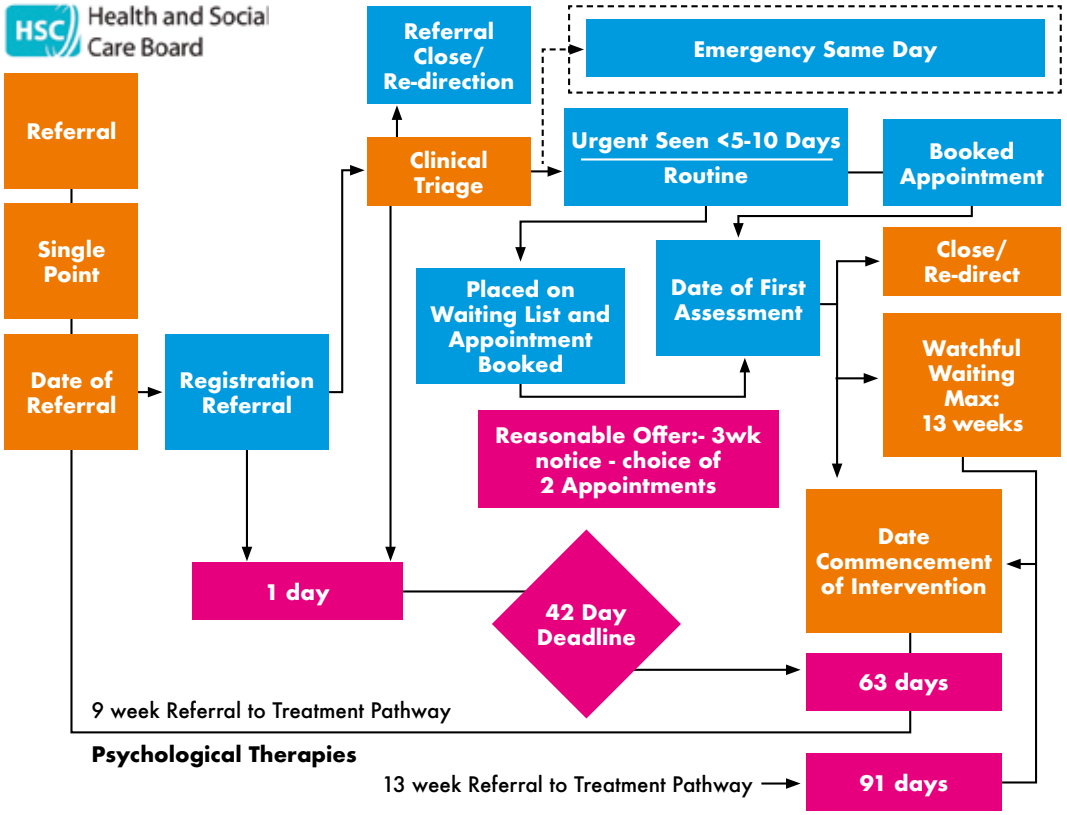
In March 2018, a CAMHS Pathway was published, which aims to set out the stages that young people should expect to go through from referral to Step 3 CAMHS to discharge (HSCB, 2018). The key stages are set out in the diagram below and a fuller description of each stage is included in Appendix 1. The CAMHS Pathway document brought together information that had been outlined in 3 separate documents, the Regional Stepped Care Service Model for CAMHS (DHSSPS, 2012), Referral Guidance for Child and Adolescent Mental Health Services – Regional Threshold Criteria (HSCB, 2015) and the Integrated Elective Access Protocol Addendum- Promoting Accessible Safe and Effective Care Guidance (IEAP) (HSCB, 2010).

Figure 1.0: Key stages in the CAMHS Pathway (HSCB, 2018)



Source: Working Together: A Pathway for Children and Young People through CAMHS – HSCB, 2018:2.

Figure 1.1: Mental Health IEAP Pathway



Source: HSCB (2010) Mental Health Services – Integrated Elective Access Protocol Addendum – Promoting Accessible Safe and Effective Care.

Health and Social Care Reform

Child and Adolescent Mental Health Services sit within the broader Health and Social Care System. Although the integrated nature of our health and social care system and the principle of free healthcare at the point of use is the envy of many countries around the world, it is also widely acknowledged that the current system is unsustainable in financial terms and does not meet the current or projected needs of the whole population. There have been a range of reports that have reviewed different aspects of the Northern Ireland Health and Social Care system and provided recommendations on how to restructure it.

Locally, the present direction of Health and Social Care service reform most recently stems from 2011 with Transforming Your Care' (TYC), the review of health and social care which acknowledged that the earlier Bamford Review (2006) set the agenda for transforming mental health services. TYC highlighted the need to focus on promoting mental health and reducing the suicide rate; the need for a consistent pathway through the regional care model and for urgent mental health care; the provision of clearer information to clients/families; the promotion of personalised care; the closure of long stay institutions and complete resettlement by 2015. In early 2016, an Expert Panel was appointed to lead debate on the configuration of Health and Social Care Services. The Panel's Report was published in October 2016, alongside the Department's report, 'Health and Wellbeing 2026, Delivering Together', which outlined 'a 10 year approach to transforming health and social care' (Bengoa, 2016; DoH, 2016:1). With respect to mental health, a number of commitments were made to achieving a parity of esteem

between mental and physical health, including better specialist services (such as perinatal mental health), expansion of community services and those to deal with trauma of the past. The then Minister for Health, Michelle O'Neill MLA, stated in the document:

"Mental health is one of my priorities as Minister of Health, and it is an issue that I will champion at every opportunity. I want better specialist mental health services. This would include further support for perinatal mental health and inpatient services for mothers, with potential to address the need that exists across the island. We will expand services in the community and services to deal with the trauma of the past. Underpinning all of this, I am committed to achieving a parity of esteem between mental and physical health to ensure that we are tackling the true impact of mental health on our communities."
(Delivering Together – DoH, 2016:1)

Service Quality Standards

The World Health Organisation (WHO) states that quality of care is 'a key component of the right to health, and the route to equity and dignity for women and children. In order to achieve universal health coverage, it is essential to deliver health services that meet quality criteria.'

It defines quality of care as 'the extent to which health care services provided to individuals and patient populations improve desired health outcomes. In order to achieve this, health care must be safe, effective, timely, efficient, equitable and people-centred.'[19]

Service quality standards or criteria set a minimum threshold that services should meet to ensure there is regional consistency in the quality of service provided.

The 'Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003' applied a statutory duty of quality on the health and social are system in Northern Ireland, namely the HSCB and HSCTs. This means that each organisation, large or small, has a legal responsibility to ensure that the care it provides must meet a required standard.

On the Department for Health website, Service Quality Standards are described as being 'part of a broader framework to raise the quality of services provided to the community throughout Northern Ireland'. It goes on to say that 'Service Frameworks are also an important element in a standards driven system for improving health and social care planning, commissioning and delivery, and the Department for Health has developed them across key areas of health and social care.'

It is concerning that gaps in service quality standards for children and young people's services, including children and young people's mental health services, were identified in the course of carrying out this Review.

In 2010, a Service Framework for Mental Health and Well Being was published, children and young people were referenced against a range of standards and key performance indicators within this Framework, and in the Appendices, specific policies and good practice guidance for children and young people were included. There was also a separate section which focused on specific conditions for children and young people, i.e. Section 5: Standards for Specific Conditions – Children and Young People.

In early 2018, a revised Service Framework for Mental Health and Well Being for 2018 – 21 was consulted on. On reading the consultation document it became clear that it

19 http://www.who.int/maternal_child_adolescent/topics/quality-of-care/definition/en/

was no longer applicable to under 18s. The consultation document did not explicitly refer to this, there was no rationale provided for the removal of children and young people from the Framework, or an explanation provided of the alternative measures that are going to be put in place. Removal of under 18s was not included as a proposal within the public consultation process. NICCY has also sought clarification from the Service Framework Programme Board, who have confirmed that the Standards no longer apply to under 18s. The Service Framework Programme Board decided that the Standards and associated key performance indicators for children and young people would be more appropriately positioned in the Service Framework for Children and Young People.[20]

The Service Framework for Children and Young People was consulted on in 2015 but has never been published.[21] This Framework is an important mechanism for monitoring the implementation of a broad set of core standards set across children's services, and it is unacceptable that it has not been finalised. NICCY has been informed in writing by the Service Framework Programme Board that 'the Service Framework is in the final stages of completion, including updates to ensure the most relevant policy documents and guidelines have been referenced. In the letter response, it goes on to say that 'it is also the case that a decision will need to be made with regards to Ministerial approval, but the Department hopes to launch the Service Framework in the near future'.[22]

It is also entirely unacceptable that young people have been removed from the 2010 service standard without something equivalent or better to replace it, thereby creating a further gap in terms of monitoring of services. Moreover, this is particularly concerning within a context where there is already limited publically available, regular and regionally standardised monitoring of children and young people's mental health services.

1.6 Funding Mental Health Services for Children and Young People

"Budgets are the most tangible expression of a government's priorities, performances, decisions and intentions. In order to engage effectively with the government it is important to understand the budget process and be able to study and analyse it. Having a proper understanding of budgetary processes, allocations and outcomes enables civil society to recognise efficiencies and successes, as well as create effective advocacy strategies for seeking more commitment from the state, holding it accountable and ensuring more effectiveness and transparency in how public money is spent." (Sneddon, 2014)

Analysing expenditure on services is one measure of their adequacy, allowing for the establishment of a baseline against which any increase, or decrease, in expenditure can be tracked. Exploring the funding of services also provides a tangible way of getting an overview of the services available to children and young people to support their emotional and mental well-being, how they are funded, who is delivering the services, how many staff are involved and the numbers of children and young people availing of the services.

Identifying budget spend on its own is a crude measure, however, it is also important to explore the efficiency and effectiveness of services. Those who commission services should regularly and robustly monitor how effective these are in delivering positive

20 Confirmed to NICCY by Letter from the Chief Medical Officer (Member of the Service Framework Programme Board) – June 2018.

21 https://www.health-ni.gov.uk/consultations/revised-service-framework-mental-health-and-well-being-2018-2021

22 Ibid, footnote 24.

outcomes for children and young people. This would allow a clearer understanding of the opportunities to better coordinate programmes and services supported by different Departments and Agencies, and to identify if improvements could be made to the commissioning and/or contracting processes. Mapping expenditure alongside outcome measurements would also help to determine whether a reconfiguration of funding for services would deliver better outcomes for the same budget.

Children and young people's mental health services have often been described as the 'Cinderella of the Cinderella services' in recognition of the fact that they are chronically underfunded. There has been no change in recurrent investment in CAMHS for many years, even though the evidence suggests that there is increasing need.

In 2017 only 7.8% of Northern Ireland's mental health budget was allocated to CAMHS services, approximately £20 million for Steps 3 to 5 services (HSCB, 2017) despite children and young people comprising almost 25% of Northern Ireland's population. This is widely accepted as insufficient.

The HSCB is the statutory body responsible for commissioning mental health services in Northern Ireland, this includes child and adolescent mental health services (CAMHS). It has calculated that investment in CAMHS should be around 10% of the mental health budget, based on a similar proportion of the UK national spend on mental health, and has thus identified a funding gap of £4.8 million per annum.[23]

While the recommendation by the HSCB is welcome, the proposed increase in resource allocation assumes that the overall mental health budget in England is similar per head to Northern Ireland, and that the prevalence of mental ill health is the same across the two jurisdictions. Furthermore, even if this were the case, the gap in funding would only bring investment in CAMHS up to a comparable level to England, but is not a measure of what is required to meet the needs of children and young people in Northern Ireland. Without evidence of the prevalence of mental ill health among children and young people, it is impossible to determine the level of investment required to meet need.

In addition, there is widespread recognition of the importance of prevention and early intervention services, largely those within Steps 1 and 2 of the CAMHS Stepped Care Model. However, to date, these services haven't been included in analyses of the funding of services provided to support the emotional and mental health of children and young people. Including Step 1 and 2 services in this work not only recognises their importance for ensuring best outcomes of children, but the involvement of a much wider range of actors in the funding and delivery of CAMHS in Northern Ireland.

Despite the general acceptance that more resources are required to fund emotional and mental health services for children and young people, it is notable that, on two recent occasions when the UK government allocated additional resources to CAMHS in England, the proportionate 'Barnett Consequential' resources were not then allocated to CAMHS in Northern Ireland.

More recently, the additional allocation of £10 million per annum for five years to mental health services in Northern Ireland through the 'Confidence and Supply' agreement between the Conservative government and Democratic Unionist Party has provided an

23 Letter to NICCY from HSCB in response to request for information, March 2017.

ideal opportunity to address the inequality in funding between CAMHS and AMHS. Indeed, the Department of Finance Briefing on Northern Ireland Budgetary Outlook published in Autumn 2017 stated that, while it would be for a Health Minister to determine how this additional resource would be spent, there were seven 'key areas for investment', of which one was 'Children and Adolescent Mental Health Services and infant mental health focussing on early intervention'. (DoF, 2017).

NICCY responded to this Briefing by advising that, as a minimum, 25% of this additional resource for mental health services should be allocated to child and adolescent mental health services, in recognition of the fact that children and young people make up 25% of the population.

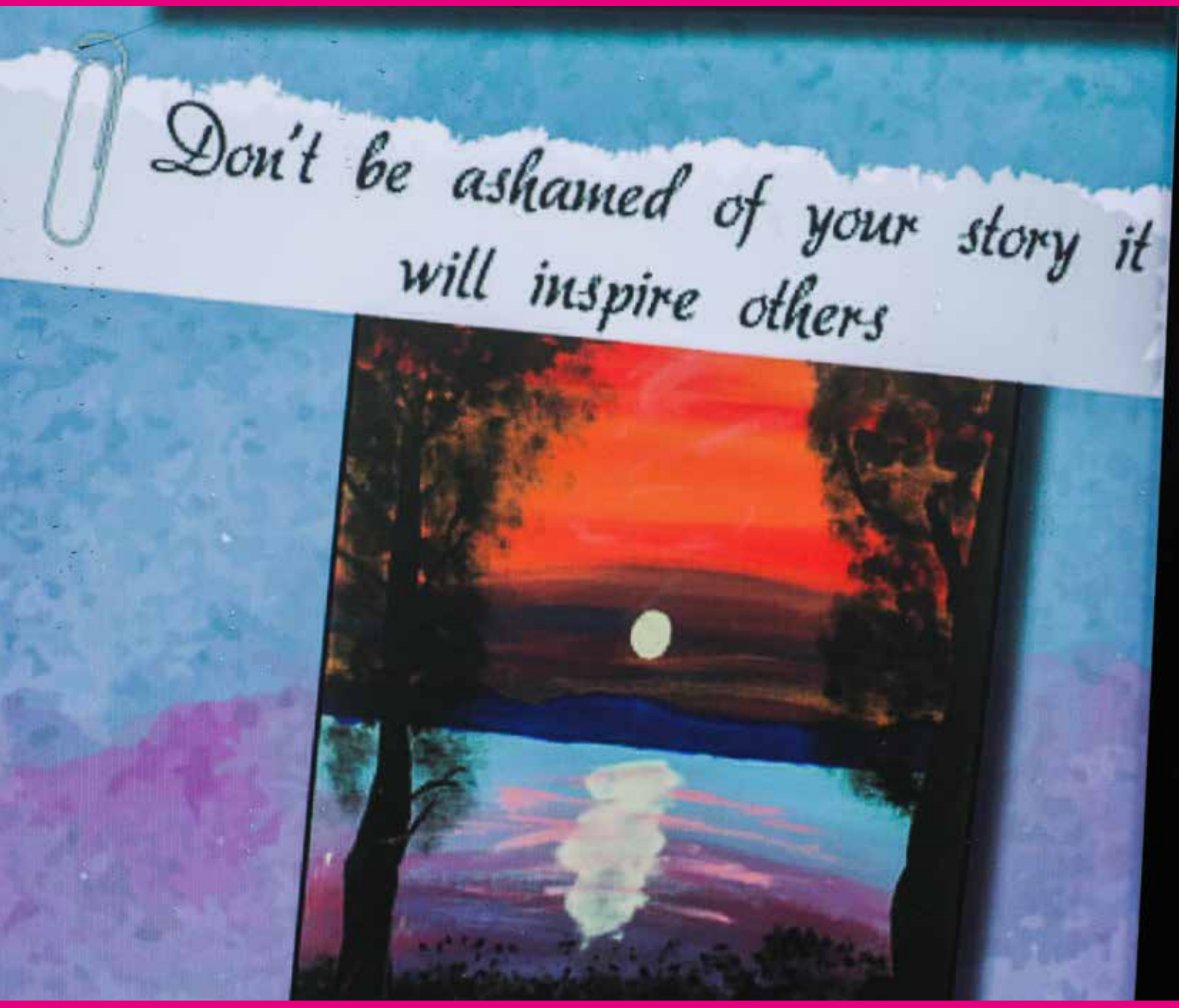
When NICCY subsequently wrote to the Department of Health to inquire as to how the first £10 million of this 'Confidence and Supply' money was to be allocated, the response was that none of it would be dedicated specifically to CAMHS.[24] Further correspondence clarified that £986k from the 'Transformation Fund' would be allocated to CAMHS including, funding research to determine the prevalence of mental ill-health among children and young people, and improving the CAMHS information systems.

While this is welcome, it remains extremely disappointing that the Department of Health has not taken the opportunity of this additional allocation of resources for mental health services to address the inequality of funding for CAMHS and AMHS. Indeed, this would have been very clear if an Equality Impact Assessment (EQIA) had been carried out on this budget decision and would have demanded mitigation of the clear adverse impact suffered by children as a result of the failure to adequately resource CAMHS. However, an EQIA was not conducted. The Permanent Secretary of DoH informed NICCY that the responsibility for section 75 impact assessment for the projects funded through the Transformation Fund lay with individual project owners.

This is clearly contrary to the advice of the Equality Commission, which stated in its response to the EQIA on Building A Better Future (ECNI, 2008):

"…the development of an EQIA of the draft PfG / Budget / ISNI simultaneous to policy and budgetary development process would have……allowed for a public debate that was better informed about equality aspects and therefore led to a more detailed and high quality consideration of these. The failure to do so represents a lost opportunity to embed equality aspects effectively in the development and finalisation of the draft PfG / Budget / ISNI. Further, the recent review of effectiveness of Section 75 highlighted the need for the EQIA to be applied as a positive tool to aid the policy development process and that an EQIA carried out after the development of the policy was not only inefficient in terms of time but ineffective when policy makers are reticent to make changes at a later stage. This calls into question the credibility of the process and Government commitment to addressing inequalities. The Commission expects that the development of the policies in future will incorporate an equality assessment simultaneous and at the earliest possible stage to ensure that consideration of equality issues will be integral to the consultation process at the outset and, therefore, to the development of the policies." (Our emphasis)

24 Information provided by letter to NICCY from HSCB, August 2018.



SECTION 2

A CHILD RIGHTS FRAMEWORK FOR EMOTIONAL WELLBEING AND MENTAL HEALTH

2.1 Introduction

As a rights based review, a central aim of this Review was to explore the challenges to realising children and young people's rights to access quality mental health services, as provided for by the UNCRC. This sections outlines the child rights framework for children's rights to mental health services and support.

2.2 The United Nations Convention on the Rights of the Child

The United Nations Convention on the Rights of the Child (UNCRC) is the most complete statement of children's rights ever produced and is the most widely-ratified international human rights treaty in history. It contains 54 articles that cover all aspects of a child's life and sets out the civil, political, economic, social and cultural rights to which all children everywhere are entitled. It also explains how adults and governments must work together to make sure all children can enjoy these rights.

The UK State Party, and Northern Ireland as a devolved administration, ratified the UNCRC in 1991 and it subsequently came into force in 1992. As a binding International Treaty, it places obligations and responsibilities on States and their institutions to uphold and realise the rights it contains in it for children and young people.

The UN Committee on the Rights of the Child ('the Committee') is a Committee of international experts with responsibility for advising states on how to interpret the articles of the UNCRC, and monitoring how effectively governments are implementing it.

States are required to submit periodic reports to the Committee on how they are delivering on their commitments within the UNCRC.

As State Parties reports are examined, the Committee also takes written and oral evidence from civil society organisations, including Children's Commissioners, and then produces a 'Concluding Observations' report. This includes specific recommendations on actions State Parties should take to more effectively implement children's rights.

In addition, and drawing the learning from examining State Party reports, the Committee publishes guidance on the articles of the UNCRC, in the form of 'General Comments'. These focus on particular themes, for example:

- General Comment No. 5: General measures of implementation of the Convention on the Rights of the Child;
- General Comment No. 7: Implementing child rights in early childhood;
- General Comment No. 9: The rights of children with disabilities;
- General Comment No.12: The right of the child to be heard; and
- General Comment No.15 on the rights of the child to the enjoyment of the highest attainable standard of health.

Definition of a Child

The UNCRC defines a child as 'every human being below the age of 18 years old' (Article 1). It also emphasises non-discrimination as a core right, and that all rights apply equally to all children under 18 years, irrespective of age (Article 2). The UNCRC acknowledges children as 'rights holders' and imposes obligations on States as duty bearers for the respect, protection and fulfilment of children's rights. The rights are grouped into three key domains of participation, protection and provision.

UNCRC Guiding Principles
There are four guiding principles of the UNCRC which underpin all other rights, including the right to health:

Article 2: Children's right to non-discrimination. In the context of health, requires State Parties to uphold and realise every child's equal right to the best possible health and access to health services without discrimination on any basis.

Article 6: Right to life and to survival and development to the maximum extent. Article 6 requires State Parties to guarantee the child the fundamental right to life and to survival and development to the maximum extent possible. The concept of "survival and development" to the maximum extent possible is crucial to the implementation of the whole Convention (UNICEF, 2007). In its General Comment No. 7, the Committee provides some detail on the obligations on Government by virtue of Article 6 of the UNCRC. It states:

"Article 6 refers to the child's inherent right to life and States Parties' obligation to ensure, to the maximum extent possible, the survival and development of the child… Ensuring survival and physical health are priorities, but States Parties are reminded that article 6 encompasses all aspects of development, and that a young child's health and psychosocial well-being are in many respects interdependent. Both may be put at risk by adverse living conditions, neglect, insensitive or abusive treatment and restricted opportunities for realizing human potential. Young children growing up in especially difficult circumstances require particular attention... The Committee reminds State Parties (and others concerned) that the right to survival and development can only be implemented in a holistic manner, through the enforcement of all the other provisions of the Convention, including rights to health, adequate nutrition, social security, an adequate standard of living, a healthy and safe environment, education and play (arts. 24, 27, 28, 29 and 31), as well as through respect for the responsibilities of parents and the provision of assistance and quality services (arts. 5 and 18)." (UN, 2005)

Article 6 of the UNCRC goes beyond the fundamental right to life to promote survival and development 'to the maximum extent possible'. The concept of 'development' is not just about the preparation of the child for adulthood. It is about providing optimal conditions for childhood, for the child's life now. The Committee expects implementation of all other articles to be carried out with a view to achieving the maximum survival and development of the child – a concept integral to the best interests of the child (UNICEF, 2007).

Article 3: Best interests of the child being a primary consideration in all matters. This principle must be adhered to in all health related decisions concerning individual children or groups of children. Individual children's best interests should be based on their physical, emotional, social and educational needs, age, sex, family and social background, and after having heard their views as required by Article 12 of the UNCRC. The Committee urges State Parties to place children's best interests at the centre of all decisions affecting their health and development, including the allocation of resources, and the development and implementation of polices and interventions that affect the underlying determinants of health. For example, the best interests of the child should guide treatment options, and include giving children and young people access to appropriate information on health issues (UN, 2013).

Article 12: Views being given due weight in accordance with age and maturity. This outlines children's fundamental right to participation, including in health promotion, the need to respect the views of the child in decisions made about their own health care, and in the planning and provision of health services (UNICEF, 2007). One important aspect of this is the recognition of children's evolving capacity to make decisions about

their own health care. Although no explicit distinction is made under international human rights law between children of different ages, the Committee does stress that implementation of rights must take account of children's development and their evolving capacities (Article 5). This is a very significant issue when one considers the lack of input and autonomy children often have in decision making about their lives. In particular, the Committee has emphasised the need to ensure that appropriate weight is afforded to the views of adolescents and has been clear that the approaches required to ensure the realisation of rights of adolescents differ significantly from those required for younger children (UN, 2016). The Committee is clear that Article 12 of the UNCRC includes the obligation to assess the capacity of the child to form an autonomous opinion to the greatest extent possible (UN, 2009). State Parties cannot begin with the assumption that a child is incapable of expressing her or his own views. On the contrary, States should presume that a child has the capacity to form her or his own views and recognise that she or he has the right to express them; there should be no conditions on the child to prove her or his capacity to realise this right. The Committee emphasises that Article 12 imposes no age limit on the right of the child to express her or his views, and discourages State Parties from introducing age limits either in law or in practice which would restrict the child's right to be heard in all matters affecting her or him (UN, 2009). The child's right to be heard, and participate in Article 12, also requires that the right to access information must also be upheld, as children cannot adequately exercise their right to participate unless they have an 'informed voice' (Article 17).

2.3 Children's Right to Health

The Committee states that health rights are inclusive in that they cover prevention, health promotion, intervention and rehabilitative services.

"The Committee reaffirms that health rights are inclusive – extending not only to timely intervention but also prevention, health promotion and rehabilitative services including the right of the child to develop to their full potential and to attain the highest standard of health in an environment where the underlying determinants of health are addressed." (UN 2013, at para. 2)

Furthermore, due to the holistic nature of the UNCRC, all rights contained within it are indivisible and inter-dependent, therefore children's access to other rights such as protection from violence and abuse (Article 19) and access to an adequate standard of living (Article 27) will directly impact on their physical and mental health.

For this reason, the need for co-operation and integration between systems is more likely to address the holistic needs of these children and young people and is key to achieving better outcomes for them. Joint working and collaboration is particularly important for young people who have a complex range of needs which require the input of more than one professional group.

"A holistic approach to health places the realisation of children's right to health within the broader framework of international human rights obligations." (UN 2013, at para. 2)

"A 'child health in all policies' strategy should be used, highlighting the links between children's health and its underlying determinants. Every effort should be made to remove bottlenecks that obstruct transparency, coordination, partnership and accountability in the provision of services affecting children's health." (UN 2013, at para. 99)

However, there are a number of rights contained within the UNCRC that are of particular relevance when one considers health; Article 24 sets out children's right to health, and builds on and develops the rights to life, survival and development to the maximum extent possible set out under Article 6. Paragraph 1 of Article 24 specifically refers to the rights of a child to the highest attainable standard of health and to facilities for treatment and rehabilitation.

Article 24 (1) States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.

Article 24 (2) provides a list of appropriate measures that States must take in pursuing the full implementation of Article 24. These include Articles 24 (2) (b) and (f) which are of particular relevance to mental health support as they focus on the role of primary health care in the provision of necessary medical assistance and health care to all children, and the need for preventative health care and guidance for parents.

Article 25 sets out the role of State Parties where a child has been admitted to hospital for treatment, and in particular their right to a periodic review.

Article 25 States Parties recognize the right of a child who has been placed by the competent authorities for the purposes of care, protection or treatment of his or her physical or mental health, to a periodic review of the treatment provided to the child and all other circumstances relevant to his or her placement.

Article 23 specifically refers to children with a disability and the need to ensure that they have effective access to services, including health care and rehabilitative services. It states that services:

23 (3) ...shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.

Article 33 sets out the obligations on States Parties to take all appropriate measures to protect children from narcotic drugs and psychotropic substances (which include legal highs). State Parties should:

33 ...take all appropriate measures, including legislative, administrative, social and educational measures, to protect children from the illicit use of narcotic drugs and psychotropic substances as defined in the relevant international treaties, and to prevent the use of children in the illicit production and trafficking of such substances.

The right to health is not to be understood as a right to be 'healthy'. The right to health contains both 'freedoms' and 'entitlements'. The 'freedoms' include the right to control one's health and body, for example, the right to decline certain medical treatment. By contrast, 'entitlements' include the right to a system of health protection which

provides equality of opportunity for people to enjoy the highest attainable standard of health. (UNICEF, 2007)

Article 4 of the UNCRC sets out the principle of progressive realisation of children's rights, which includes children's right to health, and the obligation on Governments to adopt measures to the maximum extent of available resources. It affirms that:

"States Parties shall undertake all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in the present Convention. With regard to economic, social and cultural rights, States Parties shall undertake such measures to the maximum extent of their available resources and, where needed, within the framework of international co-operation."

2.4 Vulnerability and Discrimination

The Preamble of the UNCRC states that all young people are inherently vulnerable due to their age and evolving capacity and it has consistently underlined the need to give special attention to disadvantaged and vulnerable groups across all Articles of the UNCRC.

The Preamble of the UNCRC also reminds us that some children and young people are at greater risk of developing poor health and experience discrimination in accessing good quality health care, it has stated that "in all countries in the world, there are children living in exceptionally difficult conditions, and that such children need special consideration" (UNICEF, 2007).

In the Committee General Comment Number 13, on the Rights of the Child to the Enjoyment of the Highest Attainable Standard of Health it states that:
"There is growing recognition of the need for increased attention for behavioural and social issues that undermine children's mental health, psychosocial well-being and emotional development." (UN 2013, at para. 38)

There are specific Articles of the UNCRC that set out special provisions for children particularly prone to forms of discrimination, for example, children with disabilities (Article 23), and refugee children (Article 22).

2.5 UNCRC Concluding Observations

In every set of Concluding Observations by the UNCRC in 1995, 2002, 2008 and 2016, following its examination of the UK and Northern Ireland as a devolved administration, emphasis has been placed on the need for the State Party to consider the realisation of rights for those young people at greatest risk of discrimination in their enjoyment of these.

In the most recent examination of the UK and Northern Ireland, the Committee made a number of strongly worded recommendations.

60. *(a) Regularly collect comprehensive data on child mental health, disaggregated across the life course of the child, with due attention to children in vulnerable situations, and covering key underlying determinants;*
    (b) Rigorously invest in child and adolescent mental health services and develop strategies at national and devolved levels, with clear time frames, targets, measureable indicators, effective monitoring mechanisms and sufficient human, technical and financial resources. Such strategy should include measures to ensure availability, accessibility, acceptability, quality and stability of such services, with particular attention to children at greater risk, including children living in poverty, children in care and children in contact with the criminal justice system;
    (c) Expedite the prohibition of placement of children with mental health needs in adult psychiatric wards or police stations, while ensuring provision of age-appropriate mental health services and facilities;
    (d) Support and develop therapeutic community-based services for children with mental health conditions; and

(e) Review current legislation on mental health to ensure that the best interests and the views of the child are taken duly into account in cases of mental health treatment of children below the age of 16, in particular with regard to hospitalization and treatment without consent.

62. *The Committee also recommended that the State party:*

(b) Ensure that prescription of drugs is used as a measure of last resort and only after an individualized assessment of the best interests of that child, and that children and their parents are properly informed about the possible side effects of this medical treatment and about non-medical alternatives. (UN, 2016:2)

The Committee continued to repeat its recommendation that States legislate for a specific proportion of expenditure to be allocated to children's health; that this should be made visible in budgets; disaggregate data for planning and monitoring purposes; and produce child impact assessments (UN, 2013 and UN, 2016:2).

2.6 Childs Rights Standards for Implementation of the UNCRC in Relation to Mental Health Services

The standards for practical implementation of the UNCRC have been the framework around which the Terms of Reference and Methodology for this Review was developed, and these are summarised as follows:

1. **Availability** — adequate facilities and services in place to meet need.
2. **Accessibility** — equal access to mental health services for all children without discrimination.
3. **Quality / impact** — young people are offered a quality of service which adequately meets need, is appropriate and which improves well-being.
4. **Participation** — views of children and young people are gathered, seriously considered and taken into account in their own care planning and in the development of policy and services.

2.7 Requirement to Gather Data on Mental Health of Children and Young People and Associated Services

Objective need should be the main driver in all decision-making processes that concerns children and young people's mental health.

To deliver the best services for children and young people who are at risk of developing poor mental health, or who are presenting to services with mental health problems, it is necessary to understand the scale of the need, how well existing services are meeting need and where the gaps are. There is also a need to have a clear understanding of how investment is distributed across mental health services and how much additional investment would be required to meet the identified gaps in services and support.

The UNCRC takes a holistic approach to health and the Committee interprets children's right to health, as defined in Article 24, as an inclusive right that includes timely and appropriate prevention, health promotion, curative, rehabilitative and palliative services. For this reason it was important to attempt to gather information on the full range of mental health services that young people might be accessing. However, it was recognised that it would be much easier to gather information on specialist mental health services such as those that sit within Step 3-5 CAMHS, than for Steps 1 and 2. Prevention and early intervention services sitting within Steps 1 and 2 may not be primarily defined as mental health services, but have positive impacts on young people's mental health by addressing some of factors that, if not addressed, can cause poor mental health.

In its comments and advice to State Parties, the UN Committee on the Rights of the Child has repeatedly referred to the need to collect robust data to inform policy development, and service planning and delivery.

"At the heart of the development, implementation and monitoring of policies, programmes and services that aim to realize children's right to health is the availability of relevant and reliable data. This should include: appropriately disaggregated data across the life course of the child, with due attention to vulnerable groups; data on priority health problems, including new and neglected causes of mortality and morbidity; and data on the key determinants of children's health." (UN 2013, at para. 22)

The need to ensure that the CAMHS system operates in a manner which has due regard to the need to promote equality of opportunity is a statutory obligation on the Government in line with section 75 of the Northern Ireland Act 1998. Part of ensuring compliance with the obligations under section 75 of the Northern Ireland Act 1998 is the collection of data for the purposes of the promotion of equality of opportunity. Without such data it is impossible to ensure the promotion of equality of opportunity within the operation of the CAMHS system, and also to ensure compliance with section 75 of the Northern Ireland Act 1998. In addition, many of the data sets used in Northern Ireland are not comparable across agencies, much less jurisdictions. It is widely accepted that the statistics produced in relation to the state of children's rights in Northern Ireland are limited, and that those produced cross different parameters, timescales and ages. The UNCRC Committee's General Comment No 5 stresses that:

"Collection of sufficient and reliable data on children, disaggregated to enable identification of discrimination and/or disparities in the realisation of rights, is an essential part of implementation. The Committee reminds States parties that data collection needs to extend over the whole period of childhood, up to the age of 18 years. It also needs to be coordinated throughout the jurisdiction, ensuring nationally applicable indicators. States should collaborate with appropriate research institutes and aim to build up a complete picture of progress towards implementation, with qualitative as well as quantitative studies. The reporting guidelines for periodic reports call for detailed disaggregated statistical and other information covering all areas of the Convention. It is essential not merely to establish effective systems for data collection, but to ensure that the data collected are evaluated and used to assess progress in implementation, to identify problems and to inform all policy development for children. Evaluation requires the development of indicators related to all rights guaranteed by the Convention." (UN, 2003)

Reporting guidelines for periodic reports also state that quantitative information should indicate variations between geographical areas and between groups of children.

In its 2002 Concluding Observations the Committee recommended that the UK establish a nationwide system whereby disaggregated data is collected on all persons under 18 years of age for all areas covered by the UNCRC, and that this data is used to assess policies and progress to implement the UNCRC (UN, 2002). The Committee also recommended that the Government monitor the situation of a number of groups of children exposed to discrimination and that data collection was central to this monitoring (UN, 2002).

In its 2008 Concluding Observations the Committee urged the Government to address all outstanding recommendations which have not yet been sufficiently implemented and drew the attention of the Government again to the Committee's General Comment No 5 on General Measures of Implementation (UN, 2008). This was reasserted again by the Committee in its most recent Concluding Observations following its examination of the UK Government's compliance with its obligations under the Convention:

"60. The Committee recommends that the State party:

(a) Regularly collect comprehensive data on child mental health, disaggregated across the life course of the child, with due attention to children in vulnerable situations, and covering key underlying determinants;
(b) Rigorously invest in child and adolescent mental health services and develop strategies at national and devolved levels, with clear time frames, targets, measureable indicators, effective monitoring mechanisms and sufficient human, technical and financial resources. Such strategy should include measures to ensure availability, accessibility, acceptability, quality and stability of such services, with particular attention to children at greater risk, including children living in poverty, children in care and children in contact with the criminal justice system." (UN, 2016:2)

Despite the Committee making repeated recommendations to Government regarding its data collection obligations, there remains a need to prioritise the setting up of systems for disaggregated data collection across all aspects of children's lives.

The Committee's General Comment on General Measures of Implementation refers specifically to the implementation of Article 2 of the Convention – the right to be protected from all forms of discrimination and states that:

"…this non-discrimination obligation requires States actively to identify individual children and groups of children the recognition and realization of whose rights may demand special measures. For example, the Committee highlights, in particular, the need for data collection to be disaggregated to enable discrimination or potential discrimination to be identified." (UN, 2003)

Without robust systems in place to collate disaggregated data on the lives of children and young people who are accessing or attempting to access mental health and emotional well-being services and support, it is not possible to comply with the children's rights and equality obligations outlined above.

2.8 Requirement to Demonstrate Allocation 'To Maximum Extent' of Available Resources to Realise Children's Rights

The importance of analysing spending on children's services, as a key way of monitoring how effectively governments are complying with their obligations under the UNCRC, has been consistently highlighted by the Committee based on the fundamental premise that children and young people are entitled to 'special care and assistance' because of their age and evolving capacity.

Article 4 places obligations on Government to allocate the maximum extent of available resources to the delivery of children's rights. It states:

"States Parties shall undertake all appropriate legislative, administrative, and other measures for the implementation of the rights recognised in the present Convention.

"With regard to economic, social and cultural rights, States Parties shall undertake such measures to the maximum extent of their available resources and, where needed, within the framework of international co-operation."

The Committee has provided detailed guidance on how this Article is to be interpreted in relation to public budgeting in its General Comment No.19 (2016) on public budgeting for the realisation of children's rights (Article 4).

"States parties shall undertake such measures to the maximum extent of their available resources" means that States parties are expected to demonstrate that they have made every effort to mobilise, allocate and spend budget resources to fulfil the economic, social and cultural rights of all children." (UN, 2016:3)

Article 44 of the UNCRC places an obligation on State Parties to regularly report on their progress in advancing the rights of children within their jurisdiction. The Committee has made it clear that this should involve the use of 'clear and consistent qualitative and quantitative goals and indicators', and that 'States parties are expected to regularly review and improve their measures to ensure the availability and maximisation of resources for the rights of all children'. (UN 2016: 3, para 32)

General Comment 19 outlines five principles of public budgeting for children's rights. These are effectiveness, efficiency, equity, transparency and sustainability:

1. Effectiveness – governments should plan and implement budgets and services in such a way that they deliver measurably improved outcomes for children and young people.

2. Efficiency – public resources should be dedicated to programmes for children in a way that delivers value for money through sound financial management. This includes making efforts to overcome institutional barriers that impede efficient spending.

3. Equity – public resources should be spent fairly in order to promote equality. This doesn't necessarily mean spending an equal amount on each child, but targeting resources to promote substantive equality among children.

4. Transparency – state financial systems and practices must be open to public scrutiny, contributing both to efficiency and enabling meaningful participation of civil society, including children, in the budget process.
5. Sustainability – governments should prioritise the best interests of current and future generations of children in all budget decisions, allocating resources to ensure the progressive realisation of children's rights.

The General Comment also provides guidance and recommendations on the four stages of the public budgeting process: planning; enacting; executing; and following up, and emphasises the importance of effective cross-sectoral, inter-ministerial, interdepartmental and inter-agency coordination and cooperation throughout the budgeting process to fully realise children's rights.

SECTION 3

METHODOLOGY

3.1 Overview of the Three Strands of the Review

A mixed methods approach was taken to this Review, which included the 3 strands of work set out below:

1. **Gathering children and young people's experiences of having had or trying to get help for their mental health**

   Feedback was gathered using an online survey with young people aged 11–21 years old, who had experience of accessing, or trying to access, support for their mental health. In addition to the online survey which any child or young person could complete, face to face interviews were carried out with two specific groups of young people, these were young people with a mild learning disability or difficulty (aged 17–25 years old), and those who had alcohol and drug problems (aged 14–25 years old).

   Young people were asked to comment on services or support provided by GP services (including Out of Hours GP); School / College or University; Voluntary and Community Services; Community CAMHS; Accident and Emergency and In-Patient Care.

2. **Mapping and analysis of operational data on mental health services**

   Key relevant authorities were asked for information on mental health services available to children and young people and activity data attached to them i.e. number of young people accessing services, demographic profile of service users and waiting times for accessing services.

3. **Mapping and analysis of investment in mental health services**

   Key relevant authorities were asked for a detailed budgetary breakdown of investment in services contained in the Stepped Care Model for CAMHS.

3.2 Advisory Groups

There were two groups used to inform and advise NICCY during all stages of the Review, one was a group of professionals and one was comprised of members of the NICCY Youth Panel. Engagement with both groups included a number of face to face meetings and email contact.

Mental Health Professional Advisory Group

The purpose of the Professional Advisory Group was to:

1. Support the development of the methodology for the Review;
2. Support the interpretation of data collated and the development of recommendations for key government departments and agencies; and
3. Review draft reports and provide feedback.

Young Person Mental Health Advisory Group

A subgroup of the NICCY Youth Panel provided invaluable support at key stages of the Review. This included:

1. Supporting the development of the methodology for the Review;
2. Involvement in the design and promotion of the young people's survey; and
3. Reviewing the Children and Young People's report and providing feedback on the design, findings and recommendations.

3.3 Ethical Review Process

The proposed methodology for the Review applied NICCY's ethical procedures and guidelines for research. This involved completing an Ethical Approval Form.[25]

This process involved considering how consent would be sought, identifying perceived risks associated with the research and steps to be taken to minimise these, addressing issues of confidentiality, anonymity and data protection, and managing the potential disclosure of information.

The Approval Form was reviewed internally by, the Head of the Policy and Participation, and senior staff within the Policy and Participation, and Legal Teams. In addition to this, three external academic professionals, with relevant expertise, were asked to provide feedback on the proposals. The Ethical Approval Form was amended based on the feedback from the internal and external reviewers, and formally signed off by NICCY's Chief Executive.

3.4 Definitions and Inclusion Criteria

The main focus of the Review was on children and young people's experience of using or trying to access mental health services.

The information leaflets and promotional materials used to engage with young people described 'mental health' and 'mental health services' in the following ways:
For the purposes of the Review, **'mental health'** was defined as a young person's 'emotional well-being and mental health', including conditions such as depression, anxiety, stress, bipolar disorder, eating disorders and the wide range of other mental health problems that children and young people may experience. It was made clear to young people that they did not need to have a mental health diagnosis to take part in the Review.

When engaging with young people with a learning disability and their parents/carers the language used to describe 'mental health' was adapted to reflect the terminology they were more likely to be familiar with. This included mental health as, 'how we feel inside' and 'how able we are to cope with day to day things' or 'mental health, emotional health or behavioural problems'.

'Mental health services' were defined as the wide range of services and support that a child may have used or tried to access. These include statutory specialist mental health services ('often referred to as CAMHS') but also includes services or support offered through General Practitioners (GPs), Schools / Colleges/ Universities, and Voluntary and Community Sector Services, Accident and Emergency Departments (A&E) or Inpatient Care.

When engaging with young people with a learning disability and their parents and carers, the language used to describe 'mental health services' was broadened in recognition of the wider range of health professionals from whom have sought help. They include Child and Adolescent Mental Health Services (CAMHS), Community Nurses, Psychiatrists/Psychologists who work within Disability Teams, Behaviour Support Services, and Autism Spectrum Disorder (ASD) or Autism Teams.

25 NICCY Policy and Research, Ethical Procedures and Guidelines – developed 2018

3.5 Strand 1: Children and Young People's Survey

An online survey for young people aged 11–21 years old was developed to capture their experiences of accessing or trying to access mental health services or support. The age range of 11–21 years old was chosen because the average age of young people entering CAMHS is 14 years old, but we know that children can become aware of problems before that. Young people tend to transition out of CAMHS at 18 years old, so the survey was extended to those aged 21 years old to capture their experience of moving between child and adolescent mental health services.

Respondents were not asked for their name or contact details, therefore the survey was anonymous. Parents and carers were encouraged to support their child to complete the survey.

Structure of the Survey

The Children and Young People's Survey had a number of key sections, these included:

- Experience of looking for help;
- Experience of using the following 7 mental health services / support': GP services; Schools / Universities / Colleges; Voluntary and Community Organisations; Community CAMHS; AandE; Out of Hours GP, and In-Patient Care;
- Experience of moving from child and adolescent to adult mental health services; and
- Experience of waiting to access services, mental health appointments and of making complaints about mental health services.

The following demographic questions were included in the survey: age, gender, county of residence, disability, ethnic background, sexual orientation, current living situation i.e. home with family, living independently, homeless, in care, youth justice centre, secure care, or in hospital.

Rights Based Statements or Indicators

Respondents were asked to rate their experience of the seven services / supports against a range of rights based statements or indicators. The standards of practical implementation of the UNCRC were used to develop the rights based statements or indicators that are listed below. Further details on these UNCRC standards are included in the background section of the report.

The rights based statements used in the Children and Young People's survey relate to three key areas set out below. For each service, respondents were asked to use a 5 point Likert agreement rating scale of strongly agree, agree, disagree, strongly disagree, and I don't know / I'm not sure.

Information and Access

- I was given useful information to help me to understand my mental health needs.
- I was given a choice of treatment / support.

Facilities/ Services

- The place that I received support in made me feel comfortable and safe.
- I didn't have to travel far to get help / receive services.
- I was able to access the service / support when I needed it.

Quality of Care

- I felt listened to and respected.
- I was spoken to in a way that I could understand.
- I felt involved in the decisions that were being made about my care or treatment.
- The support I received was helpful.

The survey was hosted on the NICCY website, on a webpage developed for the Review called 'Speak Your Mind'. Respondents were provided with background information and instructions to prepare them for completing the survey.

Survey – Consent and Safeguarding

All respondents were required to give their consent before completing the survey by confirming that they understood what the survey was about and were happy to complete it. Respondents aged under 16 years old were asked to get permission from their parent or carer before completing the survey. Only those who confirmed that they agreed to these statements were able to proceed through the survey. This included encouraging them to ensure someone knew they were completing the survey, and was available to provide them with support if necessary. Respondents were given contact numbers for emotional well-being/mental health support.

The opening pages of the survey reminded young people that the survey is anonymous and signpost them to relevant supports / helplines if they are concerned about the safety of themselves or others.

Piloting of the Survey

Feedback was received on the draft Children and Young People's Survey from the NICCY Mental Health Professional Advisory Group and piloting was undertaken with four young people with experience of using mental health services. They included past and present users of services, and young people with experiences of a range of different services. In general, the feedback was that the questions were relevant, the survey was easy to navigate and understand, but it was too long. Based on the feedback, some questions were removed and a number of additional shortcuts added throughout the survey i.e. skip questions and sections.

Promotion of the Online Survey

The survey was hosted on the 'Speak Your Mind' webpage, which included background information about the Review and videos of young people explaining how to complete the survey.

Posters and fliers were used to promote the survey through a range of sources, including CAMHS clinics, GP surgeries, chemists, post primary schools and university/ colleges. Over 200 Youth and Voluntary and Community organisations were contacted with posters and fliers.

NICCY Staff also carried out workshops and attended events such as fresher fayres, youth/ mental health practitioner events to promote the survey. The survey was also advertised on NICCY's social media platforms. Facebook advertising was used to promote the survey, including targeted advertising to attract groups that were under-represented in the sample, males and those who lived outside County Antrim.

A hard copy version of the Children and Young People's Survey was produced for specific groups of young people without access to the internet i.e. young people living in residential facilities and the Juvenile Justice Centre at Woodlands. These hard copy questionnaires were then manually input to Survey Monkey, the software used to capture the online responses. Young people were also given a telephone number to call if they preferred to complete the survey by phone.

The survey remained open from June – November 2017, the slightly longer data collection period was in order to promote the survey through post primary schools and universities and colleges when they returned from summer holidays in September 2017.

Parents / Carers Survey

In addition to the Children and Young People's Survey, a shorter online survey for parents/carers was developed using the young people's survey as a template. It was not promoted to the same extent as the children and young people's survey because the latter was the focus of the Review. The parent/carers survey was piloted with two parents who had children and young people that had accessed mental health services.

Response Rates to the Parent/Carer Survey

Overall, 76 parents/carers responded to the survey. The response to different sections of the survey varies depending on whether the parent/carer had experience of each of the specific services and whether they choose to answer the questions.

Response Rate to Children and Young People's Survey

604 young people started the survey, however, not all young people had experience of every service covered, for this reason the sample size varies for each service. Young people could also choose to skip any questions they did not want to answer, irrespective of whether they had experience of them or not.

The table below sets out the number of young people that responded to each of the different services covered in the survey, and the number of young people that shared their experience of moving from CAMHS to AMHS. Also, every graph or figure includes a base number below it which refers to the number of young people that answered that specific question.

Table 3.1 Survey response rates by each service

Service	Response
GP	246
School / College / Uni	145
VCS	78
CAMHS in Community	130
A&E	62
Out of Hours GP	27
In-Patient Care	28
Transitions	37

Demographic Profile of Young People's Survey Responces

In terms of the gender breakdown of respondents, 71% of the young people surveyed identified as female, 23% as male, and 6% identified as 'other', or would rather not say. Other surveys and interviews carried out on mental health services in Northern Ireland have involved significantly more females than males (Rees et al. 2014; HSCB and PHA, 2017[26]).

Slightly over half of the young people surveyed were aged 16–18 years old (54%), 20% were aged under 16 years old and 26% were aged between 19–21 years old.

There was a good range of experiences of the survey respondents in terms of their current situation in accessing mental health support: 33% had received help in the past; 23% were currently receiving services; 16% were trying to get help for their mental health; 15% had tried to get help in the past; 8% were waiting

26 See background section 'previous relevant work' for further details.

for an appointment; 4% need help but hadn't had any and 15% would rather not say.

The vast majority (92%) of the young people surveyed described themselves as being from a white ethnic background and 83% were living with family. 17% were living somewhere other than with family and this included independent or shared living, being in care, homeless, living in a hostel or detained in Woodlands Juvenile Justice Centre.

Of the young people who responded to the survey, 43% had been told they have a mental health condition or illness. Anxiety and depression were the most common conditions reported by the young people and they were also commonly reported together. Other conditions reported included eating disorders, personality disorders, ADHD and self-harm. This is typical of the type of conditions young people are diagnosed with, or treated for (Khan, 2016).

In the survey we asked young people what part of Northern Ireland they came from: 42% stated they came from County Antrim, 17% from Down, 14% from Derry/Londonderry, 13% from Armagh, 6% from Tyrone, 4% from Fermanagh and 3% didn't know or would rather not say.

Young people were also asked which Health and Social Care Trust (HSCT) area they were from, however, large numbers didn't know or didn't answer this question.

3.6 Strand 1: Thematic Interviews

In addition to the survey, interviews were conducted with two groups of young people known to have higher rates of mental health problems and who face particular challenges with accessing mental health services. These groups were young people with a mild learning disability or learning difficulty (n=15) and those with alcohol and drug problems (n=17).

The inclusion criteria for the interviews was young people aged 16–25 years old, who had experiences of accessing or trying to access mental health services.

Profile of Learning Disability Interview Participants

Fifteen young people with a mild learning disability or difficulty were interviewed across five locations: eight were male and seven were female and they were aged between 17–25 years old, with an average age of 21 years old.

Table 3.2 Profile of Learning Disability Interview Participants

Location	Response	Male	Female
Carrickfergus	3	1	2
Newry	1	1	0
Magherafelt	3	3	0
Fermanagh	3	1	2
L/Derry	5	2	3
Overall	**15**	**8**	**7**

Profile of Alcohol and Drug Use Interview Participants

Seventeen young people with drug and alcohol problems were interviewed across four locations: 10 were male and seven were female and they were aged between 14–25 years old, with an average age of 19 years old.

Table 3.3 Profile of Alcohol and Drug Use Participants

Location	Response	Male	Female
Portadown	5	3	2
Ballymena	3	2	1
Belfast	4	3	1
L/Derry	5	2	3
Overall	**17**	**10**	**7**

Consent for Interviews

Due to the nature of the subject matter and the specific vulnerability and capacity issues affecting the young people participating in the interviews, consent from parents/carers was considered on a case by case basis. As a minimum all young people under 14 yrs old required parental consent, along with the consent or assent of the young person. For those aged 14–17 yrs old, where a young person's consent was provided, it was sufficient to notify parents/guardians concerning the young person's involvement in the review. Consent was not required from parents/guardians, if the researcher and partner organisation were satisfied that consent has been given by the young person.

In line with the overarching rights basis of the Review, participants were not automatically excluded from the research because consent was more difficult to determine because of their disability or condition. Decisions about the involvement of young people in the Review balanced rights to inclusion, privacy and autonomy, alongside rights to protection from harm and exploitation.[27]

During the ethical review process, the decision was made to use both 'consent' and 'assent' (young person does not object to being interviewed) as criteria for involving young people in the research. Consent or assent was gathered orally before interviews began and at interview. Where informed consent was not possible from a young person, due to limitations to their understanding of the research and how the information would be used, the informed consent of the parent/guardian was sufficient for the young person to be interviewed. However, as a minimum the young person's assent to taking part was required and agreement gained by the partner organisation that it was appropriate.

Adaptations made to Interview process

People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people. In order to make the process for engagement in this research with young people with a learning disability as accessible and meaningful as possible, a two stage process was developed, this included a workshop followed by one to one interviews.

The aim of the workshops was to explore mental health and explain the Review to the young people. It was also an opportunity to identify young people who met the criteria and were interested in taking part. A further benefit of the workshop stage was that both young people and interviewer were introduced to each other before the interview stage. Young people recruited during the workshop for interviews were given a specific date to meet with the interviewer. Visual aids were developed to support young people during the interviews, these included example pictures of some of the things that might be

27 Ethical challenges and complexities of including people with intellectual disability as participants in research, Journal of Intellectual and Developmental Disability, Iacono. T. (Sept 2006; 31 (3): 173-179)

important to them about services/support e.g. what buildings looked like, how staff dressed and behaved.

Key Partner Organisations

Engagement with young people was carried out in partnership with three organisations known to work with the groups of young people that met the criteria for inclusion Review.

Mencap is a UK wide organisation that works with people who have a learning disability. The young people interviewed were mainly recruited through their employment support service, as the age range of the clients in this service fitted with interview age criteria (16–25 years old).

For the purposes of the Review, NICCY chose to use the term 'learning disability' rather than 'intellectual disability' as this is the terminology used by the key partner organisation. Mencap describe a 'learning disability as a reduced intellectual ability and difficulty with everyday activities e.g. household tasks, socialising or managing money which affects someone for their whole life.

The interviews with young people with alcohol or drug problems were carried out through Start 360 and Dunlewey Addiction Services. Start 360 is a delivery partner for the DAISY service (The Drug and Alcohol Intervention Service for Young People). It runs services in the Belfast, South Eastern, Western and Northern Health and Social Care Trusts. DAISY is a government funded service for young people aged 11–25 years old whose substance use is impacting on them, their families or communities. The support offered includes therapeutic mentoring, individual counselling, therapeutic group work and family based interventions.

Dunlewey Addiction Services provides youth support and substance use counselling in the Southern Health and Social Care Trust (SHSCT) area.

Interviews – Safeguarding

These key partner organisations agreed to provide practical and emotional support to the young people before, during and after the recruitment process. A formal partnership agreement was drawn up between NICCY and each of the organisations young people were recruited from. This included agreeing safeguarding/child protection procedures with partner organisations with respect to roles and responsibilities of both parties. Safeguarding messages were provided to participants before the interview. This included exceptions to participant confidentiality i.e. where the researcher has concerns about the safety or well-being of the participant or criminal activity is disclosed during the course of the research. The three key partner organisations were also regional organisations, therefore maximising the reach across Northern Ireland.

Parent/Carer Discussion Group

A discussion group of parents/carers of young people with a learning disability and with experience of accessing or trying to access mental health services or support was promoted, however, no participants who met the criteria came forward.

Focus Group Mencap Staff

A focus group was held with 10 staff working directly with young people with a learning disability or difficulty through Mencap's employment youth services. The staff focus group was an opportunity to share some of the key themes coming from the interviews with young people, and for them to raise any additional issues about young people's access to mental health services or support not covered as part of the key themes. It was also a chance to review the recruitment and engagement process with young people and parents/carers, as it was much more difficult than anticipated to recruit young people to take part in the interviews.

Practitioner Workshops – Discussion of Emerging Themes

Two practitioner workshops were held in Derry/Londonderry and Belfast during May 2018, involving 68 participants (L/Derry (n=22) / 25 May Belfast (n=46). The workshops were targeted at professionals and practitioners who worked within mental health services or supported children and young people requiring the support of these services. The workshops were attended by CAMHS staff, Voluntary and Community Sector representatives and a small number of elected representatives. The aim of the workshops was to present emerging themes from the Review, in particular the young people's experience data. The workshop began with a presentation of three key emerging themes coming from the Review, which were grounded in the young people's experience data. The thematic areas were:

1. Access to Mental Health Support via GP;

2. Access to Crisis Mental Health Support;

3. Support for young people - whilst waiting, receiving and exiting CAMHS; and

4. Service Comparisons.

Practitioners were asked to discuss each of the thematic areas by answering a number of questions, which are outlined below. Each table had a NICCY facilitator to support the discussion and a note taker.

Question 1:
(a) Is this an issue you are aware of?
(b) Do you have examples of where you have come across this problem or challenge in your own professional work?

Question 2:
(a) Do you have examples of good practice that address any of the issues raised under this theme?
(b) What do you think NICCY should be considering including under this theme as part of our recommendations?

Data Analysis

The surveys were made up of a range of multiple response (quantitative data) and open response (qualitative data) questions. The results were downloaded from Survey Monkey into an Excel spreadsheet. The quantitative frequency responses were made into charts and the qualitative information was coded using content analysis.

The transcribed interview data was uploaded into NVivo, a qualitative data analysis software package that facilitates the systematic coding and recoding of interview data as themes emerge during the analysis process. As the interviews were semi structured, the topic guide was used as the basic framework to begin the coding process.

The transcribed discussion notes from the practitioner workshops were used to inform the Themes and Recommendations section of this report.

Limitations of the Research

The most obvious limitation of the Review was the effect of self-selection bias and the potential for those who did not respond to the survey or taking part in the interviews having very different views from those who did. For the online survey we were relying on trusted adults to support young people to complete the survey. If a young person did not have this support it may have been less likely they would take part, particularly if they had current or on-going mental health problems.

Significantly more females (70%) responded to the survey compared to males (23%). Concerted attempts were made to correct this imbalance during the fieldwork period

by using targeted Facebook advertising and promoting the survey at events or places more likely to attract young males. This increased the number of male responses to the survey though not as much as we would have hoped.

There were responses to the online survey from young people from every County in Northern Ireland. However, there were also variations in response level from the different parts of Northern Ireland that young people came from, with more young people coming from County Antrim than any other part of Northern Ireland i.e. 42% from County Antrim, 17% from County Down, 14% from Derry/Londonderry, 13% from Armagh, 6% from Tyrone, 4% from Fermanagh and 3% didn't know or would rather not say. During the fieldwork phase, targeted advertising through social media, as well as press releases in local newspapers was used to increase the number of responses from areas outside of County Antrim. This strategy redressed the imbalance to some extent though not as much as we would have hoped.

There was a very limited response from young people whose living situation was other than living with family i.e. care experienced young people, homeless, in secure care or juvenile justice. These groups of young people are at a greater risk of developing mental health problems and requiring services than those living with family. It is disappointing that these groups of young people are not better represented in the sample. A hard copy version of the survey was produced for specific groups of young people who did not have access to the internet i.e. young people living in residential facilities and juvenile justice centre.

The age range and average age of the young people that were interviewed was at the higher end of the age criteria for the Review. The average age of the young people that took part in the alcohol and drug interviews was 19 years old, and for the learning disability interviews, the average age was 21 years old. Due to the age of the young people interviewed, the majority were not current users of child and adolescent mental health services, therefore they were looking back retrospectively at their experiences. A very valuable perspective can come from looking back at one's experience, and the passing of time can bring more clarity around a service experience or outcome. Recruiting young people for interviews was very challenging for both groups of young people and for this reason we were pleased with the level and quality of engagement achieved.

3.7 Strand 2: Official Statistical Information on Operational Aspects of CAMHS

In the absence of a publicly available central database holding basic operational data on children and young people accessing mental health services, NICCY initially requested a range of data from the HSCB to inform this strand of the Review. The HSCB did not collect or hold all of the information requested, in particular the demographic profile of young people using mental health services and data relating to inpatient activity, and advised NICCY to request this from each of the five HSCTs directly. Having done this, each HSCT provided a response to NICCY's request for information, however, the amount and format of information provided by each Trust varied considerably. Very little information provided by the HSCTs was disaggregated by key variables requested such as sex, age, disability, LAC or presenting need/diagnosis. The HSCTs informed NICCY that this information was not recorded or collated and to access it would require a trawl of individual patient files, and therefore was cost and time prohibitive.

It is extremely concerning that basic demographic information is not collected or monitored in relation to service user activity in any standardised way by the HSCB or HSCTs.

Where more detailed demographic information was provided, there was too much variation for it to be transferred into standardised data tables, to be used for the purposes of this report.

A range of other challenges were reported by HSCTs in being able to provide the data requested, this included changes to service structures, which meant that operational data had not been counted, or there was potential for double counting within reporting systems. There were also concerns expressed by the HSCB and HSCTs that this would result in variation in the figures presented by HSCTs and HSCB.

The HSCB provided NICCY with two statistical reports, additional data provided by the HSCTs filled some gaps in the information that was not available from the HSCB. This included figures regarding hospital admissions, occurrences of mental health detentions, occurrences of delayed discharge, admission of young people to adult mental health wards and information on Extra Contractual Referrals (ECR's). In addition, information was requested and received from a number of other agencies involved in the regulation or delivery of key services that fall within the remit of the regional Stepped Care Model, including RQIA, PHA and EA. Data from each of these agencies is also presented in Section 5 (Iveagh Centre) and 6 of the report, however, the majority of the information reported on was provided by the HSCB or HSCTs.

Challenges with Access to and Analysis of CAMHS Data

To summarise, it was extremely challenging to access basic CAMHS data for the purposes of this Review. The main issues faced by NICCY in getting data have been set out below:

- There is no central source where information on mental health services or support for children and young people is retained, where information is available it is disparately spread across directorates/ services. This means it is time consuming to try and identify and access information;
- At a regional level, very basic operational data is not being routinely collected. This includes very limited disaggregation of service user data by sex, age, mental health diagnosis or presenting need;
- The regional data available to NICCY provided a very narrow view of the system and didn't include the following - referral sources, reasons for referrals not being accepted, waiting times between first appointment and review appointment (second appointment) within Step 3 CAMHS;
- HSCTs use different data software tools and measure data in different ways, making it very challenging to access standardised information from across the HSCTs;
- Not all data is recorded electronically by the HSCTs, some basic data is only recorded in individual patient files. Getting access to this data is cost and time prohibitive; and
- The HSCB was cautious about sharing data for the purposes of this Review due to concerns about consistency and accuracy of data being held across different parts of the system and compliance with Data Protection legislation.

For all the reasons outlined above, a considerable amount of time was spent trying to access relatively basic information. As very little CAMHS data is routinely published, the data that was gathered provides a useful insight into the activity of some parts of the statutory CAMHS system, in particular Step 3 - 5. However, it is unacceptable that the data gathered on the activity of key statutory mental health services is so limited and difficult to access. From a service planning and delivery perspective, this lack of a central and reliable source of CAMHS data makes it impossible for this information to be utilised in a 'whole system' way.

The development of a CAMHS database is essential and when fully implemented should address some of the most significant barriers faced when requesting information. It is also vital that the CAMHS dataset is part of the broader work being considered through the e-health strategy, which includes exploring the potential of a fully integrated digital health and care record system (DoH, 2016:3).

3.8. Strand 3: Mental Health Review Fund Mapping

Recognising the importance of government spending on children since its establishment, the Northern Ireland Commissioner for Children and Young People has scrutinised government budgets and provided advice on how these could be improved to better realise children's rights. This has involved reviewing and analysing planned budgets, including Comprehensive Spending Reviews (CSRs), and providing advice, for example NICCY's paper on the 'Briefing on the Northern Ireland Budgetary Outlook 2018-20'. (NICCY, 2018). NICCY has also commissioned a number of analyses of publicly available information on spending on children, and a survey on family spending on children's education.

Public Expenditure on Children's Services (2007)
In 2006 NICCY, in partnership with the Office of the First Minister and Deputy First Minister (OFMDFM) and the Department of Finance and Personnel (DFP), commissioned an analysis of public expenditure on children. This took the form of two reports – one analysing Departmental Expenditure Limits (DEL) (ERINI, 2007), and the second analysing Annually Managed Expenditure (AME) for Northern Ireland compared to other parts of the UK (IFS, 2007).

The first report, by the Economic Research Institute Northern Ireland (ERINI), reviewed expenditure on a number of key areas for children and highlighted where there appeared to be significant differences in spending on children in Northern Ireland compared to other parts of the UK. Particular areas of underspend identified were Education and Health and Personal Social Services. ERINI highlighted the challenges and limitations of comparing expenditure by different countries, particularly in the case of education because the UK jurisdictions calculate their expenditure using different categories. The integrated healthcare system in Northern Ireland also makes it difficult to isolate specific beneficiaries for accurate comparison with other areas, where health and social care are separate.

Children's Budgeting in Northern Ireland: an Exploratory Study (2014)
In 2014 NICCY commissioned a report from the Centre for Effective Services (CES), examining the process for allocating government budgets in Northern Ireland and how the funding allocated results in the delivery of services for children and young people (Sneddon, 2014).

The approach taken was to identify and review publicly available information in order to understand and describe the budgeting process, and consider how far the process supported budgeting for children and young people. This involved desk research, a documentary analysis of the Programme for Government, sourcing information on the projected budget for each Department, the analysis of reports on planning and expenditure for different layers within government, and discussions with key stakeholders.

The report found that, while there was a great deal of information available on budgets, it was not necessarily the 'right' information to allow for meaningful engagement in, and consultation on, decision-making, most importantly in relation to annual and CSR

budgets. One of the challenges, when analysing budget spend on children, was identifying the beneficiaries of spending. While some programmes focused directly on children, these were in the minority. General expenditure, which makes up the majority of spending, would require apportioning by population size (crude) or by using service usage data by age groups (more accurate).

The report also highlighted the importance of recognising that budget allocation and actual expenditure on service provision are different, due to reprioritisation of funds by service commissioning bodies, and also the costs of processes such as procurement. Indeed, government procurement process can cause delays in spending, and the delivery of services. In addition, despite Departments' commissioning priorities, authority may be delegated at various levels in the system to set their own priorities for their budget.

Finally, the report emphasised the importance of recognising that levels of investment may change for a range of reasons, including a change in government priorities, or services becoming more efficient. It concluded that any quantitative analysis of public spending on children must be accompanied by an evaluation of the outcomes achieved by the funded programme.

Fund-mapping: The Investment of Public Resources in the Wellbeing of Children and Young People in Northern Ireland (2015)
NICCY jointly commissioned this research with Atlantic Philanthropies from Dartington Social Research Unit. Its purpose was to help develop an understanding of how Government agencies and public bodies in Northern Ireland invest their resources in children
(Kemp et al, 2015).

A fund mapping methodology was adopted to bring together information from across Departments and Agencies on the amount of money spent on key children's services. This guides the collection and analysis of budget and programme information, with an emphasis on understanding:

- How much is invested annually in seeking to improve outcomes for children;
- Approximately what proportion is invested in prevention and early intervention;
- To what extent investment is currently supporting evidence-based programmes (EBPs); and
- How much key categories of services cost per child/young person.

A report was produced, containing information provided by each Northern Ireland Government Department on:

- Its net expenditure on children and young people;
- The number of staff working with children and young people;
- The number of children and young people benefiting from these services;
- Unit costs, how much of the investment was on prevention and early intervention; and
- Any investment on evidence based programmes.

The project was an ambitious one, given the complex arrangements for funding and delivering services for children in Northern Ireland. Some aspects were more complete than others. The overview of total expenditure was accurate, but estimates about expenditure on prevention and early intervention and EBPs should be treated with caution. Researchers could be confident about what but not how money was spent. Departmental staff had limited time to engage with the researchers in this analysis. Despite these caveats, this exercise yielded rich high-level information which provides an important foundation for making decisions about expenditure on children.

The report concluded that expenditure on children in the report is described as an investment in children's current and future

health and well-being, seeking to promote positive development and mitigate risks to healthy development. It recommended that investments should be aligned to children's developmental outcomes and, ideally, informed by patterns of need. As there is increasing pressure on resources, it is essential that every effort is made to secure the greatest possible benefit from existing resources.

'A Free Education?' The Cost of Education in Northern Ireland (2017)

NICCY commissioned SMR to conduct a survey of over 1000 parents with school-age children to determine the cost to parents of their children's education each year, and how this varied across range of different factors including: geographical location, school type and age (SMR, 2017). In addition to this, NICCY drew on UK Treasury Public Expenditure Statistical Analyses 2016 data to produce a report containing recommendations on how children's education should be funded (NICCY, 2017:3).

Methodology for Fund-Mapping Process

The overarching aim of this fund mapping strand of the Mental Health Review was to collect and analyse budget information to understand how much money was spent annually across all levels of emotional and mental health services for children and young people. This would provide greater clarity and transparency in how finite resources are directed, in order to achieve the best possible mental and emotional well-being outcomes for children and young people.

The key objectives of the fund mapping project were:

- To capture a detailed breakdown of expenditure on services provided for children and young people's mental and emotional health, using the Regional Stepped Care Model for CAMHS as the framework;
- To quantify the cost of each service costs per child/young person;
- To gather data on the numbers of staff employed in the delivery of emotional and mental services for children and young people; and
- To use the data gathered as a baseline against which to monitor investment in the emotional and mental health of children and young people over time.
- The data gathered related to the 2015-16 financial year as, at the start of the project, this was the most recent year for which full financial returns would have been available.

The Methodology

The methodology applied in this piece of work was adapted from that used in the Dartington Social Research Unit (DRSU) children's budgeting project, commissioned by NICCY and Atlantic Philanthropies in 2015 (Kemp et al, 2015). It was originally designed to map expenditure on a range of children's services in English Health and Local Authority systems, and was adapted in the 2015 project to the specific requirements of the Northern Ireland research. With guidance from DRSU, NICCY adapted the methodology further for this project, aligning it closely with the CAMHS Stepped Care model.

Data Factsheet

A data factsheet was developed, adapting the version used by Dartington Social Research Unit in 2015 (NICCY, 2017:2). This was reviewed following feedback from HSCB and HSCT staff to ensure that it provided clarity as to the process and data required.

The data sheet, along with detailed guidance was provided to the PHA, EA and HSCTs to record data on expenditure on emotional and mental health services for children, on service use by children, average costs and on staffing numbers. The factsheets were provided as Excel spreadsheets for data entry and efficient collation and analysis. Each Agency was asked

to complete one sheet for each emotional and mental health service it funded/provided for children and young people within the Regional Stepped Care Model.

The data collection used the CAMHS Stepped Care Model as the framework for seeking returns. NICCY recognised that it would be most straightforward to collect data for services in Steps 3-5, as these are generally specialist mental health services. While recognising that it would be more challenging to gather information on the universal and targeted early intervention services in Steps 1 and 2, we felt it was important to attempt to do so, accepting that the information received was likely to be partial.

One challenge in collating information on Step 1 and 2 services was that some services do not focus entirely on supporting children and young people's emotional and mental health. For most, this is one aspect of the work, adopting a more holistic approach to supporting children and young people's health and well-being. Examples of these critically important services are Health Visitors, GPs, safeguarding services, and child development services. We requested HSCTs to include data sheets on these services, where reasonably robust assumptions could be made as to the proportion of these services relating to the delivery of emotional/mental health, as we wanted to record as much of the expenditure across all Steps in the Stepped Care Model.

The datasheet contained five sections:

Section 1: Background to the service
This required a brief description of the service, its geographical spread and delivery Agency.

Section 2: Expenditure on the service
Agencies were required to provide gross expenditure on the service, in addition to any external funding provided from other sources. This was to quantify all the costs associated with the provision of a service, including overhead and administrative costs. This was not inclusive of broader organisational overheads and 'back office' functions in place to support the work of a wide range of services, for example across a whole Trust.

This section of the form also contained questions on the number of 'whole time equivalent' (WTE) staff involved in delivering the service (including professional staff, managers and administrators) and the number of children availing of the service. Where possible, we asked that this reflect the actual number of children, rather than the number of episodes of care, or admissions.

Section 3: Spend by Steps in the regional Stepped Care Model
This recorded the primary purpose of the expenditure in terms of its level of intervention, as categorised in the regional Stepped Care Model. Where a service is delivered on more than one level, staff were asked to provide an estimated breakdown across Steps.

Section 4: Evaluation of the service
In this section the evidence base for the service delivering positive outcomes was recorded.

Notes:
Those completing the form were asked to provide any explanatory notes to aid understanding of the data, including any codes of the budget lines included, assumptions made and information on how calculations were carried out.

Data collection
NICCY met with key staff in the HSCB, HSCTs, EA and the PHA to explain the information required and the method by which it would be gathered, through completion of the data sheets.

As we were aware that the majority of data was likely to come from CAMHS Service Managers, we began by meeting with them, along with the CAMHS leads from the HSCB, and Information and Finance staff. This allowed us to review the data sheets and agree ways of ensuring consistency in how the forms would be completed.

During this meeting staff emphasised the importance of including financial data on the services provided at Steps 1 and 2, due to their importance in preventing mental ill-health, or providing services before mental ill-health became more serious. They also recognised that changes to funding of these services had 'knock-on' impacts on the demand for services at Steps 3 to 5.

We subsequently met with a wider range of staff from the HSCTs, EA and PHA to request data on services provided to support children and young people's emotional and mental health. In each case some services primarily or entirely focussed on this, while for others, supporting the emotional and mental health of children and/or young people was only one intended outcome, often not the primary purpose of the service. In the end the EA was the only agency which provided information on these services, although it did not indicate what proportion of the broader services it estimated as being dedicated to supporting children's emotional and mental health. The data from these returns is included in a separate section at the end of this chapter.

Another challenging aspect of the work was gathering data on the services provided to children and young people with disabilities. In general children with disabilities cannot access the mainstream services at Steps 3 to 5. It was therefore very difficult to gather information on the emotional and mental health services in place for these children. This is explored further earlier in this section.

There were considerable delays in the submission of this data, as HSCTs had to go through internal sign off processes, and a range of staff were involved in these.

Data analysis

In total NICCY received data sheets with information on 90 services, the largest number completed by the PHA, followed by HSCTs and the EA.

The information provided was collated and analysed. The results are outlined below. While financial data was provided in almost all sheets, the information on the number of children availing of the services, the number of WTE staff, and the evaluation of services was less complete.

As discussed above, the information submitted related solely to services provided by HSCTs or commissioned by EA or PHA, with the primary purpose of supporting children and young people's emotional or mental health and well-being. Despite this, it is vital to also recognise the important and diverse services in place to support children and young people's emotional and mental well-being, while delivering against a wider range of outcomes. Any consideration of the allocation of resources must also take cognisance of the need for investment in these services.

Many services were delivered in limited geographical locations, while others were provided on a regional basis. The tables in Section 8 attempt to provide some indication of where services are delivered, or rather, where the young people who avail of the services are located. To do this, in some cases, we have had to use quite crude divisions of budgets across two or more areas. We have not been able to divide budgets across HSCT areas by the numbers of service users or, less accurately, by comparing the numbers of children and young people in each area. We have, in the cases where a service was delivered to young people over

more than one Trust area, simply divided the budget equally between areas.

Some services in Steps 1 and 2 were delivered to a wider age range, including older young people and the wider population. In some cases the individual completing the form was able to identify the proportion of beneficiaries who were aged under 18, and then calculate the proportion of the budget allocated for the delivery of services for children and young people. However, this wasn't the case for all services delivered for a wider age range. In these situations a crude calculation was carried out, assuming similar uptake of the service across all eligible ages. So, for example, where a service was delivered to 15–20 year old young people, the budget was split equally between under 18s and young people aged 18+.

In many cases, for Steps 1 and 2 services, the boundaries between some different types of services weren't entirely clear. Many services, for example might provide counselling to individual children, but primarily focus on supporting families through adverse experiences, such as the loss of a family member from suicide. Alternatively the primary focus of the service could be counselling, with an element of family support. We have made judgements as to how to allocate each service to one category, based on the limited information contained in the data sheets. This should be taken into account when interpreting the tables. Nevertheless, while the allocation of services to particular categories within a Step may not be entirely clear, it was clear under which Step each service fell.

SECTION 4

CHILDREN AND YOUNG PEOPLE SURVEY RESULTS

4. Children and Young People Survey Results

4.1 Introduction

This section of the report details the results of the children and young people's online survey. The survey was targeted at young people aged 11-21 years old with experience of accessing, or trying to access, mental health services and support.

The survey asked young people about 7 services:

- General Practitioners (GPs);
- Schools/Colleges/Universities;
- Community CAMHS (out-patient);
- Voluntary and Community Services (VCS);
- Out of Hours GP;
- Accident and Emergency Departments (A&E); and
- Inpatient Hospital Care.

They were asked to rate services against a range of rights based statements or indicators, which are clustered around information, and access, facilities and services and quality of care.

Where percentages within graphs/tables do not add to 100%, this is due to rounding up or down to the nearest whole number. The number of responses will vary from question to question as not all respondents replied to every question, because either the question was not relevant to them or they chose to skip it. The base number is included under every graph or table to indicate the number of respondents who answered the question.

Although children and young people were the main target audience for the survey, a shorter survey for parents/carers was made available. Parent/carer responses to the statement, 'the support my child received was helpful' has been reported against each of the services. This provides a point of comparison with the young people's views and in acknowledgment of the important role that parents/carers have in supporting their child to access mental health support.

Quotes have been left unmodified, unless it was felt that the information contained might make the respondent identifiable, or where it was necessary for readability i.e. including commas and full stops.

4.2 Summary Tables of Children and Young People Survey Results

In the survey, young people were asked to rate **7 services against 3 key** areas which related to **'Information and Access', 'Facilities and Services' and 'Quality of Care'**. The rating system used was a 5 point Likert scale i.e. strongly agree, agree, disagree, strongly disagree and 'I don't know/I'm not sure'.

The colour coded summary tables below have been used to visually illustrate the extent to which young people agreed (agreed or strongly agreed) with each statement, for each service. **Red** indicates that between 0–50% of young people agreed with the statement, **Yellow** indicates that between 51–69% agreed with the statement and **Green** indicates that 70% or over agreed with the statement.

Agreement Rating (Agreed or Strongly Agreed)

	0–50%
	51–69%
	70+%

General Overview

Overall, across all of the indicators, the VCS rated much higher than any other service. This difference was particularly apparent for the statements, 'I was given useful information to help me to understand my mental health needs' (VCS 80%, average score 49%); 'I felt involved in the decisions that were being made about my care and treatment' (VCS 75%, average score 42%); and 'the support I received was helpful' (VCS 76%, average score 49%).

Generally, across all of the statements, services scored most highly on the statements, 'I felt listened to and respected' (average score 57%); I didn't have to travel far to get help/receive services (average score 68%), and 'I was spoken to in a way that I could understand' (average score 73%).

Table 4.1: Information and Access

	I was given useful information to help me to understand my mental health needs	I was given a choice of treatment / support
GP	35	43
School /College / University	48	38
Community CAMHS	54	46
VCS	80	67
Out of Hours GP	39	43
A&E	31	23
In-Patient Care	55	19
Average rating	**49**	**40**

The average rating across services on the statements that related to 'Information and Access' did not go above 50%. The statement 'I was given useful information to help me understand my mental health needs' had an average rating of 49% and 'I was given a choice of treatment/ support' had an average rating of 40%.

The VCS scored much higher against the statements under the 'information and access' cluster than any of the other services – 80% of young people agreed that the VCS gave them 'useful information to help them understand their mental health needs' and 67% of young people agreed that they were given a choice of treatment/support.

A&E and GP services scored lowest on the statement 'I was given useful information to help me to understand my mental health needs'- 31% of young people agreed that A&E had given them useful information to help them understand their mental health needs, and 35% agreed that information from their GP was useful. School/College/University, Community CAMHS and Inpatient Care scored in and around 50–55%.

On the statement 'I was given a choice of treatment and support', none of the services apart from the VCS had an agreement rating above 50%. The VCS had an agreement rating of 67%; the remaining services had an agreement rating that ranged between 19% (Inpatient care) and 46% (Community CAMHS).

Table 4.2: Facilities/Services

	The place that I received support in made me feel comfortable and safe	I didn't have to travel far to get help / receive services	I was able to access the service / support when I needed it
GP	56	70	41
School /College / University	63	83	60
Community CAMHS	61	65	38
VCS	85	77	68
Out of Hours GP	40	n/a	44
A&E	45	68	53
In-Patient Care	43	42	42
Average rating	**56**	**68**	**49**

Overall, there was variation in how different services rated against the statements under the 'facilities and services' cluster. The average rating across the three statements ranged between 49% and 68%. 56% of the young people agreed the place they received support in, made them feel comfortable and safe; 68% agreed that they didn't have to travel far to get help/receive services, and 49% agreed they were able to access services and support when they needed them.

There were differences between services with respect to how comfortable and safe young people felt when attending them for mental health support. The results show that the young people surveyed felt most comfortable going to a VCS organisation for support (85%), this was followed by GP, School/College/University (these service scored between 56% and 63%). Less than half the young people agreed they felt comfortable and safe in Inpatient Care (43%) or A&E (45%).

In general, apart from Inpatient Care (42%), young people agreed they did not have to travel far to access services. The agreement rating for services, other than Inpatient Care, ranged between 65% and 83%.

The agreement rating for services against the statement 'I was able to access services when I needed it' ranged between 38% and 68%. GP services, Community CAMHS, Out of hours GP and Inpatient Care had an agreement rating below 50% on this statement.

Table 4.3: Quality of Care

	I felt listened to and respected	I was spoken to in a way that I could understand	I felt involved in the decisions that were being made about my care or treatment	The support I received was helpful
GP	56	70	42	44
School /College / University	71	83	52	56
Community CAMHS	59	74	36	45
VCS	84	82	75	76
Out of Hours GP	52	72	40	52
A&E	40	68	30	34
In-Patient Care	39	65	16	39
Average rating	**57**	**73**	**42**	**49**

There were four statements included under the quality of care cluster. In general, services rated higher on the statements 'I felt listened to and respected' (average score 57%) and 'I was spoken to in a way that I could understand' (73%), and considerably lower on the statements 'I felt involved in the decisions that were being made about my care or treatment' (42%) and 'The support I received was helpful' (49%).

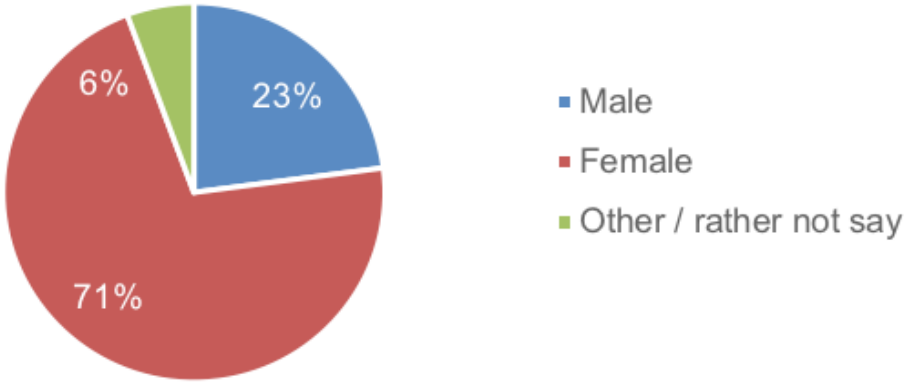
The statement 'I was spoken to in a way that I could understand' had the highest overall average rating across the statements within the survey – 73% of survey respondents across all of the services agreed with this statement.

The VCS was the only service that had obtained a consistently high agreement level across all of the quality of care statements, scoring 75% or above on each of them. The difference in the rating between the VCS and other services is particularly apparent for the statements 'I felt involved in the decisions that were being made about my care or treatment' and 'The support I received was helpful'. The average agreement rating for the statement 'I felt involved in the decisions that were being made about my care or treatment' was 42%, some of the statutory health services scored well below this average i.e. Inpatient Care (16%), A&E (30%), Community CAMHS (36%), GP (42%) and Out of Hours GP (40%). School/College/University (52%) scored above average, and the VCS (75%) scored well above average.

There was some variation on the agreement rating to the statement 'The support I received was helpful'. The statutory health services, Inpatient Care (39%), A&E (34%), Community CAMHS (45%), and GP (44%) scored below the average agreement rating for this statement, which was 49%. School/College/University (56%) and Out of Hours GP (52%) scored above average, and the VCS (76%) scored well above average.

4.3 Demographic Profile

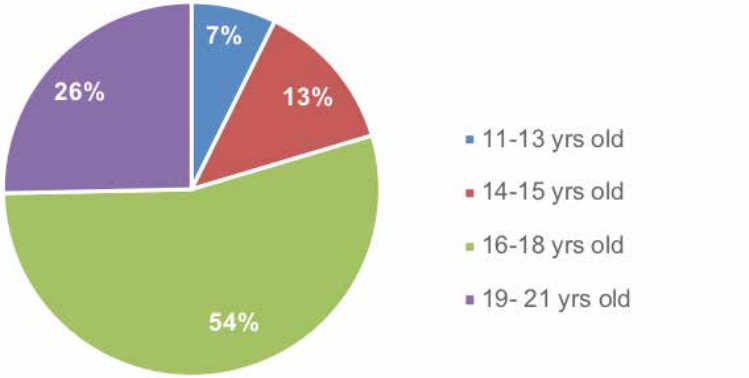
Figure 4.1: Gender identity of respondent



Base: 545

Over 70% of the young people surveyed were female, 23% were male and 6% identified as other or stated that they would rather not say.

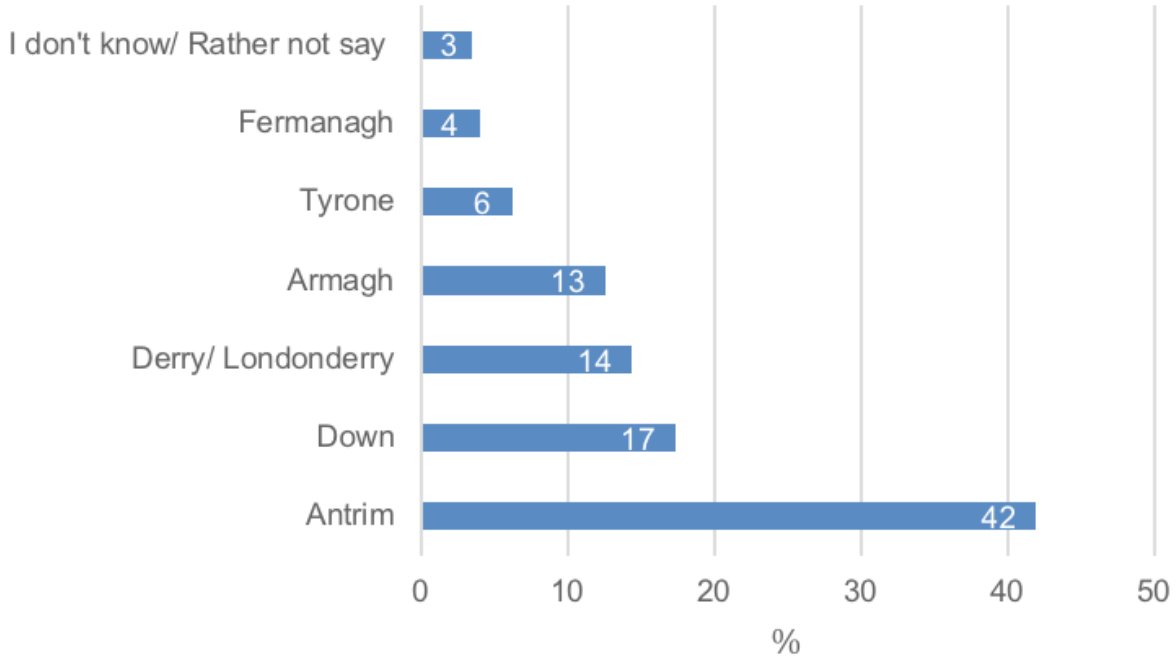
Figure 4.2: Age of respondent



Base: 604

Slightly over half of the young people surveyed were aged 16–18 years old (54%), 20% were aged under 16 years old and 26% were aged between 19–21 years old.

Figure 4.3: County Profile: Which part of NI do you live in?



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Overall, 42% of the young people that completed the survey stated they came from County Antrim, 17% from County Down, 14% from Derry/Londonderry, 13% from Armagh, 6% from Tyrone, 4% from Fermanagh and 3% didn't know or would rather not say. Young people were also asked which Health and Social Care Trust they live in, but unfortunately a large proportion did not know and therefore, 'County' has been chosen as the most reliable way of representing the geographic area where the young people reside.

Ethnic Background/Living Situation

The vast majority (92%) of young people surveyed described themselves as being from a white ethnic background. The remaining 8% described themselves as being from either Irish Traveller, mixed or Indian background. Furthermore, 83% of the young people surveyed described themselves as living with family. A further 17% were living somewhere other than with family. This included independent or shared living, in care, homeless, living in a hostel, or being detained in Woodlands Juvenile Justice Centre.

Age When Young People Became Worried About Mental Health

On average young people estimated they were aged 13 years old when they started to become worried, or noticed things about their emotional or mental health.

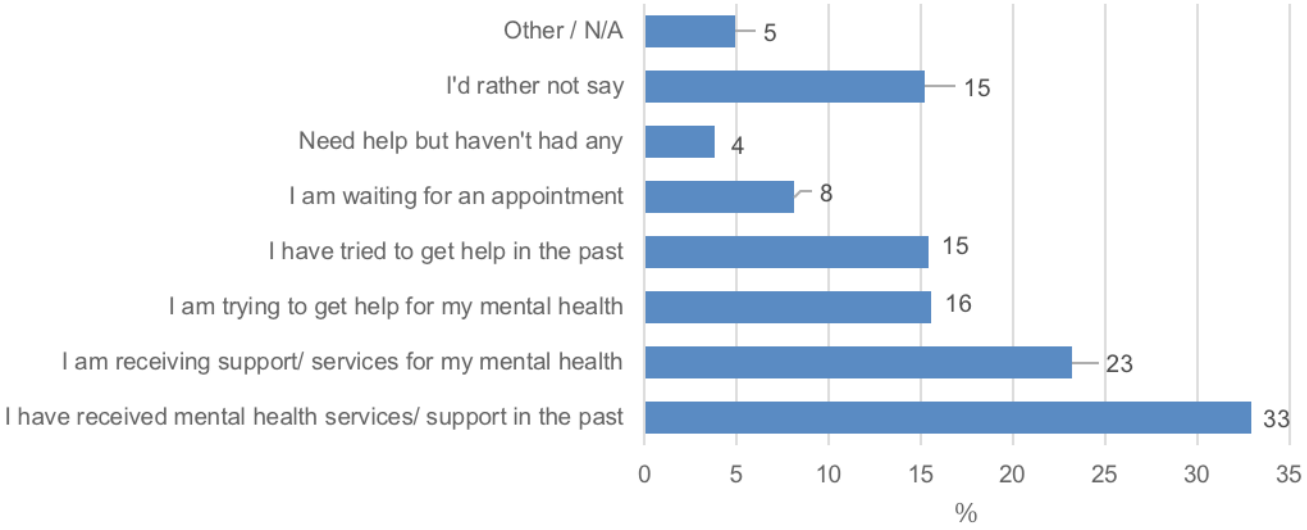
Age When Young People Started Looking for Help

Young people were also asked what age they were when they or their parent or carer started looking for help for their mental health. On average young people estimated that they were aged 14 years old when they started to look for help.

Access to Services - Overview of Experience

Young people were asked to provide an overview of their experience of accessing services or support for their mental health. The graph below illustrates that 33% of young people had received help in the past; 23% were currently receiving services; 16% said they were trying to get help for their mental health; 15% had tried to get help in the past; 8% were waiting for an appointment; 4% need help but haven't had any, and 15% would rather not say.

Figure 4.4: Which one of the following best describes your situation? (multiple response question)

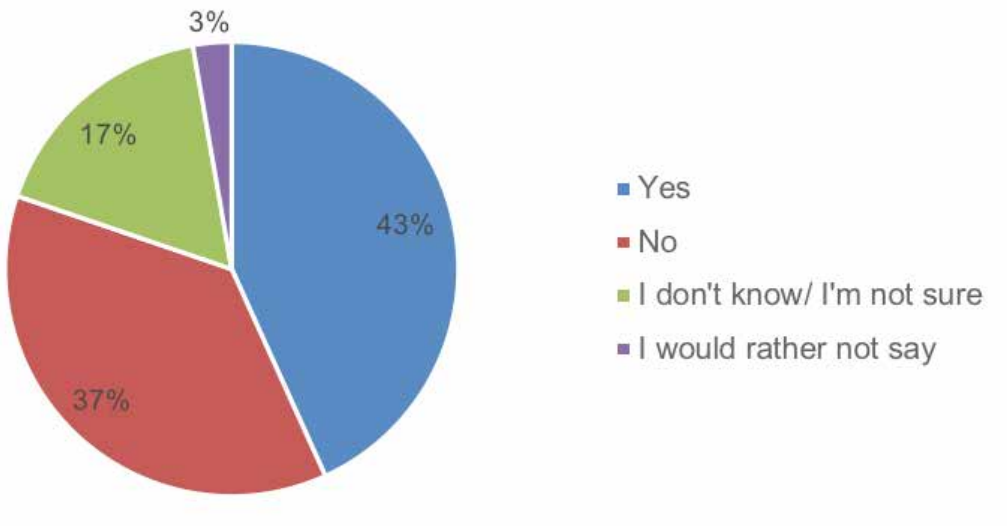


Base: 552

Mental Health Condition(s)

Of the young people who responded to the survey, 43% had been told they have a mental health condition or illness, 37% said they had not, 17% said they did not know or were not sure and 3% would rather not say. Anxiety and depression were the most common conditions reported by the young people that took part in the survey, and they were also commonly reported together. Other conditions reported by the young people surveyed included eating disorders, personality disorder, ADHD and self-harm.

Figure 4.5: Have you been told that you have a particular mental health condition or illness?



Base: 546

4.4 Causes or Contributing Factors to Young People's Poor Mental Health

There are many issues that can impact on a child or young person's emotional well-being and mental health, the causes of mental ill health can be classified as 'internal' or 'external' environmental factors.

Internal factors include genetic or biological links that increase a young person's predisposition to poor mental health. Some mental health problems can run in families, suggesting that the disorders or a vulnerability to the disorders, may be passed on from parent to children through genetics. Mental health problems can also be caused or affected by chemical imbalances in the brain, which can be triggered by all sorts of different things, and sometimes the reason is unknown.

It is also often the case that certain **environmental factors**, sometimes referred to as stressors or traumatic events, can trigger mental ill health and can contribute to mental health problems. This includes actions or lack of actions by:

- Children and young people themselves e.g. social media use;
- Families e.g. unstable family environment i.e. domestic violence, parental substance misuse, bereavement or divorce;
- Communities/Neighbourhoods (to include peers/friendship groups) e.g. social and cultural expectations i.e. dressing a certain way, being a certain weight, low self-esteem, loneliness, anger, anti-social behaviour or the impact of paramilitarism;
- Schools e.g. bullying or exam pressure; and
- Health and Social Care Services/Governments e.g. lack of investment in Child and Adolescent Mental Health Services (CAMHS) and long waiting times to get help from specialist services.

What Does the Survey Tell us About Cause or Contributing Factors?

A total of 388 young people provided information on the causes or factors that contributed to their poor mental health. The most commonly occurring words raised by young people were school (242 times), family (161 times), stress (71 times) and bullying (68 times).

Figure 4.6: Word cloud for causes and factors that contributed to poor mental health

School factors were frequently associated with the other commonly occurring words, bullying and stress. Young people referred to bullying in school, exam stress, pressure to perform academically and dealing with peer pressure. A number of the young people talked about their sexual identity and the struggles they faced within their families, communities and peer groups.

In terms of family life, there were a wide range of issues raised by young people that they believed caused or contributed to their poor mental health. These included bereavement of a close family member or friend, poor relationships or lack of emotional support within the home. Poor relationships in the home were often associated with divorce, mental health or alcohol or drug issues for parents/carers or siblings.

For the most part, young people associated more than one cause or contributing factor to their poor mental health. The cumulative effect of pressures at home and school, without the buffer of supportive friends or adult family members, was a toxic mix that left young people feeling less able to cope and with heightened levels of stress.

Root Causes of Poor Mental Health

Many of the young people we spoke to as part of this Review referred to experiencing considerable adversities during their childhood, and in many cases they were adversities that had

not been picked up or addressed at the time. Young people were very clear in their feedback about services, that it was essential that the root causes of young people's poor mental health were addressed as part of the overall support. Young people articulated very strongly that they needed practical support to address the issues causing them distress, anxiety or depression:

"Counselling for mental health does help but it does not help people solve some problems. Most problems with mental health begin at home and no help can be given for anything to change at someone's home...."

"For kids growing up in families where mental health issues are ongoing there is little support for these kids mental health and well being."

"[My School] were fully aware that me and my sisters were being abused and neglected, however once my parents spun a story they also thought I was a lazy useless b**d and deserved to be bullied and ignored."***

4.5 Seeking Help

Young people were asked about who they had spoken to when they started looking for help. They identified a range of people they had spoken to: the most common source of support and information was friends or family (61%); followed by a GP/Doctor, Accident and Emergency Services (A&E), CAMHS and Hospital (49%); or a school counsellor or teacher (40%). Other people that young people said they had spoken to included a Charity/Community or Voluntary Sector organisation (14%); Social Services (12%); and faith or youth leaders (10%).

Table 4.4: When you started looking for help, who did you speak to? (multiple response question)

	%	Freq (n=)
Family / Friends	61	250
GP / Doctor, A&E, CAMHS, Hospital	49	200
School Counsellor/ Teacher	40	165
Support from a Charity	14	58
Social Services i.e. social worker	12	48
Faith / Youth Leader	10	42
I'd rather not say	3	12
Other (please specify)	2	9

Base: 408

The critical role of a 'trusted adult' came out very clearly in both the survey responses and the interviews with the young people. The main trusted adult young people spoke to about their mental health in most cases was a parent or carer. However, for some young people the most significant person was a youth worker or project worker from a Voluntary or Community Sector organisation. Young people described the role that a trusted adult had in supporting them at all points, from first seeking help, to managing appointments, and supporting them between appointments:

"It was my Mum trying to get me help but I didn't think I needed it."

"At the beginning I was in denial and didn't want help but eventually came round and began the road to recovery."

"I was so dismissive when first getting help for my mental health. I couldn't see that I was ill and needed help. Although there were ups and downs in my treatment overall it was great as the help and support I received saved my life and helped me get to where I am today- healthy, happy and enjoying life."

Although parents or carers have a critical role in supporting their child to access services, it is important to acknowledge and understand that some of the most vulnerable young people do not have parents or carers that can identify their poor mental health, or respond to their requests for help. When this is the case it is important that other 'trusted adults', including statutory services, are able to do this:

"It's hard for me to talk about as I am definite that I have depression but I asked my mum to take me to my GP about this and she said no as I was just making everything up."

"(..) when I was drunk it used to come out and then I couldn't cope anymore and then I told my mum and – but she's never really wanted me going to the doctors or anything about my mental health and then I think it was I took an overdose and tried to end my life just to get rid of it all and then I ended up in hospital." (YP U)

Keep Offering Support

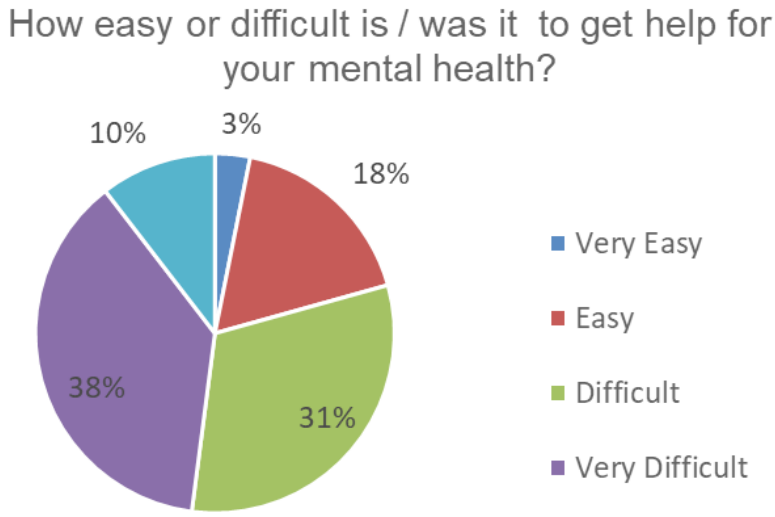
The young people talked about the difficulty they faced in getting over fear, stigma and denial in order to access help. Many young people who took part in the Review were able to look back retrospectively on their experience of looking for help. One of the key things for these young people was that people did not give up offering them support:

"I know I need to help myself with trying to get help, but with me I need pushed or even someone do it for me, as I see a stigma with it myself. I don't want to be seen as the guy that has problems or is messed up in the head."

"Once I spoke about it, it almost instantly didn't feel as big and scary, talking helped."

How Easy or Difficult Was it to Get Help for Your Mental Health?

Figure 4.7: How easy or difficult is/was it to get help for your mental health?



Base: 411

Young people were asked how easy or difficult they found it to get help for their mental health. The majority of young people found it difficult or very difficult to access support. 69% of young people surveyed said they had found it difficult or very difficult, 21% said they found it easy or very easy and 10% weren't sure or didn't know.

Parent / Carer Survey (n=59)
85% (n=50) of parents / carers reported that it was difficult or very difficult to get help for their child's mental health.

Experience of Looking for Help

Young people were asked to describe their experience of looking for help for their mental health in their own words. A total of 278 responses were provided to this question and they are summarised below under key themes. The number of issues raised by young people with respect to looking for help demonstrate the considerable hurdles they face.

Talking About Problems

Young people described how difficult it can be to talk about their mental health problems, part of the fear experienced by young people is having to address the issues causing their poor mental health:

"It's a scary concept to process as there is the overwhelming fear of everything coming out and your entire life being uprooted and rearranged in order to fix deep rooted issues."

"Having courage to talk to someone or not having the family support is hard because they are the ones causing the problem but you are scared to talk but having someone u click with to talk to is good."

Young people talked about the need for greater awareness raising and education for young people about mental health, and the importance of looking after your mental health. They also emphasised the need for greater mental health training for teachers, on how to identify young people with poor mental health and knowing the best way to support them:

"I wish there was more taught about mental health and how important it is to look after your mind in order for you to achieve your full potential."

Young people also described being worried about how people would react to them opening up about their mental health issues:

"I think I was more scared about how people would react to what I was telling them rather than actually telling them how I felt."

Not Being Taken Seriously or Understood

Many young people didn't feel their mental health problems were taken seriously enough by professionals when they started looking for help. Many described not being listened to and how their feelings were dismissed as 'normal teenager problems':

"I wasn't taken seriously. I was told it was probably just stress from school and that I should just go home." (Told by GP)

"Make it easier for people to get help - many counsellors need to listen more to children's problems instead of saying that it's just 'hormones' or 'a phase." (CAMHS)

Stigma and Stereotyping

Young people talked about the stigma and stereotyping that surrounds mental health, and asking for help. Young people thought that asking for help can be perceived as attention seeking:

"There is a stigma that going to GP for help is attention seeking and making a big deal about nothing."

Young people thought there was a lot of stereotyping about who mental health services are suitable for. Some young people's experiences led them to believe that unless you are presenting with serious mental health problems, you don't need help:

"The help I received was amazing and it truly changed my life, it did take a while for me to apply the help I got to everyday life but I got there in the end. The one thing I would change is the stigma and stereotype that accompanies getting help for mental health, that u need to be a loner or self-harming or have an awful life experience for it to be considered normal or acceptable to get help with mental health but that was just what I had observed. I know it is hard for young people to talk but if they felt as though their friends wouldn't judge them for getting help then I think mental health in the country would greatly improve."

"Being told they thought you were just down and weren't ill enough to need CAMHS help."

"My parents really had to fight to get access to relevant services. It took 4 years before I finally saw someone who helped. I felt that because I wasn't saying that I was going to harm myself that services couldn't help - unless I got to that point."

Waiting Too Long for Help

One of the most common issues raised by young people was having to wait too long in order to get access to mental health services. They also raised the point that a lack of a timely response by services can be very damaging to their mental health, but it can also affect future help-seeking behaviour:

"I was referred to CAMHS at the end of January and didn't get an appointment until May on an urgent referral, and when I changed therapist I had to wait 5 months for a new therapist. This meant I was left without professional help for long periods of time. My experience is very bad and it makes me not want to go to therapy."

"I feel like young people are not taken seriously. I was passed about multiple doctors and places like CAMHS without really getting any help. I was told it was "normal" or "hormonal". Once I turned 18, I gave up on the adult mental health system. I was given a time of about 3 months before I could get an appointment with a simple therapist, which was far too long as it was an emergency. I have no faith in the mental health system. I have even given up on my medication because it only makes me worse and I was given no other option but medication."

Some young people interpreted the poor resourcing of mental health services as a reflection of the lack of importance Government placed on young people's mental health, and a lack of parity between physical and mental health:

"The waiting lists like everywhere are shocking. I'm currently waiting on an emergency two week referral to my local mental health services, that referral was put in over a year ago. Mental health should be treated with the same respect and care as a broken bone, you'd not expect someone with a broken bone to wait over a year for treatment so why is it acceptable for someone who's mentally ill to wait that long?"

This Review has highlighted the huge amount of effort it takes for young people to ask for help. Many young people we engaged with had tried to deal with emotional and mental health distress on their own for some time before asking for help. They only sought professional help at the point at which they could no longer cope on their own:

"It took a while to see someone and I felt like no one really cared about me because it took so long and I was on a waiting list for quite some time."

It is important to recognise that for some young people delays in receiving services can lead to much poorer mental health. For some of the most unwell young people, this can lead to them requiring crisis or emergency care:

"(...) having to wait upwards of 6 months for an appointment can cost lives - it almost cost me mine. However, the support that I have received from those working at CAMHS once I finally got through has been exceptional, and I believe that, had they been capable of doing so, they would have seen me much earlier than they did."

"They are very busy and not enough staff. It was too long to wait to get help. I got a lot worse when I was waiting."

"It was difficult as once I saw my GP there was a 3 month wait for services, during that time I ended up in hospital."

Appropriateness of Signposting

The most common professionals young people spoke to about their mental health were school teachers or school counsellors, GPs, Voluntary and Community Sector organisations and CAMHS. It was very common for some young people to have spoken to 2 or 3 professionals before getting access to specialist mental health services:

"For me, I first was talking to my teachers and school counsellor (the counselling at school didn't go so well). My teacher suggested about speaking to my GP. I spoke to my GP about how I was feeling and he referred me to CAMHS but mentioned there could be a waiting list. Things were getting worse and worse for me and I began having serious suicidal thoughts and had already attempted suicide once before (something I didn't mention to my GP, at the time thinking it wouldn't matter because it had been a few years previous). When I told my GP about the suicidal thoughts, he sent another letter to the CAMHS service and I received an appointment within a week or two."

It was also common for young people to talk about being passed around a number of different services, before they found the one that was able to help them. This issue came out very strongly during the interviews with young people that have alcohol or drug problems:

"First few people did not help. Took a few years and a lot of fighting by my Mum before I finally saw the right person."

"Some issues are tackled by the wrong tiers and if a problem is too severe for the current tier the patient should be referred on to the tier above who may be more able to help. Despite presenting with serious issues I was referred to Tier 2 CAMHS who did not help and did not refer me on to anyone who could help - I had to be re-referred by my GP to the appropriate tier after discharge."

The Role of GPs

Many young people talked about how daunting they found having to go to their GP to talk about their mental health problems. This included young people not knowing their GP, only having a short appointment slot available to them, and the symptoms of their mental health problems making it difficult for them to attend appointments:

"Giving young people a more accessible and friendly resource to speak about their mental health problems as going to a GP can often be quite daunting, especially if an individual suffers from an anxiety disorder, and the fairly short (usually 10 minute) appointment time is not long enough for many people to adequately express their feelings and need for help."

"Having places to go without needing a GP referral would have been a good opportunity as I don't like going to the GP about my mental health."

Young people described difficulties having to speak to a GP multiple times, before getting referred on to another service:

"The amount of times I had to go to the GP about my mental health before being referred for help was ridiculous. Then waiting on a specialist appointment took months in which I got a lot worse. It was just a terrible experience and still is."

"The GP was one of the worst parts of my experience with trying to help my mental health. I was made to feel embarrassed and stupid for my feelings. It stopped me from getting help as I was deterred when I was told my feelings were normal."

Young people also described problems with the processing of referrals, and being unclear about whether referrals had been made, and the status of them:

"I went to the doctors to get counselling, they referred me to a counselling group. I got a phone call a month later saying they would be in touch with me. It's now been 3/4 years later and they never got back to me. If it wasn't for a strong foundation of friends and family I more than likely wouldn't be here due to the lack of services provided."

Access Thresholds

Young people commented on needing to get more unwell before services would take them seriously. In the examples below, young people talked about issues with the GP not referring them on to statutory CAMHS until they became a 'high suicide risk', and some young people's experience having to speak to multiple professionals before getting access to support:

"The GP did not take my illness seriously until I became a high suicide risk."

"Was told my suicidal thoughts and low mood were hormonal and part of being a teenager. It took multiple appointments with my GP to be able to get referred to CAMHS."

"I was turned away from a CAMHS service twice which only made my mental health worse as I was being told what was wrong with me was not serious enough to be treated, it took two trips back to the doctor, moving trusts and an urgent referral from my doctor to finally get me an appointment which I am finally going to now."

Young People with Additional Needs

Difficulties with getting access to appropriate services was particularly the case for young people with additional needs such as autism, or who were already waiting for an assessment. We also heard that young people had not been able to access interim support if they are waiting on a referral or assessment by another service. This includes not able to access school counselling if a GP is making a referral to statutory CAMHS. It was also common for young people awaiting an assessment for ADHD/Autism/ASD, to have difficulty accessing support for their mental health:

"GP did not refer me for support (for my mental health) because I am waiting for ASD service testing. School counsellor met me once but I felt uncomfortable. Other NHS providers also turned me down. Finally a charity (x) took me on and give me counselling."

"Getting help was difficult. I was referred to CAHMS but everyone I seen decided that they "weren't the best person for me to see." I believe this was because I'm autistic. I was referred to Autism Intervention Service but they had an extremely long waiting list, I never got to see them. My problem continued to deteriorate, what started as thoughts to self harm now became me actually self harming and feeling suicidal. It wasn't until I devolved a balance that I received "proper help". I had a depressive episode during my stay at hospital as an inpatient. My doctor referred me back to CAHMS. I received an excellent counsellor whom I saw every 2 weeks."

"I had very mixed experiences in CAMHS due to not understanding my needs. CAMHS need to have more understanding/training about Autism and sensory issues. Everyone has to stop putting young people with Autism into different boxes because we are all different."

Privacy and Confidentiality

Young people talked about being unsure about the boundaries of confidentiality between themselves and their health professionals, and how a lack of clarity about how much they could say to a health professional in confidence, had put them off seeking help:

"I was afraid to go to the GP alone because I was unsure what was allowed to remain confidential."

"In my experience I found confidentiality was an issue, everything I said was brought back to my parents. I don't feel I could trust my support givers. I no longer trust counsellors because of this. Young people need a supportive and trustworthy service, it's hard enough for us young people to talk about emotional problems without having to worry about someone reporting everything back to your parents, this leads to constant questioning from parents."

"My experience with CAMHS made me feel worse. It put me off seeking support to this day. It made me wary of who I open up to. It made me scared that something would go back to other people and confidentiality would be broken even when it didn't need to be. I have really strong negative feelings about CAMHS and I pity anyone who has to receive support from them."

Young people also talked about how a bad experience, where their confidence was broken by a mental health professional, had made it more difficult or stopped them from seeking help in the future:

"My counsellor broke the confidentiality agreement. I feel like I cannot talk to anyone in confidence as anything I say will be sent straight to my parents and that caused more problems."

"I have struggled to get help due to the fact I am worried my family/friends would judge me. If my school got involved suddenly everyone would know, as previously I seeked counselling in school and a senior teacher, rang home to inform my parents, even though the counsellor had not advised me i.e. they breached my privacy and made my situation 20 times worse."

4.6 Service Experience

Within the survey, young people were asked about seven key services or support that they may have received for their emotional well-being or mental health. These services were GP services, School/University/College, Voluntary and Community organisations, CAMHS in the Community (Out-Patient) appointments, Accident and Emergency Department (A&E), Out of Hours GP, and inpatient hospital care. Young people were also asked about their experience of transitioning between CAMHS and AMHS

Young people were asked to rate their experience of the seven services/supports against a range of statements or indicators. The statements related to three key areas that are listed below:

Information and Access

- I was given useful information to help me to understand my mental health needs; and
- I was given a choice of treatment/support.

Facilities/Services

- The place that I received support in made me feel comfortable and safe;
- I didn't have to travel far to get help/ receive services; and
- I was able to access the service/support when I needed it.

Quality of Care

- I felt listened to and respected;
- I was spoken to in a way that I could understand;
- I felt involved in the decisions that were being made about my care or treatment; and
- The support I received was helpful.

For each service, young people were asked to use a 5 point Likert agreement rating scale of: strongly agree, agree, disagree, strongly

disagree, and I don't know/I'm not sure. The table below outlines the number of young people who had experience of these services, and the overall number of young people who agreed to answer a range of questions about their experience.

Response Rates for Different Services

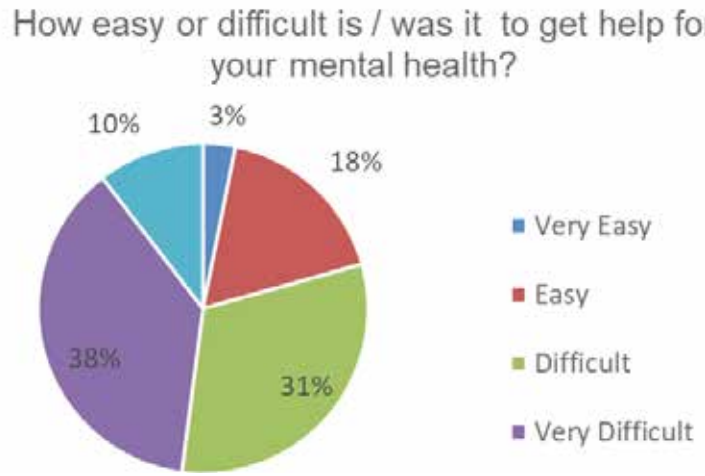
Table 4.5: Number of Respondents by each Service

Service	Response
GP	246
School / College / Uni	145
VCS	78
CAMHS in Community	130
A&E	62
Out of Hours GP	27
In-Patient Care	28
Transitions	37

Note: the overall sample size varies for each section of the survey, this is due to young people electing to skip sections of the survey because they did not have experience of that service or they choose not to answer questions.

4.7 GP Services

Figure 4.8: Have you been to your GP about your mental health?

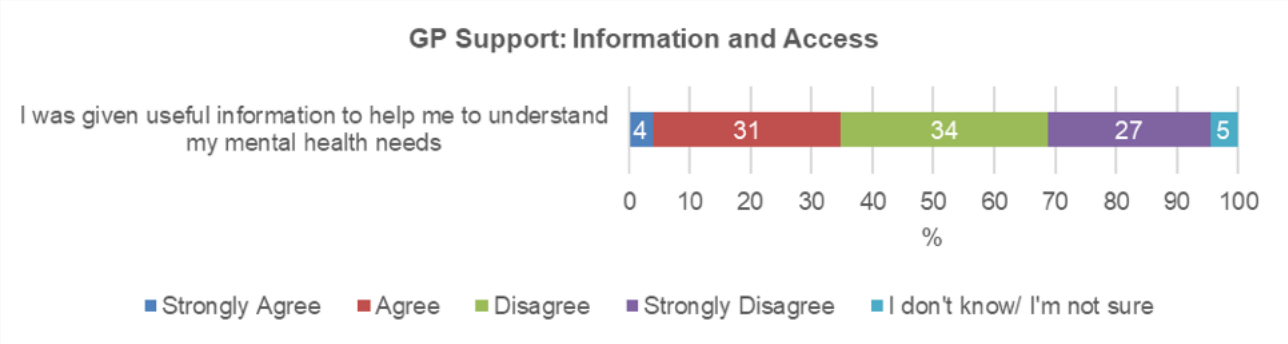


Base: 369

Almost 70% of the young people surveyed had been to their GP about their mental health, 28% indicated that they had not, and 3% didn't know or were unsure.

Information and Access

Figure 4.9: GP Support: I was given useful information to understand my mental health needs



Base: 244

Unfortunately, for many of the young people who responded to our survey, GP services did not rate highly in any of the three main areas. Over 60% disagreed or strongly disagreed, that the GP gave them useful information to help them understand their mental health needs.

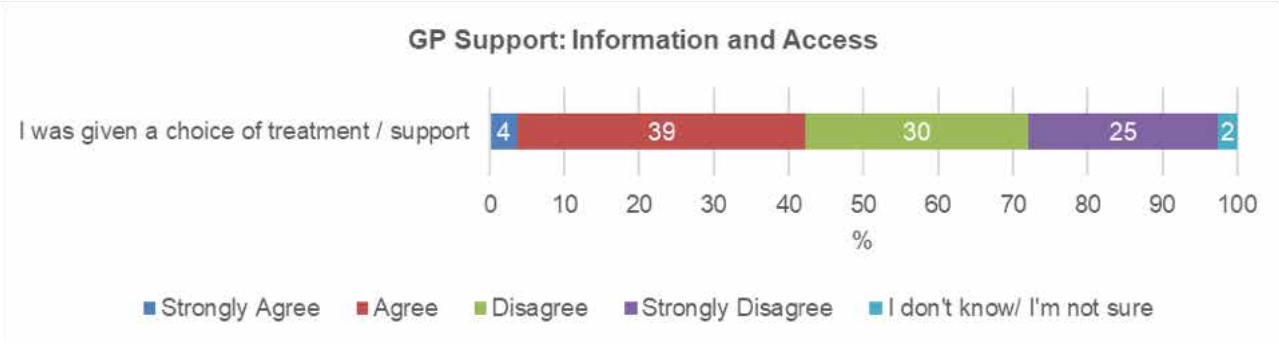
Some young people reflected on this point further in their response to the open questions, stating they felt that GP's understanding of mental health is limited, and that GPs need to be better trained in this area:

"I think the GP I was speaking to is a very experienced man about health and definitely great at his job. Although (they) did not have the skills to deal with the mental health side of things, to make someone feel better about it, the connection of 'I feel and understand your pain' needs to be there, not just take these tablets and come back."

"GPs are not the best trained around mental health and this has a major impact as when I told my doctor about my mental health, they couldn't help me understand as they aren't trained very well with mental health, self harm and suicide."

"My GP right in front of my eyes googled "help for OCD belfast" because there was "nothing else he could do". I was gobsmacked. "

Figure 4.10: GP Support: I was given a choice of treatment/support



Base: 244

Just over half of respondents (55%) disagreed or strongly disagreed that they were given a choice of treatment or support from their GP, and 42% agreed or strongly agreed. These results would suggest that young people experience significant variation, with respect to being given a choice of treatment/support.

Some young people did not have a problem with this, but others said it was something they would have wanted to discuss with their GP, if given the opportunity:

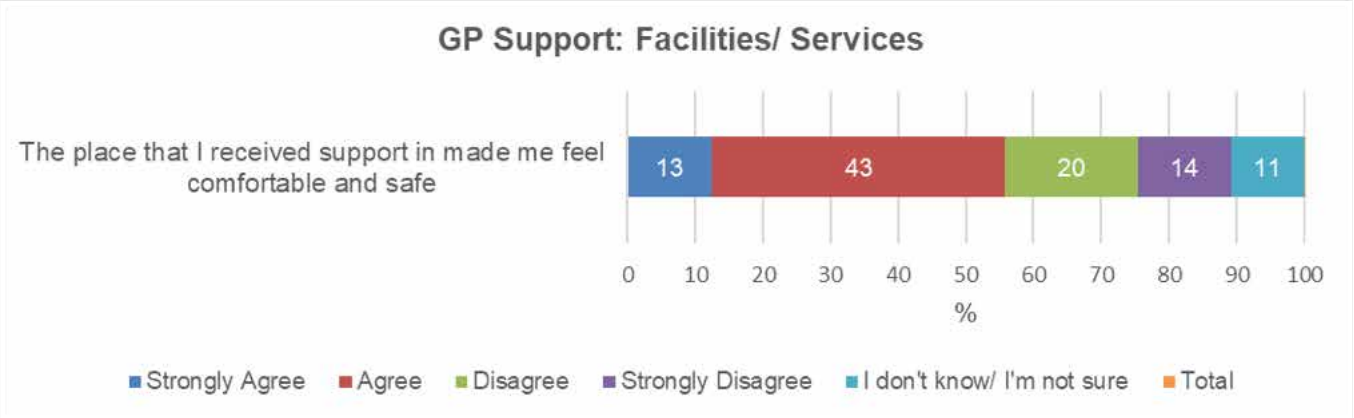
"I was prescribed antidepressants but the GP did not seem to care about any of my symptoms or feelings. He gave me a prescription and sent me away."

"My doctor was wonderfully understanding and gave me lots of information, but I was not given the option about which service to go into, but I'm glad it was CAMHS."

"I was given medication for a month's trial, however I noticed no change in levels of depression and was urged to try another month at a time for a few months after, until I refused which made my mental state even worse. No other suggestions of treatments were made before I started taking anti-depressants."

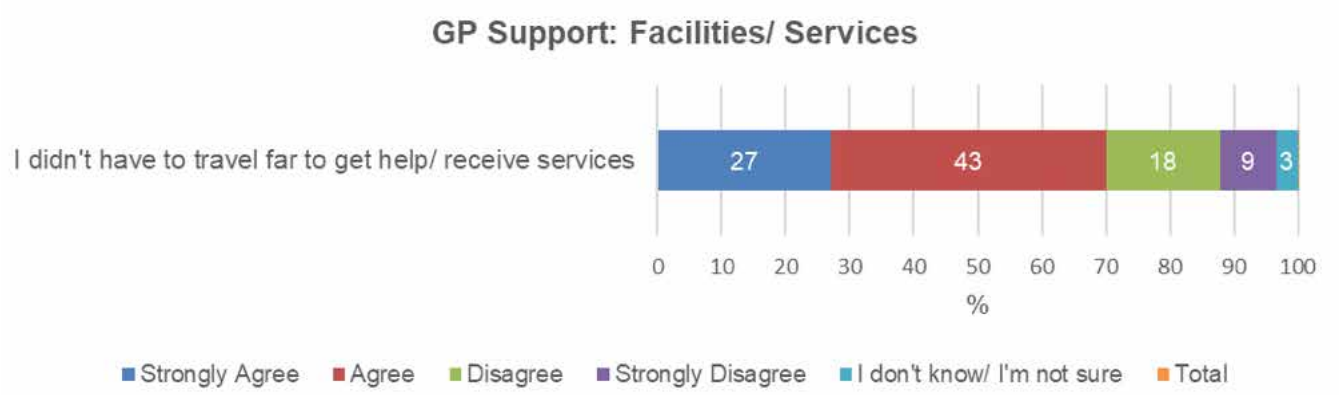
Facilities/Services

Figure 4.11: GP support: The place that I received support in made me feel comfortable and safe



56% of young people, either agreed or strongly agreed, that the place they received support in made them feel comfortable and safe, 34% either disagreed or strongly disagreed and 11% stated 'I don't know' or 'I'm not sure'.

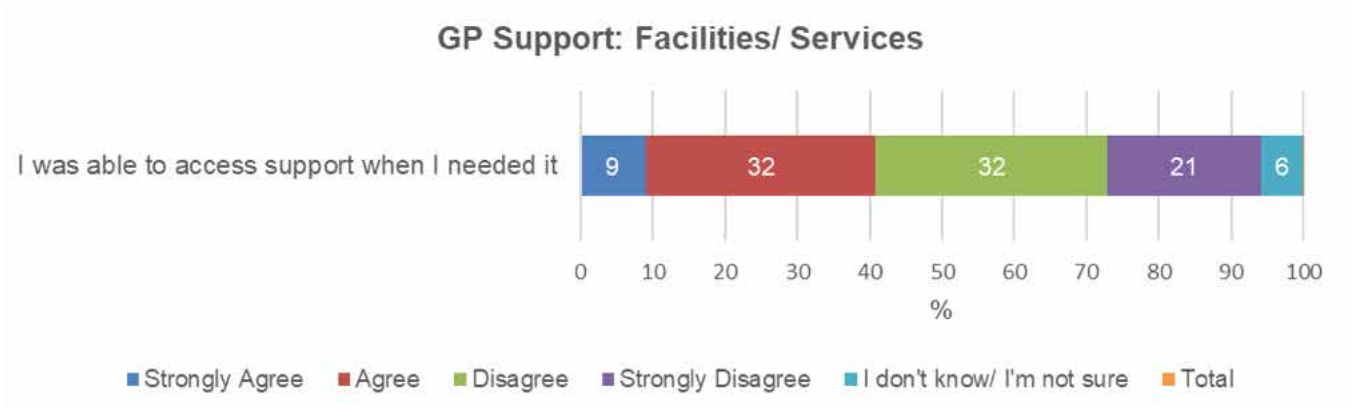
Figure 4.12: GP Support: I didn't have to travel far to get help/receive services



Base: 240

Overall, the majority of young people (70%) either agreed or strongly agreed that they didn't have to travel far to see their GP, 27% either disagreed or strongly disagreed and 3% said they did not know or were unsure.

Figure 4.13: I was able to access the service / support when I needed it



Base: 240

There was a mixed response to the question about whether young people were able to access support from their GP service when they needed it. 53% disagreed or strongly disagreed that support was accessible and 41% either agreed or strongly agreed.

Even when young people had a good experience accessing services themselves, they were very aware that this was not always the case for other young people:

"Although from my experience I was attended to well, for many people I know they were thrown on to long waiting lists and were not given the help they needed, there's a real lack of funding for mental health and that's evident."

Young people talked about some of the difficulties they experienced in getting access to their GP, especially when they needed help quickly:

"I could contact the doctor but it was hard to get an appointment and was hassle to get an emergency appointment. I often felt like a burden when I tried to get an emergency appointment as the receptionists always tried not to give you them. However CAMHS have been good in facilitating appointments."

Some young people commented on needing to get more unwell, before their GP would take their concerns about their mental health seriously:

"The GP did not take my illness seriously until I became a high suicide risk."

Young people also talked about appointments not always being convenient or taking account of school. The survey included specific questions on the ease or difficulty with making appointments, and these are explored further on, in this section of the report:

"Often [the GP appointments would be] between 9-4pm no account taken of school or fact if need family support consideration around parents work."

GPs provided a range of advice or support to young people about emotional or mental health problems. The most common support provided was a referral to other services or support, followed by prescribing medication. The most common agency that young people were referred on to was CAMHS.

Parent / Carer Survey
Parent / carers also reported that the most common advice provided to their child was referral to another service (n=40) and the service was most commonly to CAMHS (n=23).

Table 4.6: What advice or support did your GP give you? (multiple response question)

	%	Freq (n=)
Referred me to other services / support	66%	157
Prescribed / changed medication	43%	102
Suggested I talk to family / friends more about my feelings	33%	77
Suggested I did more exercise / relaxation	30%	71
Provided me with information / leaflets on mental health	19%	44
They didn't provide any advice or support	12%	29
Was there something else? What was it?	10%	24

Lack of Support Whilst Waiting for an Appointment

Young people also described having to deal with mental health issues/symptoms on their own, whilst they were waiting for someone to help them. One young person said it would be helpful if their GP was able to provide them with coping strategies, whilst waiting to be referred to a specialist mental health service. A lack of support whilst waiting for a referral and also a lack of additional support between appointments was raised by young people, and this is discussed further in Section 9:

"If my GP was able to provide me with some information on the effects of my mental health and maybe some coping strategies while I was waiting for my referral to be completed."

Young people talked about being signposted to services by GPs, without being given support about how to get in touch with these services, or to get an appointment arranged.

"I was told (by my GP) to self-refer myself but I don't know how."

"I haven't went to any of the services that where giving to me. As I had to do it myself which was never going to happen."

Waiting Times for Appointments

Young people described having to wait significant amounts of time between their GP making a referral to Step 3 CAMHS and getting an appointment:

"Was only ever given referrals, which then would take weeks/months until I actually get anything."

"We were able to get a GP appointment, however the referral took some time and a booklet was sent out for me to fill in and then I went on to a waiting list so I wasn't able to access the support I needed straight away."

Referral Not Being Processed

There was a significant number of young people who talked about referrals being made to a service, but never receiving an appointment:

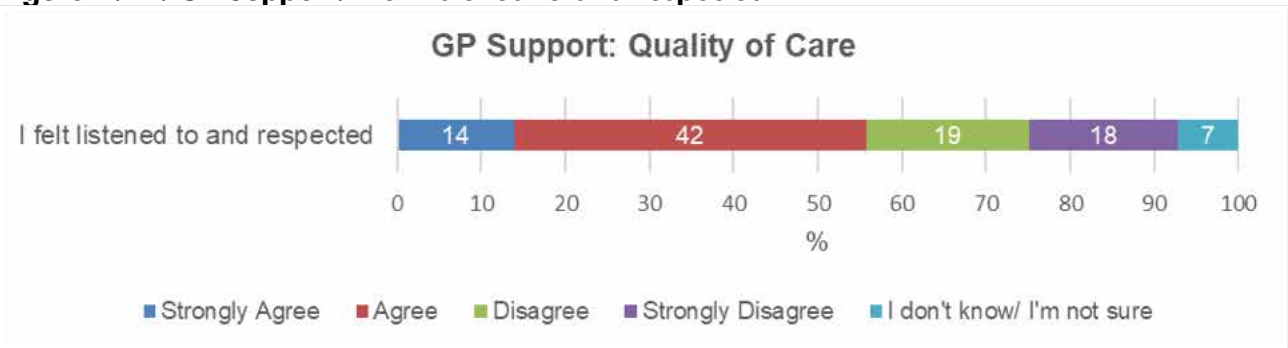
"I was referred to counselling and never received any."

"I didn't receive the support I was told I would get."

"They (the GP) forgot to refer me."

Quality of Care

Figure 4.14: GP Support: I felt listened to and respected



Base: 237

Slightly over half the young people surveyed (56%) agreed or strongly agreed they felt listened to and respected when accessing support from their GP, and 37% either disagreed or strongly disagreed.

In the open response section of the survey, young people talked about their GP not taking them seriously or dismissing them, and having to go back to the GP on multiple occasions before being referred to other services:

"My doctor did not treat it in a sensitive manner at all and I left feeling much worse then when I had come in. The only thing we were told about treatment was that it would take a long time to get an appointment through the NHS."

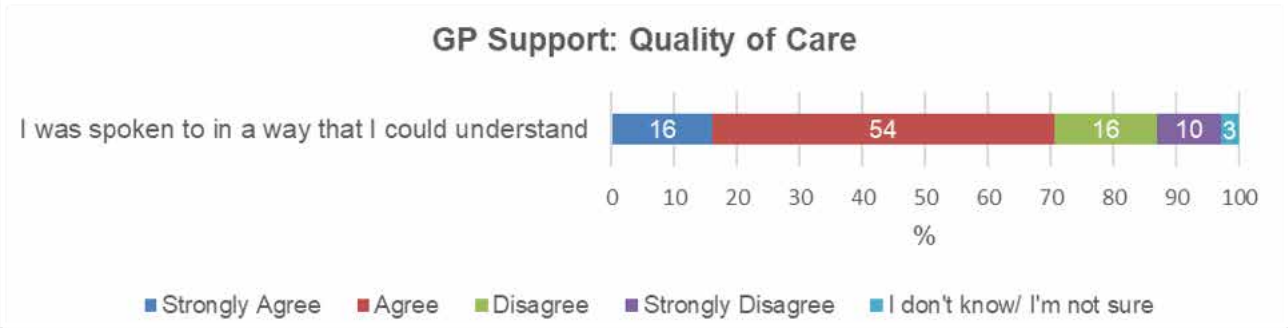
"I was advised to go for walk or try yoga when I asked for emergency appointments for feeling so low at least five times within six months."

"The first few times I went they treated me like a whiny teenager. The last time I went I was taken a little more seriously but I felt as though they referred me to "get me out of the way" almost."

It was common for young people to talk about feeling rushed, when they attended a GP appointment, to talk about their mental health. Young people felt the GP should be able to spend longer with young people when they want to talk about their mental health problems:

"I had to wait 3 weeks on a GP appointment. And I was given 5 minutes. Mum said he couldn't have got us out quick enough."

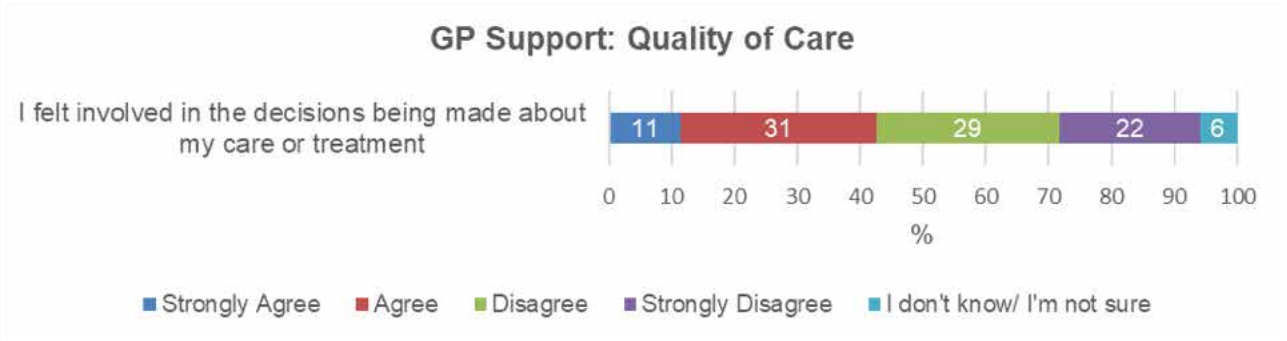
Figure 4.15: GP Support: I was spoken to in a way that I could understand



Base: 237

A high proportion of young people (71%) agreed or strongly agreed their GP spoke to them in a way they could understand. However, a significant minority (27%) disagreed or strongly disagreed this was the case.

Figure 4.16: GP Support: I felt involved in the decisions that were being made about my care or treatment



Base: 237

There was a mixed view from young people about whether they felt involved in decisions being made about their care or treatment: 42% either agreed or strongly disagreed this was the case and 51% either disagreed or strongly disagreed:

"I was told I can go to CAMHS or get no help at all."

"I often felt dictated to as if we're trying to tell me how I feel."

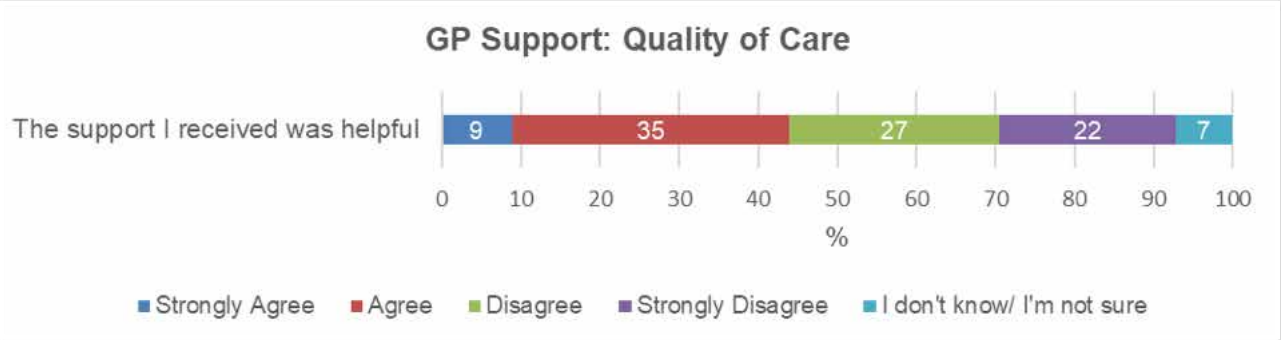
"I feel that I'm not taken seriously and am rarely asked for my opinion on treatment."

Young people often found it difficult to open up and give their point of view, especially when the support was not working. They recognised that because GPs are not mental health specialists, it can be difficult for them to fully understand:

"I couldn't say because of social difficulties that this isn't working, when I did with support of mum no alternative offered. Also focus on just pushing me into groups which heighten my mental health issues."

"Within my GP appointments I felt respected to an extent as my GP didn't have a great understanding (..), I felt like I wasn't being listened to at times and was in and out as quick as I could. When my GP was talking I found it hard to understand her at times because she was saying words I found hard to understand, she didn't cater it to my needs. At times I felt involved in decisions about my treatment and what was going to happen next with my support and how to cope and deal."

Figure 4.17: GP Support: The support I received was helpful



Base: 237

There was a mixed view from young people about whether they felt the support they received was helpful: 44% either agreed or strongly agreed and 49% of either disagreed or strongly disagreed.

Parent/Carer Survey
22 (46%) parents disagreed or strongly disagreed that the support their child received was helpful, 20 (43%) agreed or strongly agreed and 5 (11%) didn't know or were unsure.

Some young people described having a very positive experience of their GP service:

"The support from the GPs has been supportive – much better than the mental health team."

"Without the support they gave me, I simply would not be alive today."

Young people described issues with communication between their GP and other mental health services they were accessing:

"Initially my family GP was very supportive and got the ball rolling, however she retired and it has been pot luck and I feel GPs don't know or understand enough about Anorexia and the ED[28] team don't communicate to my doctors enough. I know my surgery feel they are in the dark and I am stuck in the middle at times."

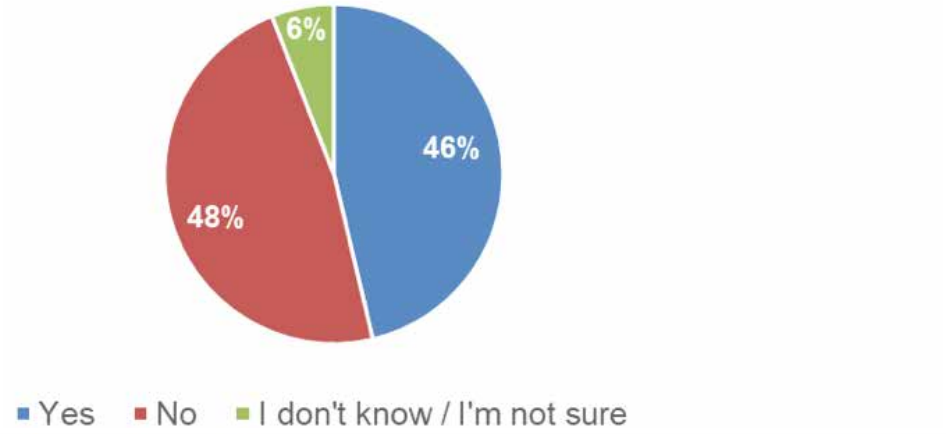
Another young person with an eating disorder also raised a similar issue. Eating disorders are one of the conditions young people may be expected to work between a GP and a mental health team:

"Better communication between mental health services and GPs. Asked to get bloods taken on a regular basis by ED team and GPs are saying it not up to them. We are being asked to organise this and sometimes feel we are really caught in the middle between the two. Boils down to cost at the end of the day and as we don't have the facilities in the mental health end the GP is left to facilitate. My GP has asked a couple of times now who is looking at blood results and taking action so there is obviously no communication between the two. My mum was asked to get the mental health team to ring the DR's and explain and the DR phoned back saying he still hadn't heard and was concerned. It has been resolved but it proves the communication between the two needs to be better. We should all be working together."

Young people were asked to indicate which service their GP had referred them on to. Only 51 of the 157 young people who had been referred on, answered this question. This may indicate a lack of knowledge about the services they were being referred on to. Within the survey and during the interviews, young people mentioned that the referral system can be confusing. Of the young people who did answer this question, 80% (n=41) reported they had been referred to CAMHS by their GP.

4.8 School/University/College

Figure 4.18: Have you received support for your mental health from School/University/College?

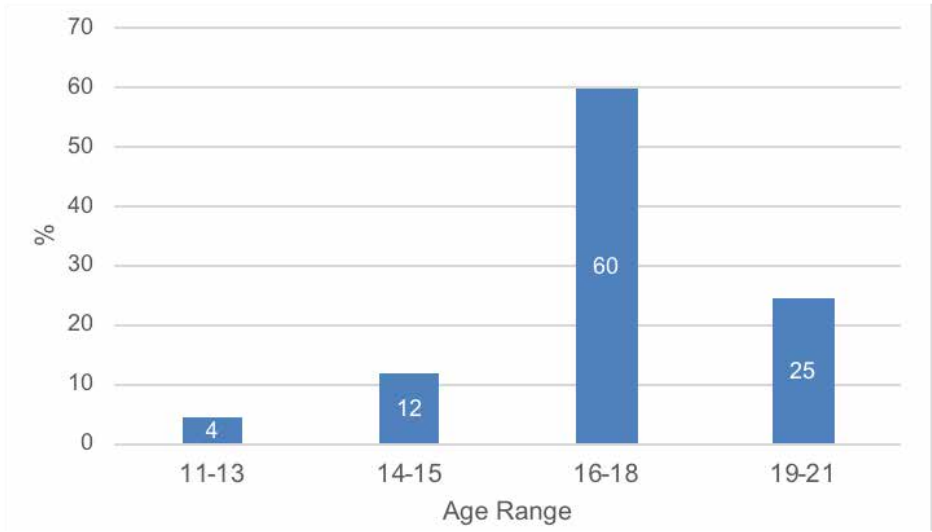


Base: 352

28 ED=Eating Disorder

Slightly less than half (46%) of the young people surveyed had received support for their mental health from school, University or College. The survey did not ask the young people to specify which part of the education system their experience related to. However, the age range of the respondents outlined in the graph below indicates that the majority of responses relate to post primary school and college age.

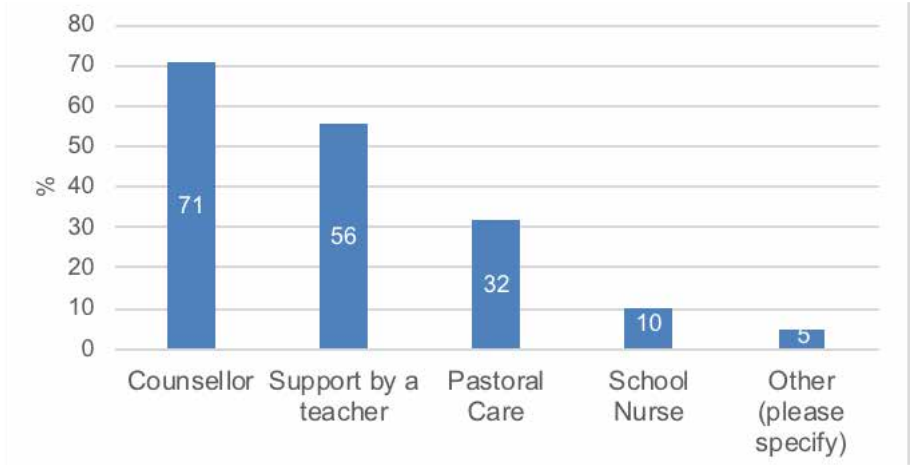
Figure 4.19: Age Range of Young People Accessing Support through Education Service



Base: 163

The vast majority of young people who completed the questions on the support they received from within the education sector were of school or college age (16-18 years old). A further 25% were College or University age (19-21 years old) and 16% were post primary school age (11-15 years old).

Figure 4.20: Who have you received support from? (multiple response question)



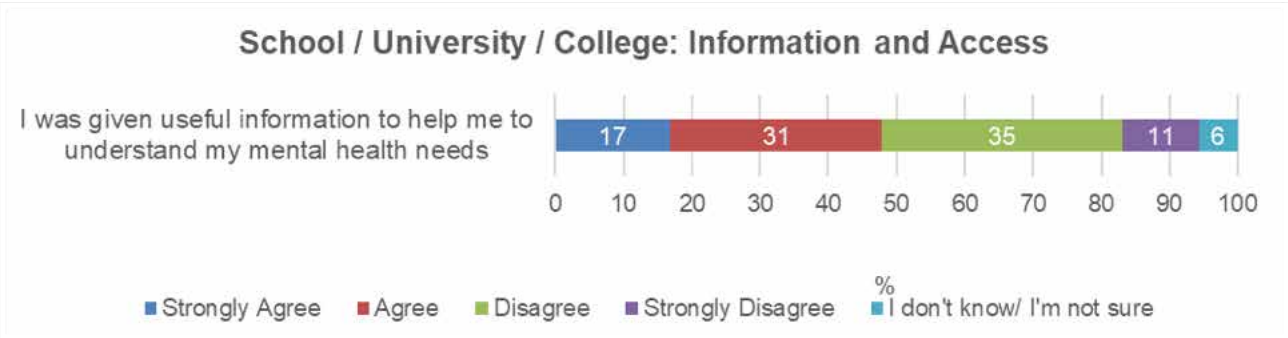
Base: 161

The most common form of support young people received within the school, university or college, was from a counsellor (71%), followed by support from a teacher (56%).

Young people also mentioned they had received pastoral support (32%) or spoken to a school nurse (10%). These results show that many of the adults young people approach for support, have a variety of roles within the educational environment, and may not necessarily be trained in child and adolescent mental health, or have the knowledge of who to signpost young people on to.

Information and Access

Figure 4.21: School/University/College: I was given useful information to help me to understand my mental health needs

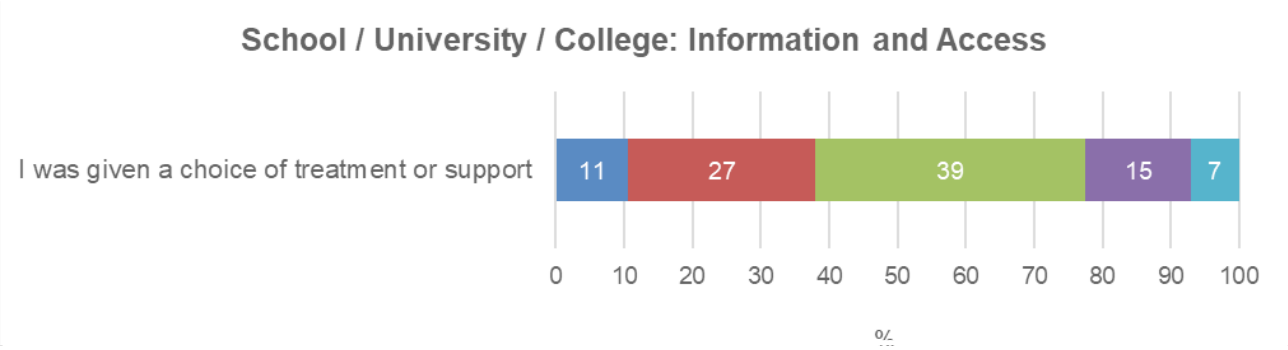


Base: 142

There was an almost equal divide in terms of how useful young people found the information they had been given on their mental health, by their school. Almost half (48%) either agreed or strongly agreed they were given useful information to help them to understand their mental health needs, while the remaining 46% disagreed to strongly disagreed. This indicates considerable variation in the experience of young people when receiving support from within school:

"I felt school was a major factor in my mental health improving however the only bad thing about this is that not every school is the same as my school. Every school needs to have the point of view that a pupils mental well being is above all else."

Figure 4.22: School/University/College: I was given a choice of treatment / support



Base: 142

Over half of young people surveyed (54%) disagreed or strongly disagreed that they had been given a choice of treatment or support at school, and 38% agreed or strongly agreed:

"People in the school including the counsellor just talked to me and didn't give me info."

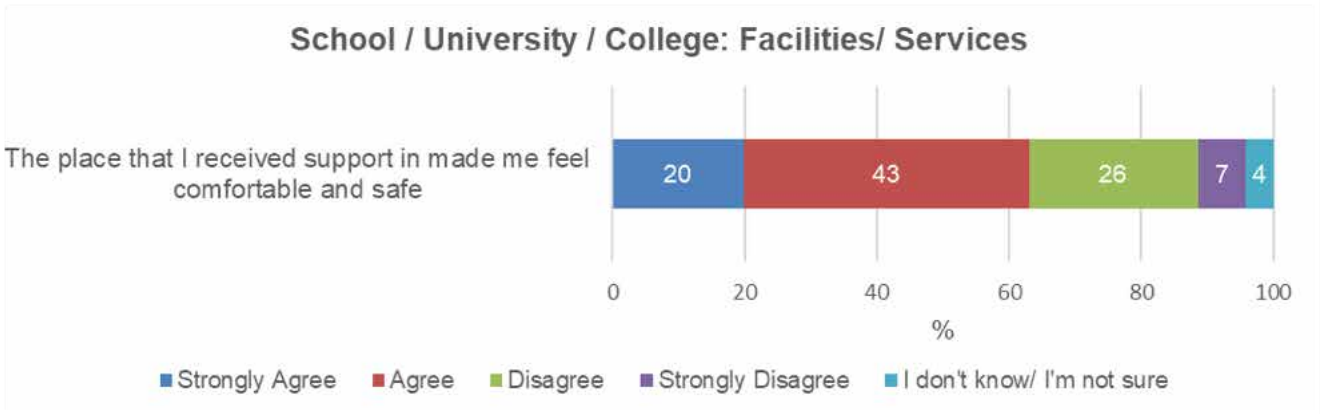
Overall, young people's experience of the usefulness of the support in their school for mental health, and the choice of treatment or support, varied significantly:

"I confided in specific teachers during my worst times and many of them were very helpful and supportive for me, albeit in an informal and unstructured manner."

"There was one specific teacher who seemed to understand completely but the majority of them would make fun of me and one who was made aware said that my problem 'isn't even a real thing'."

Facilities/Services

Figure 4.23: School/University/College: The place that I received support in made me feel comfortable and safe



Base: 141

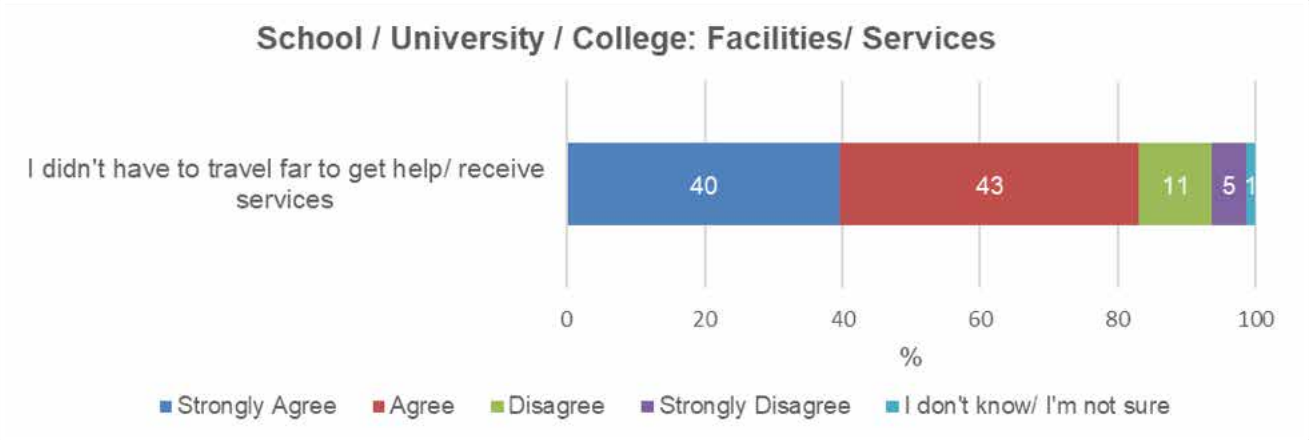
The majority of young people surveyed (63%) agreed with the statement 'the place I received support in made me feel comfortable and safe'. However, a significant minority of young people (33%) either disagreed or strongly disagreed:

"I didn't want to get help in school, because I didn't want it to be a school thing, I didn't want anyone knowing where I was or asking where I was going if I went to the counsellors office, also, the counsellors office is incredibly cramped, and uncolourful."

"I did not feel comfortable in the room as the woman sat across from me, making me feel judged. Other students clearly seen me walk into the room advertised for people who had problems to go to. My sessions were always during class time so I was constantly pulled from class, stressing me further as I had to catch up/ think of excuses as to why I had to leave the room every Wednesday."

"The place I had my counselling sessions at school was a small room with a window. Was easily seen in there with a counsellor when I would have liked complete privacy. Also hall outside was very noisy. Would have liked somewhere more remote."

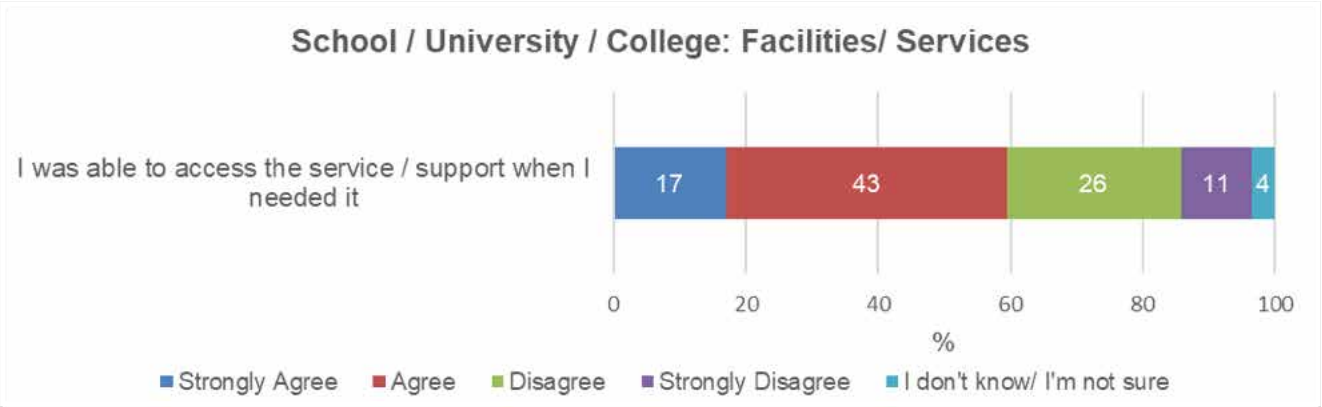
Figure 4.24: School/University/College: I didn't have to travel far to get help / receive services



Base: 141

83% of the young people agreed or strongly agreed that they did not have to travel far to get help. 16% said that they did have to travel far.

Figure 4.25: School/University/College: I was able to access the service/support when I needed it



Base: 141

The majority of young people surveyed (60%) agreed or strongly agreed they were able to access services or support within school when they needed it:

"My school was definitely the best support I received in my struggle with mental health. I had constant support from teachers I knew and trusted and knew that there was always someone there to help me, and that they genuinely cared about my well-being too."

A significant minority of young people either disagreed or strongly disagreed (37%) they were able to access services or support within school when they needed it. The following responses highlight some of the challenges they faced when attempting to access support from within school:

"Limitations on number of counselling hours and when sessions are available."

Young people said that it would be helpful if there was more flexibility in the number of counselling hours available to them, and less restrictions on the day and time sessions were available:

"Don't have a limit on how many sessions people can have. Sometimes they still need help beyond their limited number of counselling sessions."

"Certain teachers would talk to me and it would help a bit but was not professional help. Was told to go to school counsellor. Went for 2 MINUTES and was told she had someone coming in now and that I was now being put on a waiting list. This is another source of help that I was told was going on a waiting list."

The challenge of being able to attend appointments with services was a general issue raised by young people. This related to many services or support included in the survey, such as school/ University/College, CAMHS out-patient appointments and Voluntary and Community services:

"I cannot always access support as my mental health becomes a burden where I cannot attend college I had a written warning last year as I had low attendance."

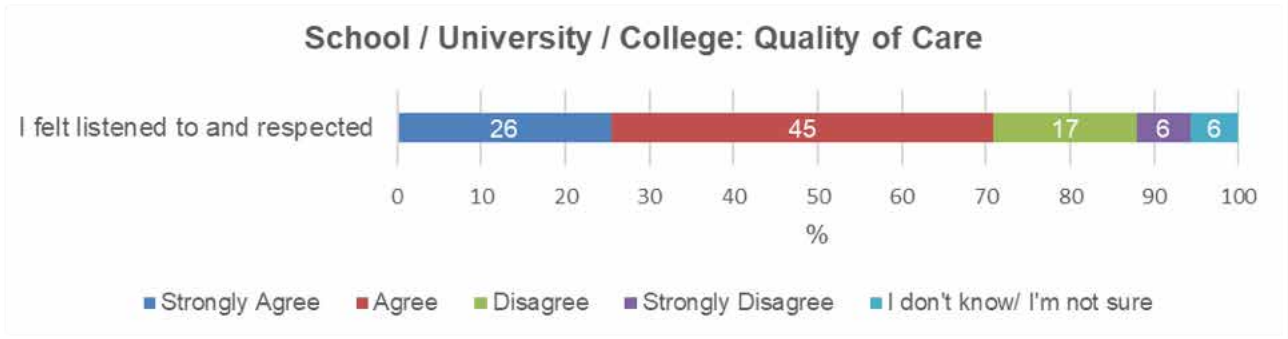
Young people were asked specific questions in the survey about their experiences of making appointments and this is explored further in Section 9.

Young people said, teachers in general, provide a really important form of support, and suggested that it would be helpful if there was more structure or clarity on when teachers can be available to them:

"Sometimes it would be difficult to speak to the member of staff / teacher as there were no set times when I could have spoke to them. I think if each pupil had one member of staff that they could go to and possibly have a set time a week when they're allowed to go to speak to them – so they know there is a time when they aren't disturbing anyone or worried about interrupting anything."

Quality of Care

Figure 4.26: School/University/College: I felt listened to and respected



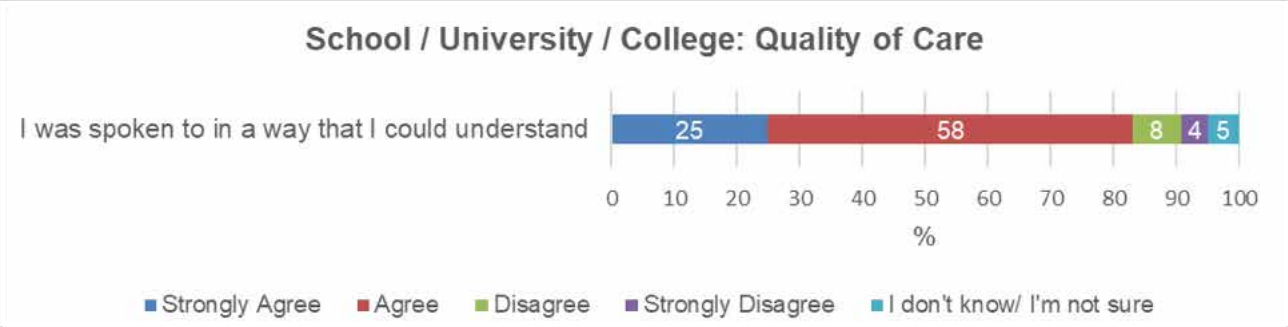
Base: 141

71% of young people surveyed felt listened to, and respected when they sought help from school for their mental health: 23% said they disagreed or strongly disagreed:

"My principal has been very accommodating and communicates with my teachers when I am struggling. However, many teachers don't know how to respond or help someone with mental health issues despite wanting to."

"I felt as if I wasn't taken seriously at all, certain teachers told me it wasn't serious and to "grow up". I then attempted suicide."

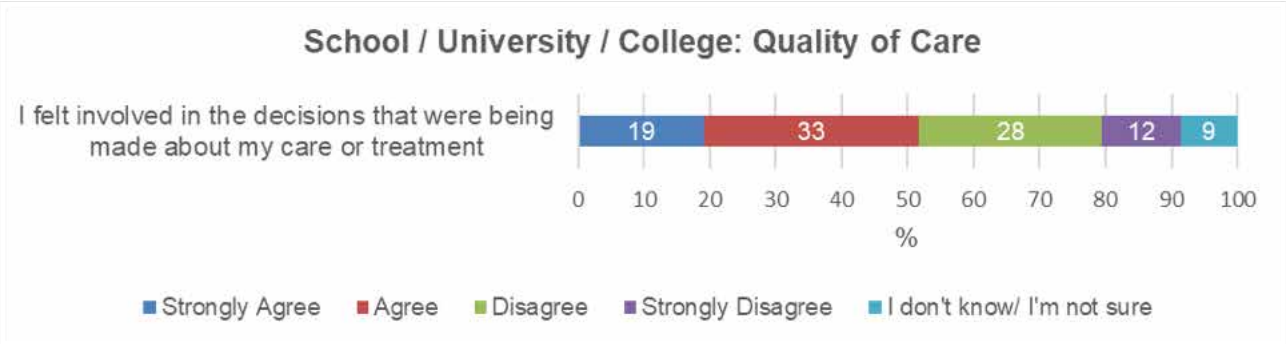
Figure 4.27: School/University/College: I was spoken to in a way that I could understand



Base: 141

83% of young people surveyed agreed or strongly agreed that they were spoken to in a way that they could understand. 12% disagreed or strongly disagreed that they were spoken to in a way they could understand.

Figure 4.28: School/University/College: I felt involved in the decisions that were being made about my care or treatment

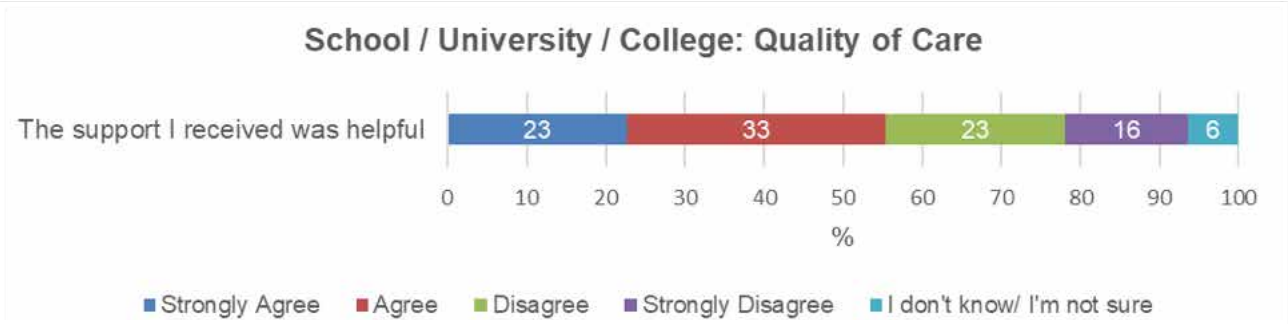


Base: 141

Just over half the young people surveyed (52%) felt involved in the decisions that were made about their care or treatment, 40% said that they disagreed or strongly disagreed:

"The member of staff and teacher were not able to keep certain things confidential so certain decisions, in my case, had to be made without my consent (for my safety), which is good, I suppose."

Figure 4.29: School/University/College: The support I received was helpful



Base: 141

Over half of young people (56%) agreed or strongly agreed the support they had received was helpful. However, 39% disagreed or strongly disagreed.

Parent / Carer Survey (n=22)
Eleven (50%) parents / carers agreed or strongly agreed that the support their child received in school, college or university was helpful, seven (27%) disagreed or strongly disagreed and five (23%) didn't know or were unsure.

In terms of the four key indicators[29] used to measure 'quality of care' in schools, young people provided higher agreement ratings with 'being listened to and respected' and 'spoken to in a way they could understand' and lower agreement levels with 'feeling involved in decisions being made about their care and treatment' and the 'support being received being helpful':

"Teachers do not get enough credit for the work they do in trying to support pupils with mental health. They do not have the specific training that is needed but do their best to support every pupil who approaches them. I think teachers should be given a lot more training for mental health issues and how to deal with them so that if a child/ pupil approaches a teacher they are able to help them without having to tell the pupil to speak to someone else (CAMHS service, ChildLine, lifeline etc.)"

In general, young people reported they wanted a school environment in which young people's mental health was supported and nurtured, and where they could feel comfortable and safe to talk about their emotional well-being and mental health.

They referenced the need for greater attention to mental health in lessons and school assemblies, more focus on mental health in teacher training, easier access to school counselling and the availability of quiet/time-out spaces in school.

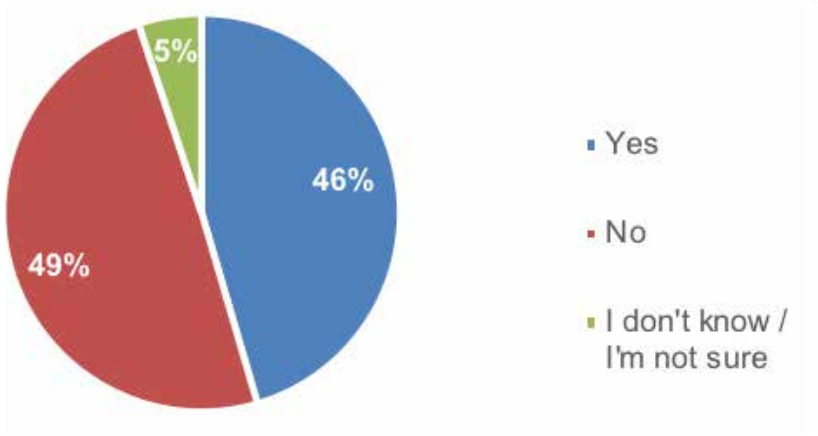
The following quote from one young person, summarises key things that were raised by young people in the survey regarding mental health support within educational settings:

29 Indicators are explained in Section 3

"Schools need to bring mental health into school lessons and school assemblies more as mental health is becoming and is a huge problem in NI. It should be a problem that can be easily spoke about with no stigma around it. All Teachers should be specially trained in how to deal with young people and how to deal with those who have mental health problems and how to spot out someone who has problems and how to support them through this. Schools should have counselling available for all students and should have a quiet place for young people to take some time out if needed. Schools should be made an environment where young people feel comfortable to talk and speak out as young people spend most of their time in school through their life."

4.9 CAMHS in the Community

Figure 4.30: Have you experience of receiving support for your mental health from CAMHS in the Community?



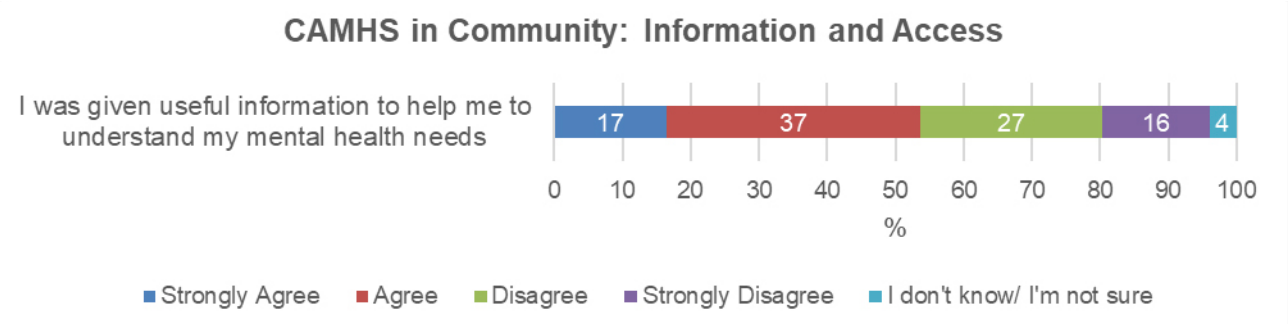
Base: 330

Just under half (46%) of young people surveyed had experience of receiving services from CAMHS in the community, 49% had not been to CAMHS in the community, and 5% were not sure or did not know.

Information and Access

Overall, there was a very mixed response from young people with respect to the usefulness of information provided by CAMHS in the community, to help them understand their mental health, and in the choice of treatment and support.

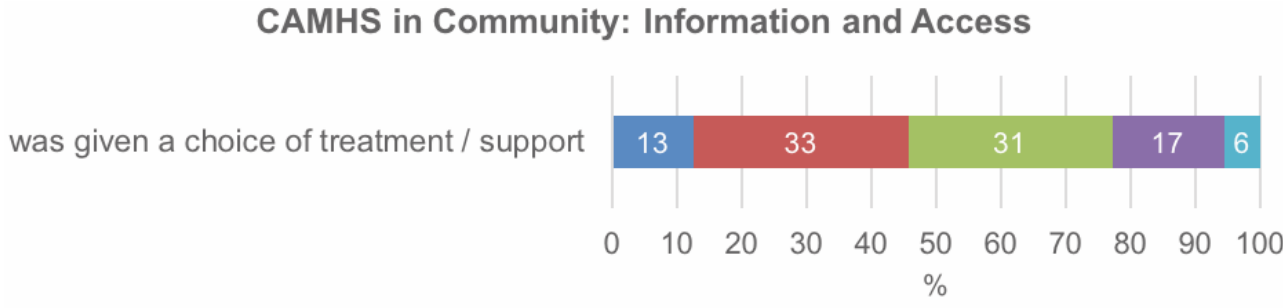
Figure 4.31: CAMHS in the Community: I was given useful information to help me to understand my mental health needs



Base: 127

Just over half (54%) of young people with experience of CAMHS in the community, agreed or strongly agreed that they had been given useful information to help them to understand their mental health needs, and 43% either disagreed or strongly disagreed.

Figure 4.32: CAMHS in the Community: I was given a choice of treatment / support



Base: 127

In terms of young people's experience of being given a choice of treatment or support, 46% either agreed or strongly agreed that this was the case, and 48% either disagreed or strongly disagreed.

Young people who found the choice of treatment and support through CAMHS helpful, elaborated by stating they had found new ways to cope with their mental health problems, by going to CAMHS in the Community:

"I learnt new techniques to control my anxiety and intrusive thoughts."

A number of young people also said they understood the reasons why they were not given a choice, as they wouldn't have made the right decision, because of their poor mental health:

"In my situation I wasn't given a choice in terms of my treatment. But that was what was needed to be the case when dealing with an eating disorder. The treatment I received was entirely appropriate."

Young people also provided further information to help explain the reasons why they disagreed they had been given a choice of treatment and support. These included a lack of choice in terms of psychotherapies and medication, and having to wait too long to receive helpful advice, support, or to access a specific therapeutic intervention:

"No choice in psychotherapies or medication."

"I didn't know you could get a choice of treatment or support. Most of what I know about my mental health I had to research myself. It took 4 years of working with CAMHS before they asked me any useful or progressive questions, gave me useful advice, coping mechanisms or diagnosis."

It is also important to reflect on the fact that many young people feel that waiting to receive help puts a lot of their other life plans on hold, like their education and career:

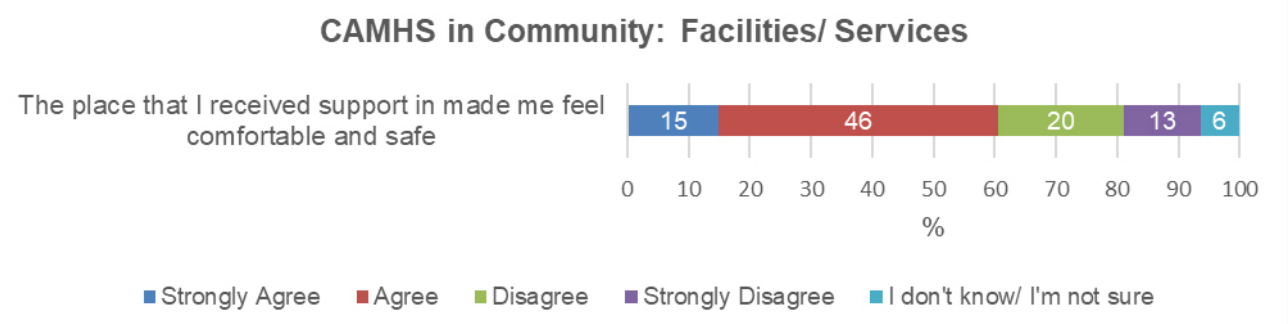
"I have also been waiting nearly a year and a half to do CBT therapy and waiting this long is actually ridiculous, I can understand that there's only so many therapists and the demand is high, however, if there was more money put into the services this could change and this could help improve people's lives like myself. Due to this delay in therapy I know I have to delay my education and my university plans to go and study as I am not going to be able to do this therapy while on a full time nursing course. Massive thanks NHS."

Involving a young person in the decision making process about the choice of treatment and support is important, as it can help them understand why health professionals are working in a particular way, and in fact can be part of the therapeutic process itself:

"I feel that when being given help from CAMHS I wasn't involved in the treatment I wanted and this made me isolate myself further from receiving help because I didn't have any insight into what was going on."

"[I] was just put on medication and came to appointments to 'talk', literally just 'how was your day', 'did you go to school' etc., no actual help with my emotions and mental health."

Figure 4.33: CAMHS in the Community: The place that I received support in made me feel comfortable and safe



Base: 127

61% of young people agreed or strongly agreed the support they received as a CAMHS out-patient made them feel comfortable and safe, and 33% disagreed or strongly disagreed. Young people mentioned that the physical appearance of the buildings, and the professional approach of staff, were factors in how comfortable and safe they felt when attending CAMHS out-patient appointments:

"Before I went for my first appointment I was terrified, but the CAMHS staff are very welcoming."

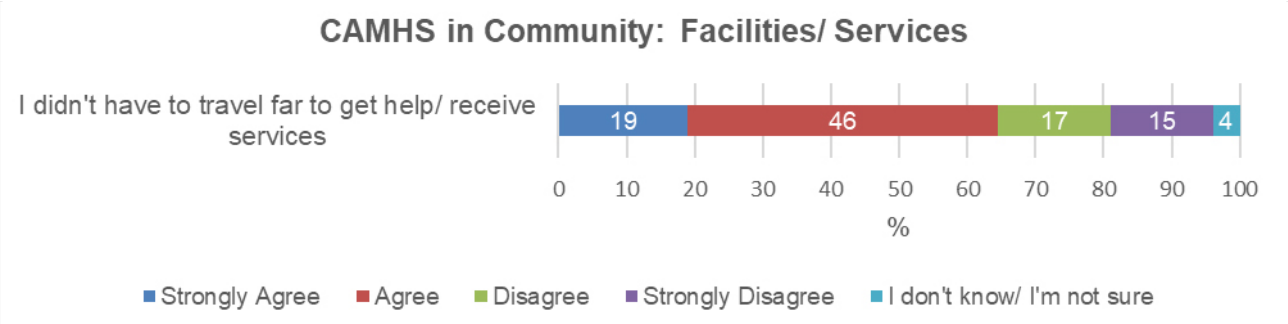
"I feel really uncomfortable within the statutory sector as it is more formal and the room layout is like a doctor's room this made me feel like I was worse than I was."

Young people reported that they would feel more supported if they were given more flexibility in how they access and communicate with services, and for the support they received to be better tailored to their age:

"Having to have a telephone consultation made me avoid this service, even though I could have done with it. Understanding, that some people with anxiety, find it very difficult to speak on the phone to a stranger about their problems and different options (in person/online etc.) would be really helpful."

"As a teenager sitting in a room with toys made me feel even more stupid."

Figure 4.34: CAMHS in the Community: I didn't have to travel far to get help / receive services

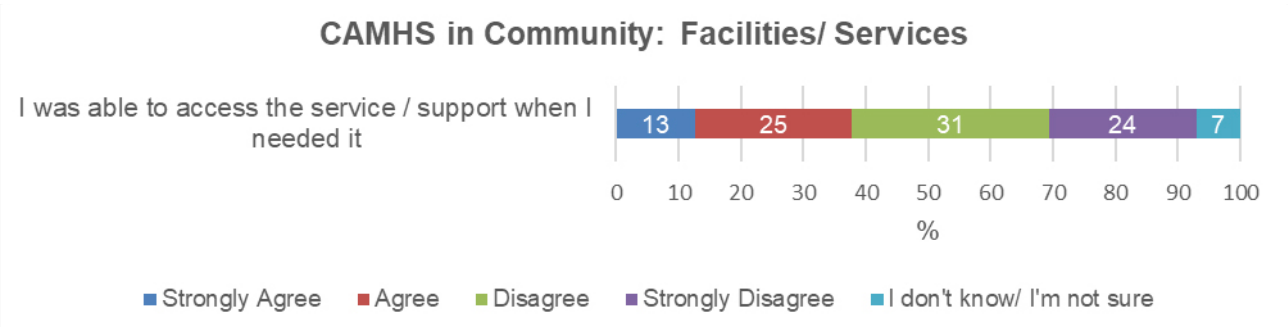


Base: 127

65% of young people agreed or strongly agreed they did not have to travel far to attend a CAMHS appointment, and 32% disagreed or strongly disagreed:

"With the CAMHS service I felt uncomfortable as I had to travel very far to receive support and I didn't understand what my treatment was so I therefore disengaged with services."

Figure 4.35: CAMHS in the Community: I was able to access the service / support when I needed it



Base: 127

Over half of young people who had received CAMHS out-patient service (55%) disagreed or strongly disagreed they were able to access services/support when they needed it. A further 38% of young people agreed or strongly agreed.

The most common issue raised with respect to accessing CAMHS in the community, was the length of time they had to wait to receive a service, and also the length of time between appointments:

"When they say they're going to contact someone they should do it, they told me they'd be in touch in a few days and didn't contact me for 5 months. In that time my mental health deteriorated severely and I could've made a very silly decision to end my life. CAMHS in my opinion needs a lot more staff and resources."

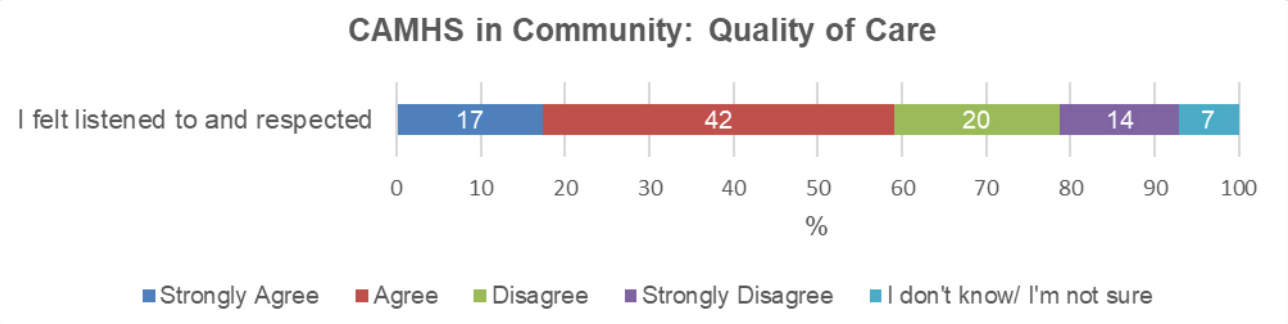
"I was made to wait months for my appointment and had to wait months in between sessions. The sessions I did receive did not help me, they were too short and too few. The staff were fine but they were over stretched and under staffed."

"The support wasn't always there as it was every month to 6 weeks for an appointment and this just made me feel even more disengaged as at the time I needed more support than I was receiving, again this just felt like nobody wanted to help me."

"CAMHS were great. My therapist was really nice. But I think the appointments were so far apart, each session felt like the first. It only added to my anxiety."

Quality of Care

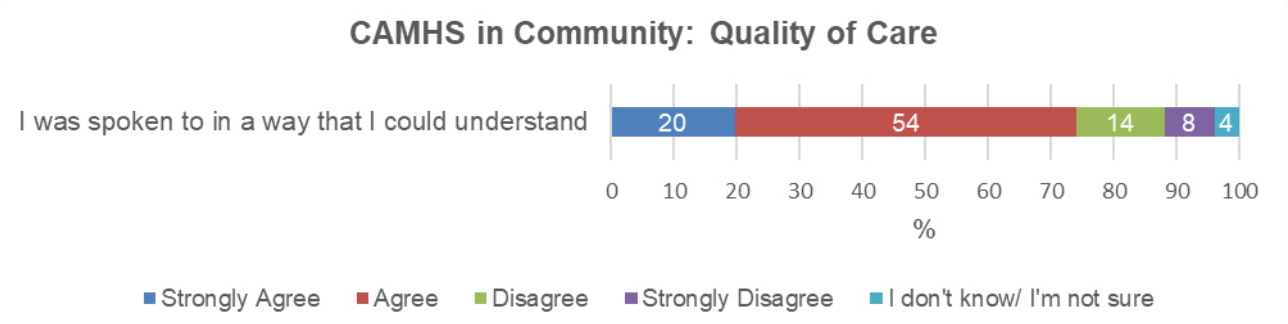
Figure 4.36: CAMHS in the Community: I felt listened to and respected



Base: 127

The majority of the young people surveyed (59%) agreed or strongly agreed that they felt listened to and respected when they attended CAMHS. 34% disagreed or strongly disagreed that this was the case.

Figure 4.37: CAMHS in the Community: I was spoken to in a way that I could understand

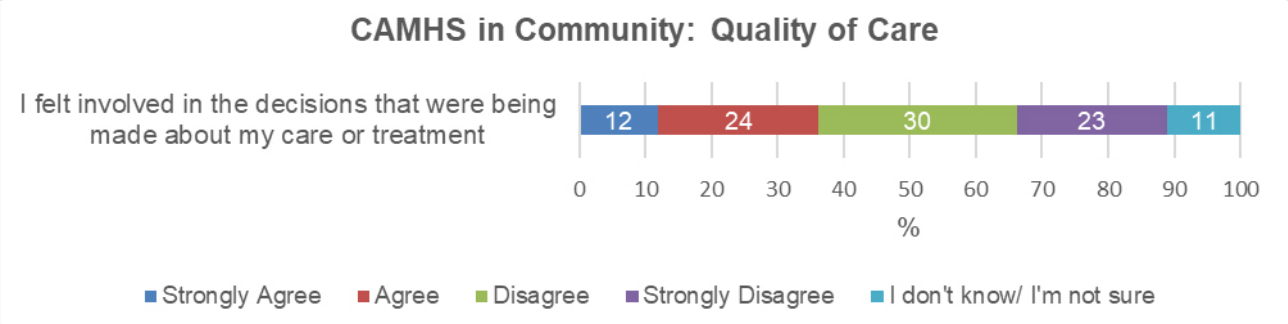


Base: 127

74% agreed or strongly agreed they were spoken to in a way they could understand when they attended CAMHS out-patient services, and 22% disagreed or strongly disagreed that this was the case:

"I disengaged because I didn't feel listened to, and couldn't understand the person I was engaging with because she used very professionalised words. They should be more supportive and less professional or at least have a balance with both as young people won't open up to those who aren't on their level."

Figure 4.38: CAMHS in the Community: I felt involved in the decisions that were being made about my care or treatment



Base: 127

Over half the young people surveyed (53%) disagreed or strongly disagreed they were involved in decisions that were being made about their care or treatment, and 36% said that they agreed or strongly agreed.

A considerable number of young people used the open response section of the survey to explain their reasons for this. A common message was ensuring that therapy or treatment was both age appropriate and needs led:

"A wider range of treatments offered would be helpful as there was only so much CAMHS could offer - many of the staff were lovely people but were very ineffective in actually addressing any problems."

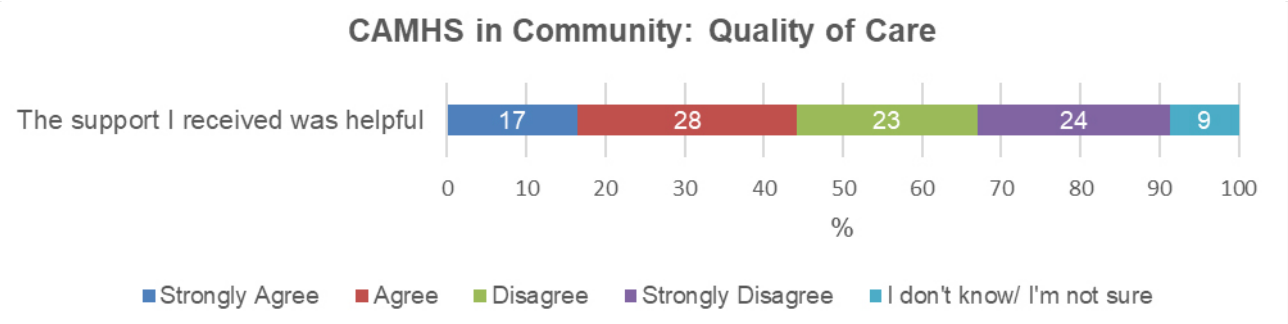
"(…) I felt very disrespected as my treatment wasn't explained to me very well and just felt like anything I said wasn't listened too. The treatment I was receiving was far too much for me to understand at the age of 16 as it was very in depth in which I couldn't get my head around it this confused me very much and made me feel like I didn't understand most things in my life and felt like I was again helpless."

"Pushed into doing Art Therapy but didn't like it and felt that it was very childish."

"I was not listened to at all, the psychologist cut me off and made a decision about my treatment based on other young people my age and their experiences and what she thought would suit my AGE not my NEEDS."

"CAMHS likes to put people in boxes: this person has anxiety or PTSD so we will do the same as for every person with anxiety or PTSD but that simply doesn't work. Usually, mental health problems are far more complex than that and everyone should be treated as an individual. I went to CAMHS initially due to making myself sick and they wanted me to do worksheets about my self-esteem which was far too simplistic for my problems."

Figure 4.39: CAMHS in the Community: The support I received was helpful



Base: 127

There was considerable variation in young people's overall assessment of how helpful or unhelpful attending CAMHS out-patient service was. Slightly less than half (47%) disagreed or strongly disagreed the support was helpful, and 45% of young people agreed or strongly agreed:

"The professionals who were with me for most of my CAMHS journey (Nurse, key worker, dietician) were absolutely great and really helped save my life."

"Without CAMHS ED Team support I would not be here today."

"Some of the things done actually set me back in recovery rather than forward."

Parent / Carer Survey (n=34)
15 (44%) parents / carers agreed or strongly agreed that the support their child received in Community CAMHS was helpful, 11 (32%) disagreed or strongly disagreed and 8 didn't know or were unsure (24%).

Although this Review cannot determine how many young people are seeking support privately online, two young people mentioned buying medication online because the support being offered to them by statutory services wasn't helping them:

"More needs to be invested in specialist doctors and councillors offering the correct treatment and prescription. I have now had no choice but to order myself CBD oil online as it is my last option but the reviews with its use with anxiety, depression and sleep are 100 times better than the tablets prescribed to me."

Diagnosis

Young people who had experience of both child and adult mental health services said when they were given a diagnosis in adult services, it allowed for much clearer and structured support, and greater choice of treatment. Young people talked about feeling in limbo because they were not given a diagnosis whilst in CAMHS:

"I'd also like it if diagnoses were not withheld as I had to wait until I turned sixteen to receive any diagnoses (three at once) despite clearly exhibiting symptoms for years and

could only receive medication for these symptoms whenever I turned sixteen; an earlier intervention could have made a huge difference to my life."

"There was not sufficient help for me at my age, I was simply told we cannot diagnose you until you reach adult mental health, and if I had been given an appropriate assessment I may have been able to challenge the problems in a more structured way, and maybe not having to deal with the consequences I now have to live with the rest of my life. I have been one of many failed by our system which is a breach of my basic human rights."

Young people also talked about having a sense of relief after being given a diagnosis. This included young people feeling that it helped to validate their feelings and experiences:

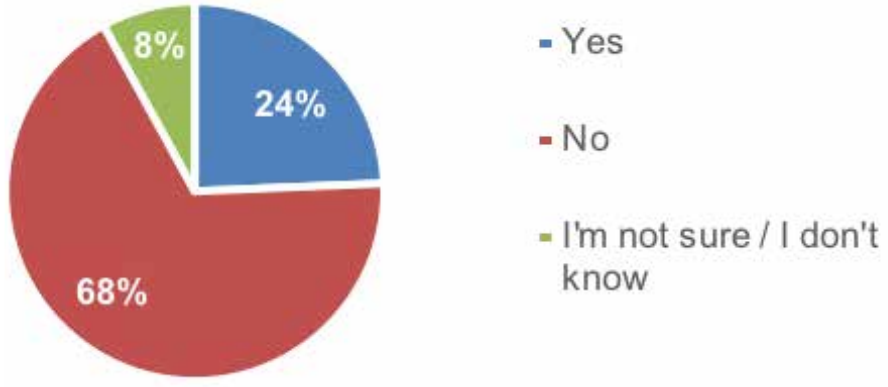
"If doctors/counsellors did not tell people that they don't want to 'label them'. This caused me confusion, worry, doubt and prevented me from getting further help."

There is a need for mental health training of nursing staff in paediatric wards. This is particularly important if young people are periodically admitted as part their treatment, such as young people with eating disorders:

"There was no choice in treatment. We have no specialised ED units here in NI and all that was available was an ordinary hospital with staff who were not considerate or understood the illness. In fact there were a few staff who made it clear that they did not agree with anorexics being admitted and it was a waste of a bed. Completely ignorant of illness! Having said that a few staff really good and the ED team trying to train staff to make them aware but difficult as this is only ward they have."

4.10 Voluntary and Community Sector

Figure 4.40: Have you experience of receiving support for your mental health from a community organisation

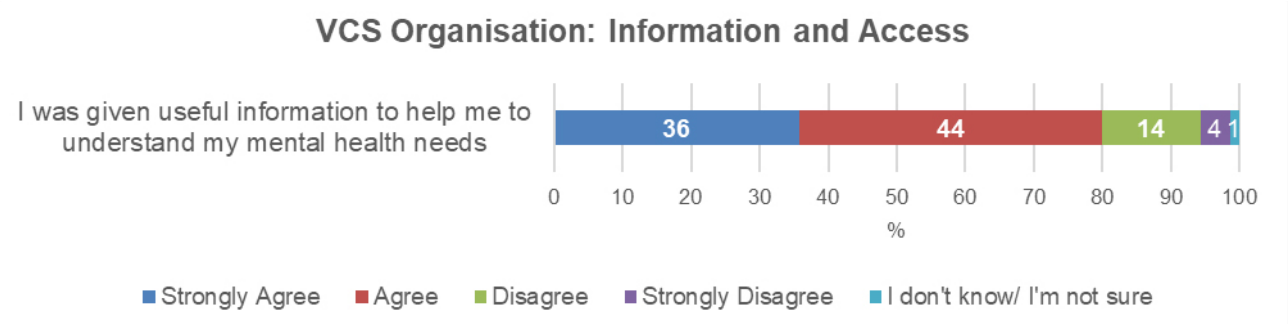


Base: 337

Approximately a quarter (24%) of young people surveyed had received support from Voluntary and Community Sector organisation (VCS) and 68% had not.

Information and Access

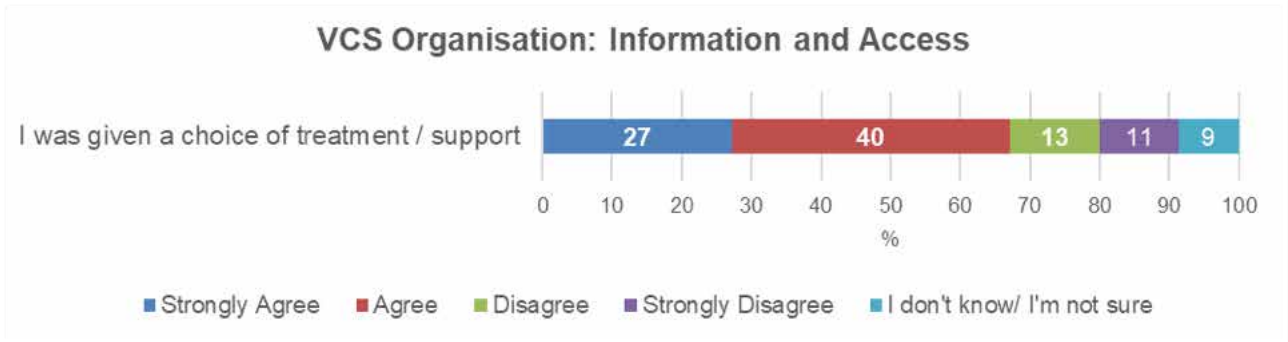
Figure 4.41: VCS Organisation: I was given useful information to help me to understand my mental health needs



Base: 70

The vast majority (80%) of young people who had been supported by a VCS organisation agreed or strongly agreed they had been given useful information to help them to understand their mental health needs. A further 18% disagreed or strongly disagreed.

Figure 4.42: VCS Organisation: I was given a choice of treatment / support



Base: 70

67% of young people agreed or strongly agreed they were given a choice of treatment or support. A quarter (24%) disagreed or strongly disagreed:

"If it wasn't for the support I was am getting I would be dead."

Facilities/Services

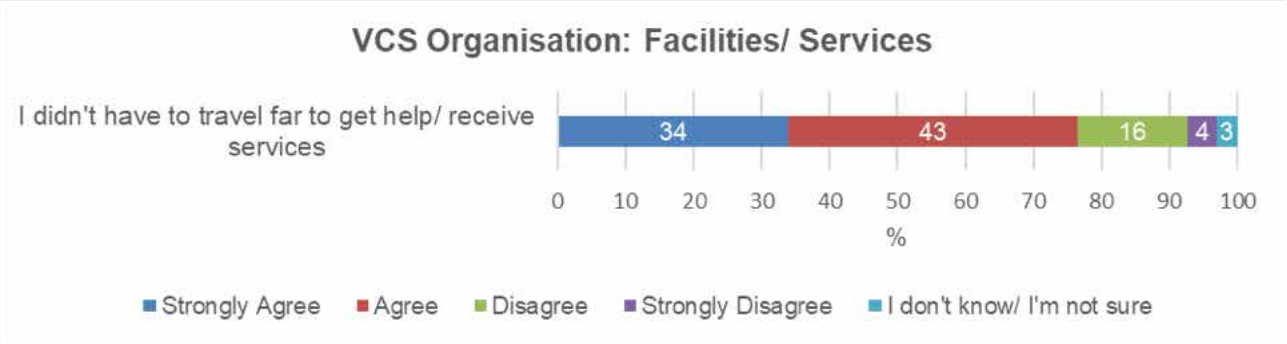
Across all of the statements that related to young people's experience of facilities and services within VCS organisations, the vast majority of young people were positive about their experience.

Figure 4.43: VCS Organisation: The place I received support in made me feel comfortable and safe

Base: 68

The vast majority (85%) of young people surveyed agreed or strongly agreed the place they received support made them feel comfortable and safe.

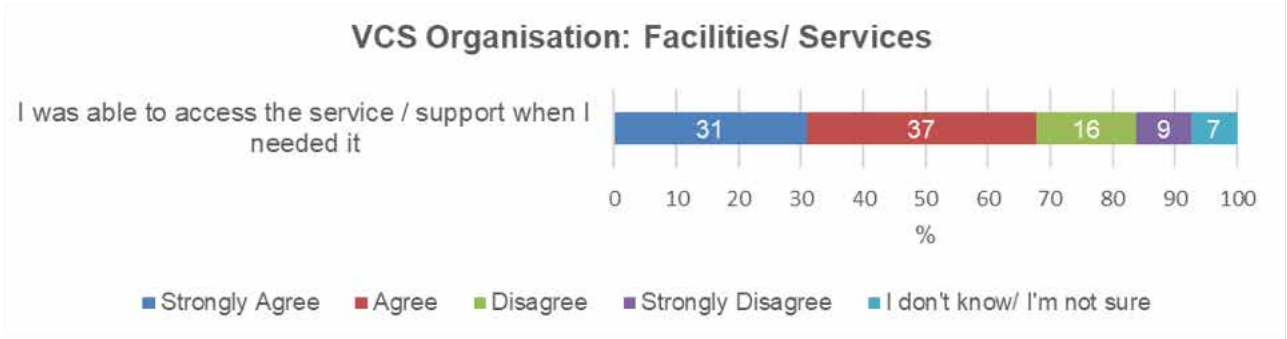
Figure 4.44: VCS Organisation: I didn't have to travel far to get help / receive services



Base: 68

The majority (77%) of young people surveyed agreed or strongly agreed they didn't have to travel far to get help or receive services. A fifth of young people (20%) disagreed or strongly disagreed with this statement.

Figure 4.45: VCS Organisation: I was able to access the service / support when I needed it



Base: 68

68% of young people agreed or strongly agreed they were able to access services or support when they needed to. A quarter of young people (25%) disagreed or strongly disagreed with this statement.

Some young people also talked about having trouble getting access to support through a VCS organisation:

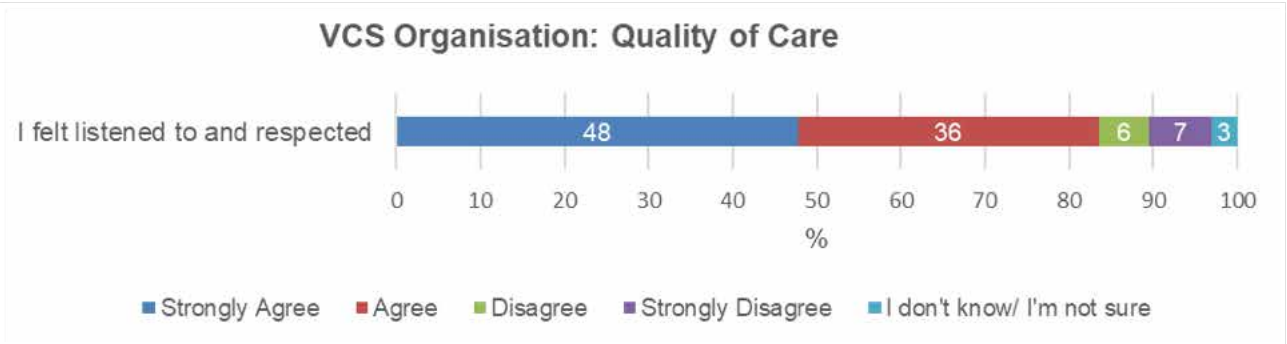
"The support wasn't always easy to access as it wasn't always reliable, most times appointments were cancelled and support couldn't be given. However they did have a helpline to ring if you ever needed help."

Young people talked about some of the ways that VCS organisations work that make attending appointments easier:

"Appointments were made for times that suited me like Saturday's as I didn't have to miss school."

Quality of Care

Figure 4.46: VCS Organisation: I felt listened to and respected

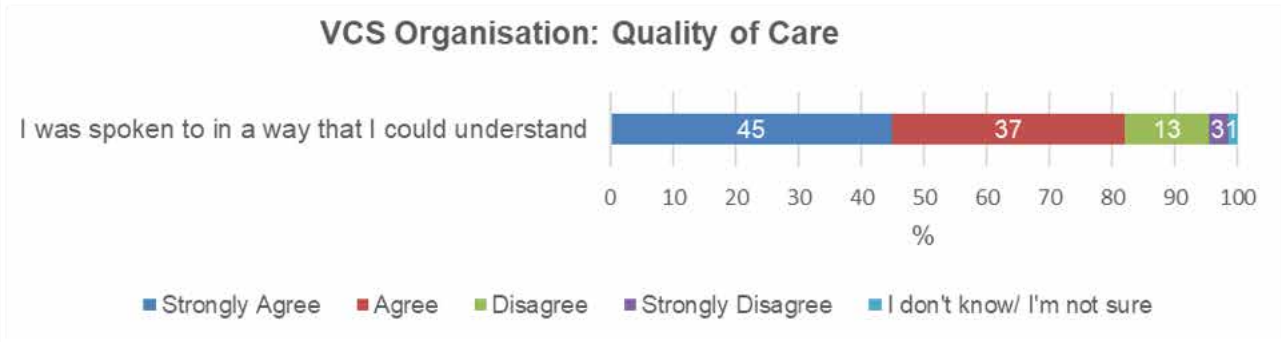


Base: 67

The vast majority (84%) of young people who accessed VCS organisations agreed or strongly agreed they felt listened to and respected. 13% disagreed or strongly disagreed:

"I felt respected and listened to within this organisation as the counsellor was able to remember my name and remember my situation and all the problems that were going on in my life as she was able to refer back to them most of the time, this made me feel more at ease to open up to an extent most of the time."

Figure 4.47: VCS Organisation: I was spoken to in a way that I could understand



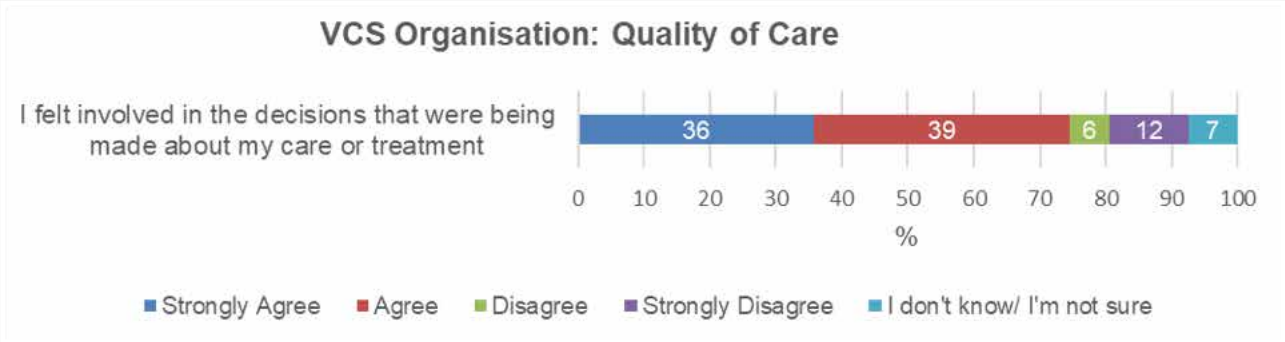
Base: 67

82% agreed or strongly agreed that they were spoken to in a way they could understand. 16% disagreed or strongly disagreed:

"They don't judge and used language I understand."

"The Counsellor I used to see was very respectful towards me and always helped me understand anything she talked about, she always involved me in any decisions with my treatment but moreover ensure I was always made aware of any changes."

Figure 4.48: VCS Organisation: I felt involved in the decisions that were being made about my care or treatment

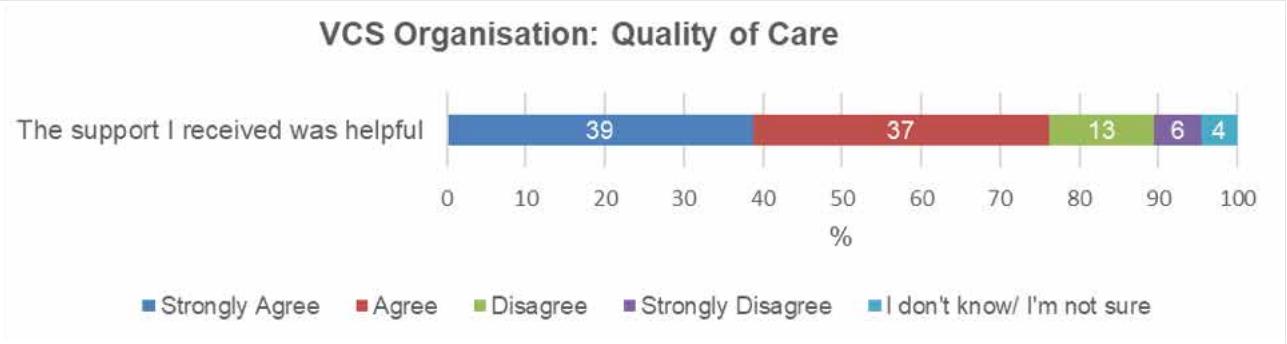


Base: 67

Three quarters (75%) of young people surveyed agreed or strongly agreed they felt involved in decisions being made about their care or treatment. 18% disagreed or strongly disagreed.

"I was always the one making the decisions unless they had a big concern but even then I was informed about what was going to happen. I've never felt that I have to go there and that I will get told off if I don't want to."

Figure 4.49: VCS Organisation: The support I received was helpful



Base: 67

76% of young people surveyed agreed or strongly agreed the support they received was helpful. 19% disagreed or strongly disagreed:

"I got good help and learnt some calming, self-soothing techniques."

"Absolutely amazing staff in x project it give me the strength to go back and volunteer and train for a career in the field of mental health and community work."

Parent / Carer Survey (n=14)
Thirteen (93%) parents / carers agreed or strongly agreed that the support they received was helpful and one (7%) disagreed or strongly disagreed.

A common issue raised by young people who received support through a VCS organisation, was support did not last long enough or there was not enough of it:

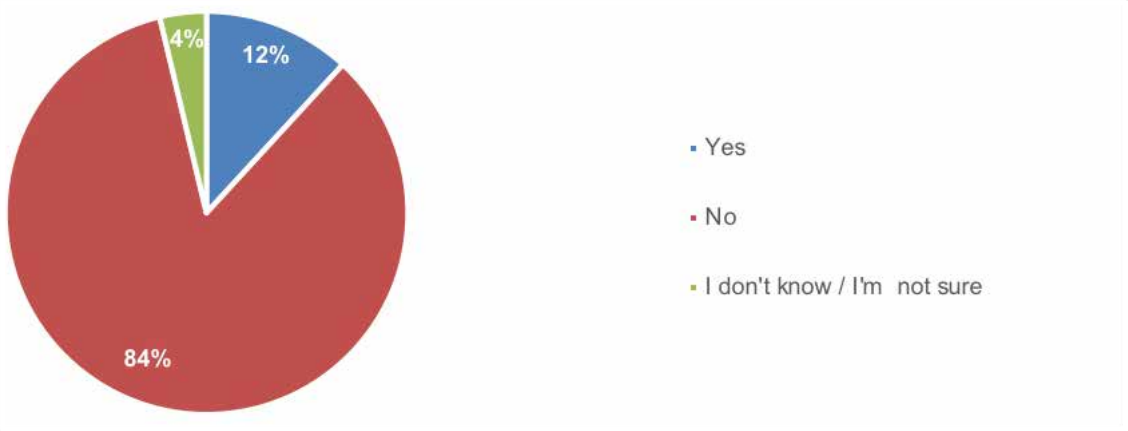
"The support was only for a certain amount of time and sometimes wasn't enough- the support only lasted for a while which is very hard when there is a lot to deal with."

"I received help from x and they were excellent. I wish I could've had more sessions with them but sadly they only offer 6 sessions."

"Because there's so many young people there's not enough youth workers but they're always helpful when they can."

4.11 Out of Hours GP

Figure 4.50: Have you experience of receiving Out of Hours GP Services?

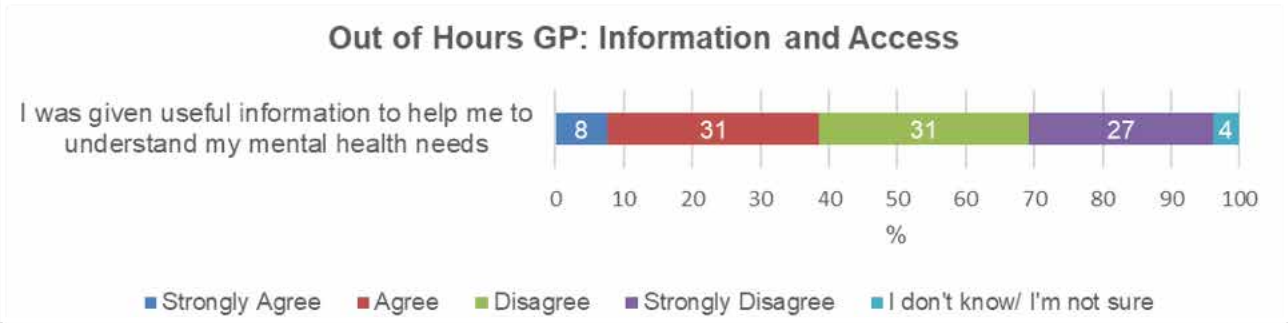


Base: 321

A small proportion of young people surveyed (12%) had used the Out of Hours GP service for mental health support, the vast majority had not (84%).

Information and Access

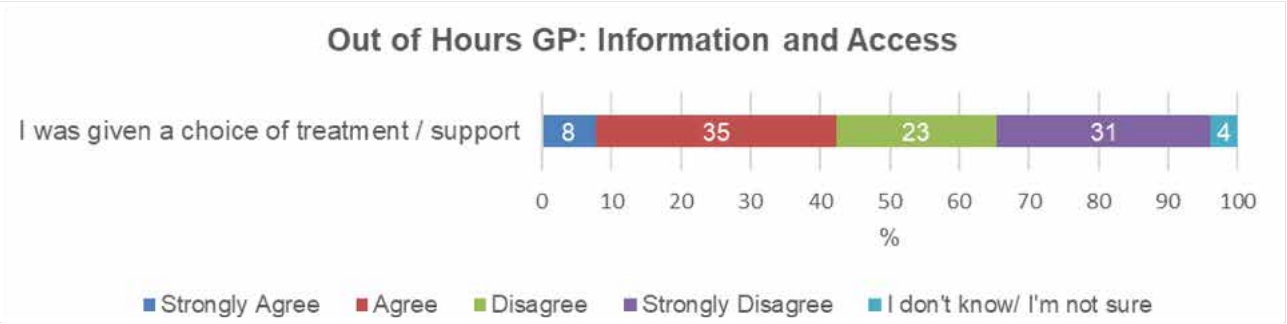
Figure 4.51: Out of Hours GP: I was given useful information to help me to understand my mental health needs



Base: 27

Young people who had used an Out of Hours GP Service for mental health support were asked to describe their experience. 39% either strongly agreed or agreed they had been given useful information to help them to understand their mental health needs. A further 58% either disagreed or strongly disagreed this was the case.

Figure 4.52: Out of Hours GP: I was given a choice of treatment / support



Base: 27

54% disagreed or strongly disagreed they were given a choice of treatment or support when they contacted their Out of Hours GP service. A further 43% agreed or strongly agreed.

Lack of Support for Onward Referral

Young people also described, in their own words, some of the problems they had faced when contacting the Out of Hours GP service. This included the Out of Hours GP service being unable to help, or support young people to access more relevant services:

"They should have numbers of who could help if they can't especially when a crisis situation!"

"My mum had to contact the out of hours GP one Friday evening after a really bad day with me. She was told "you would know more than me, there is no point in me coming out". My dad was having to restrain me from hurting myself and my mum told the doctor this. They were not offered any support or advice on what to do and we suffered a long and stressful weekend until my mum phoned CAMHS on Monday morning."

"Never any point using outta hours ! They don't know u, they just send you to AandE! There should be a team of mental health people, connected to each community or a rapid response team."

"Don't just tell people to hang on until the psychiatrist is in on Monday."

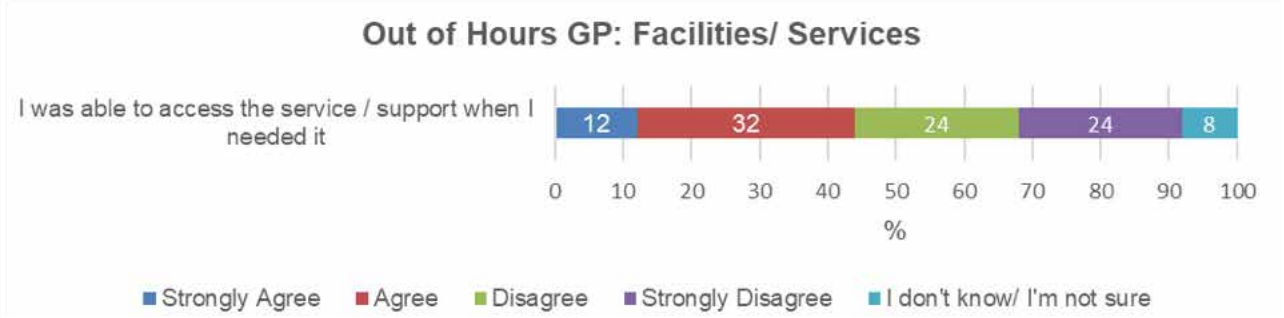
Facilities/Services

Figure 4.53: Out of Hours GP: The place that I received support in made me feel comfortable and safe

Base: 27

40% of young people surveyed stated they agreed or strongly agreed the place they received support in made them feel comfortable and safe, and 40% disagreed or strongly disagreed that this was the case.

Figure 4.54: Out of Hours GP: I was able to access the service / support when I needed it



Base: 27

44% of young people surveyed stated they agreed or strongly agreed they were able to access Out of Hours GP support when they needed it, and 48% disagreed or strongly disagreed that this was the case.

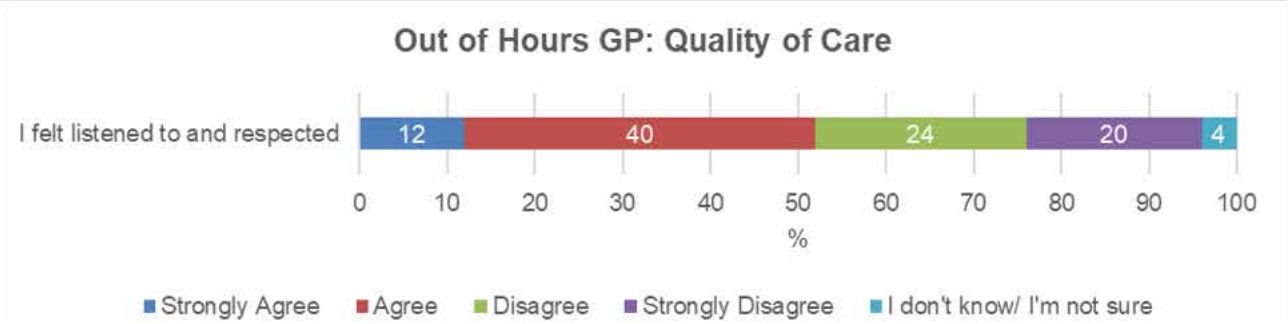
The experience of the Out of Hours GP service, by young people surveyed, reflects a very mixed view of this service:

"There's no point in phoning the out of hours. My dad is police man and he handles many many calls from people in a crisis, the out of hours never go to the calls and police end up responding which is a disgrace. Who wants the police to turn up when they're having a meltdown?"

"I was referred straight back to CAMHS and was simply told to be happy."

"As it is better than the GP there have been times that I have purposely waited until the evening to get help as I know I'm normally treated better."

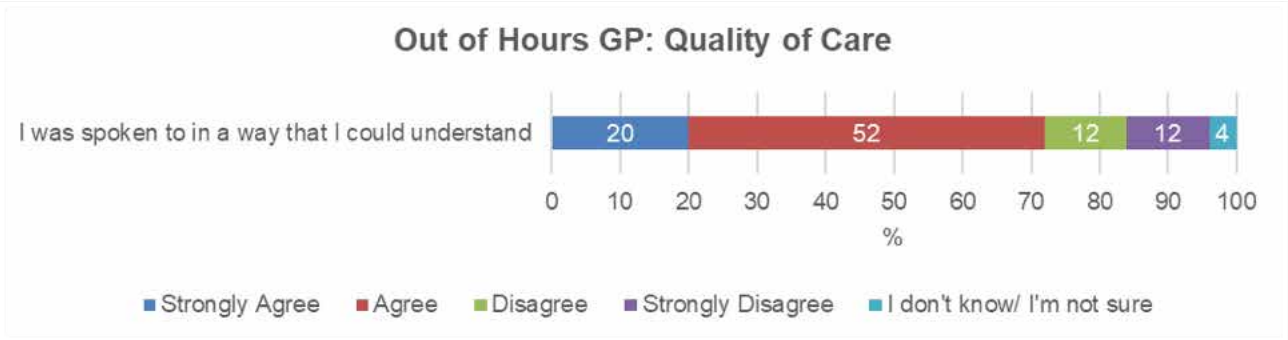
Figure 4.55: Out of Hours GP: I felt listened to and respected



Base: 27

Half (52%) the young people agreed or strongly agreed they were listened to and respected, when they were seen by the Out of Hours GP. A further 44% disagreed or strongly disagreed.

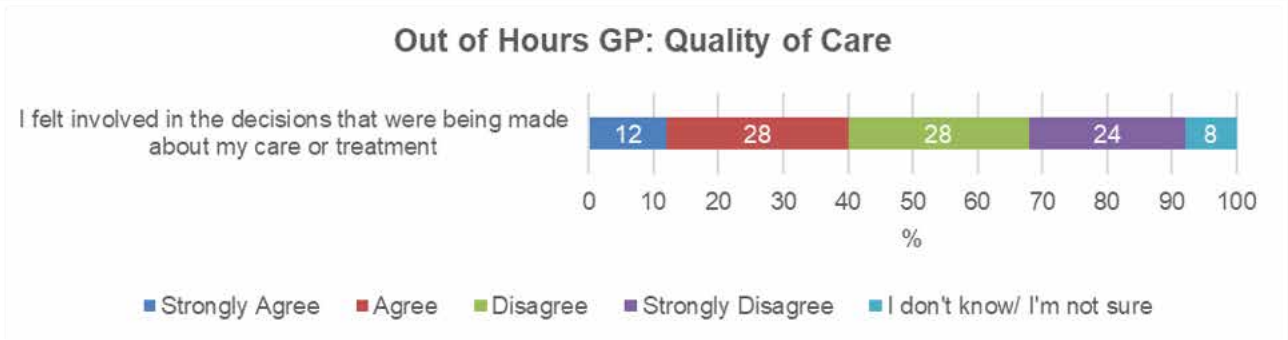
Figure 4.56: Out of Hours GP: I was spoken to in a way that I could understand



Base: 27

The majority of young people that had used an Out of Hours GP service (72%) agreed or strongly agreed they were spoken to in a way that they could understand. A quarter (24%) disagreed to strongly disagreed this was the case.

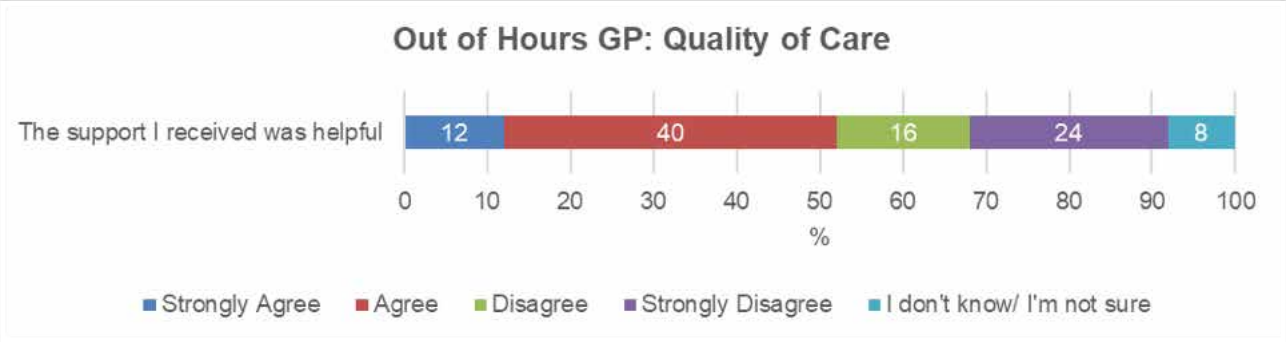
Figure 4.57: Out of Hours GP: I felt involved in the decisions that were being made about my care or treatment



Base: 27

Over half (52%) the young people who had used an Out of Hours GP service disagreed or strongly disagreed they felt involved in decisions that were being made about their care or treatment. 40% agreed or strongly agreed they felt involved in these types of decisions.

Figure 4.58: Out of Hours GP: The support I received was helpful



Base: 27

Just over half of young people agreed or strongly agreed (52%) the support they received from the Out of Hours GP was helpful. 40% disagreed to strongly disagreed the support they received was helpful:

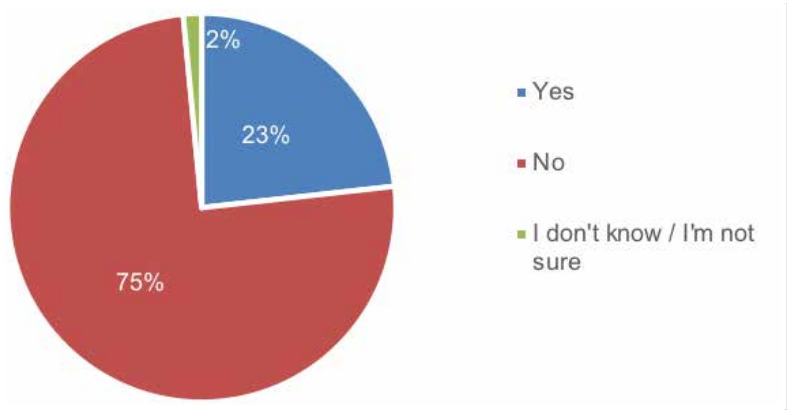
"I found this to always be better than my GP even if they could only help in the short term."

"I was seen very fast and given medication to help me."

Parent / Carer Survey (n=6)
Two parents / carers agreed or strongly agreed that the help their child received from the Out of Hours GP was helpful and four disagreed or strongly disagreed.

4.12 Accident and Emergency

Figure 4.59: Have you been to A&E due to your mental health?

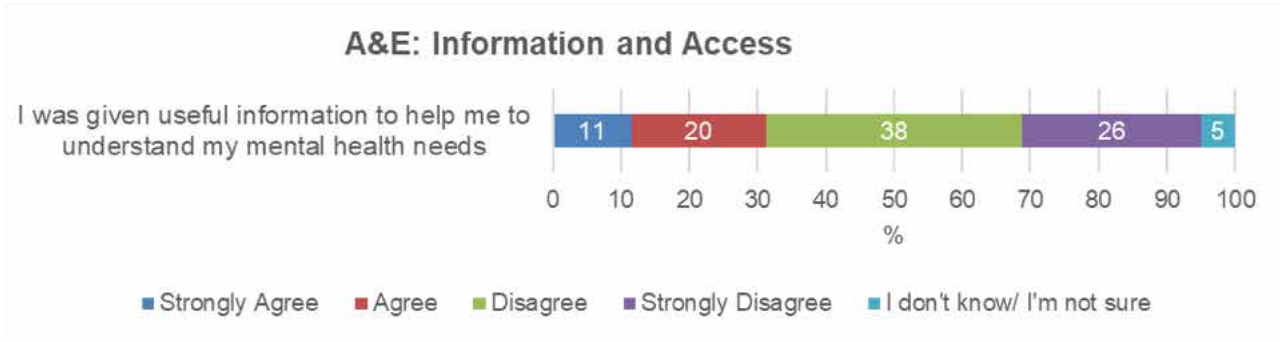


Base: 327

Approximately a quarter (23%) of young people had attended A&E due to their mental ill health, and 75% had not.

Information and Access

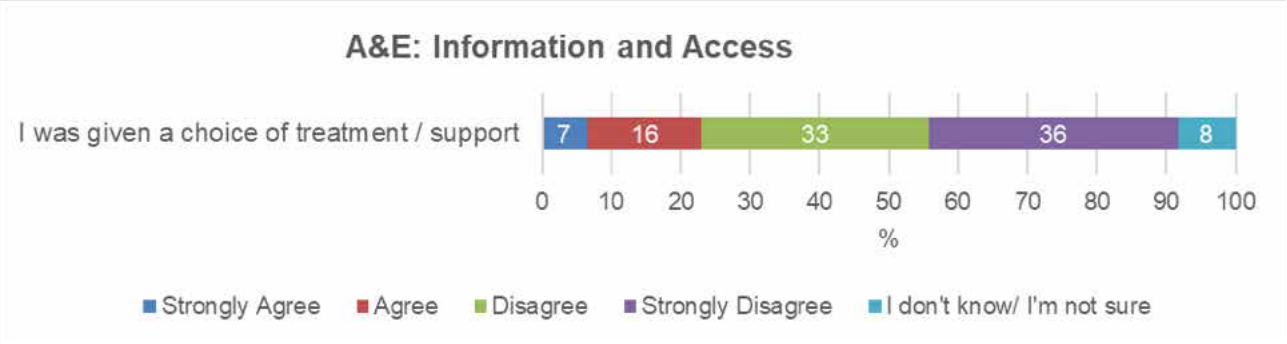
Figure 4.60: A&E: I was given useful information to help me to understand my mental health needs



Base:61

A large proportion (64%) of young people who had been to A&E with mental health problems, disagreed or strongly disagreed, they were given useful information to help them to understand their mental health needs.

Figure 4.61: A&E: I was given a choice of treatment / support



Base:61

Similarly, in the main, young people disagreed or strongly disagreed they were given a choice of treatment and support when they attended A&E (69%):

"No help given in A&E. No referral."

"Most of them weren't trained so how could they give me information."

"Within the A&E I was seen by a doctor who done a mental health test on me he answered most of the questions for me without me being able to open my mouth and speak, he then didn't involve me in anything to do with my treatment and then just referred me on as quick as he could. I found this quite unprofessional as it wasn't me who was answering the questions and this made it harder for those who took over after him as they didn't have any understanding as I had more problems than what he had discovered."

Facilities/Services

Figure 4.62: A&E: The place that I received support in made me feel comfortable and safe

Base:61

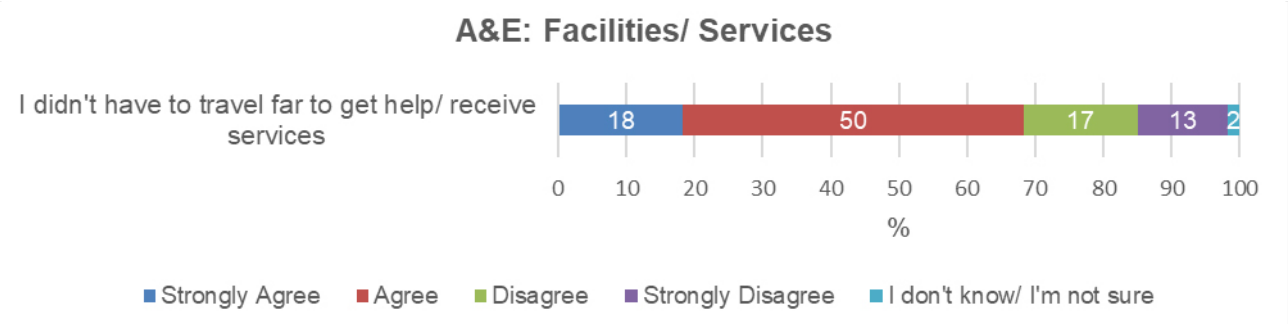
Just over half of young people (54%) disagreed or strongly disagreed they felt comfortable and safe, when they attended A&E about their mental health. Young people in their open response to this question elaborated on the reason for rating the service this way. They talked about the physical space, and the professional approach taken by staff in A&E, as factors which affected how comfortable and safe they felt. They also talked about the benefit of having a separate room for patients that attend with mental health problems:

"Within A&E I didn't feel comfortable as it was in a hospital cubicle where I was seen to. I felt like I was supposed to feel sick as only sick people are meant to be in a hospital bed. I was able to attend A&E very quickly however attending made me feel 10 times worse."

"A&E need separate rooms where you can take patients who need help with their mental health such a room that make young people feel comfortable so they can open up and also they should have a trained staff team of mental health specialists working so that young people are receiving the help they need."

"I didn't feel comfortable because I didn't have a great understanding as to why I was in A&E for my mental health. I feel that A&E should have a separate part for mental health with trained doctors in mental health."

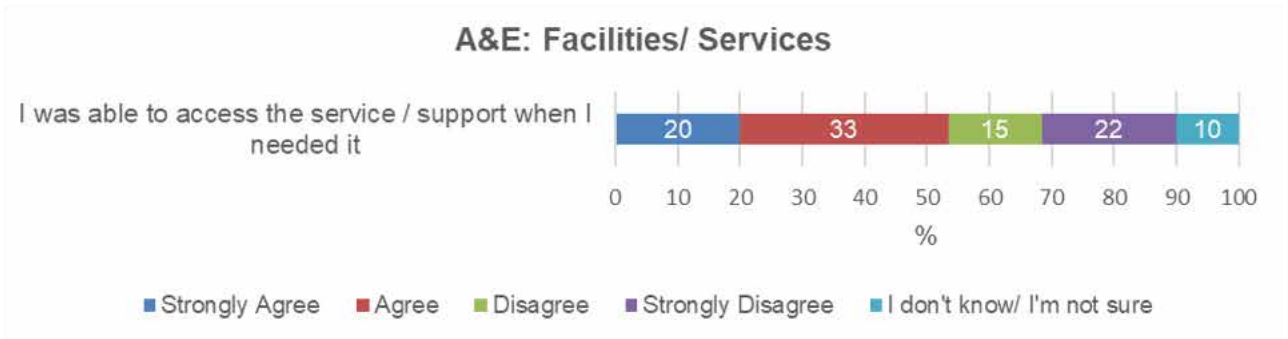
Figure 4.63: A&E: I didn't have to travel far to get help / receive services



Base:61

In the main young people (68%) agreed or strongly agreed they did not have to travel far to get to A&E. For 30% they reported that they did have to travel far to get to A&E.

Figure 4.64: A&E: I was able to access the service / support when I needed it



Base:61

Just over half of young people surveyed (53%) agreed or strongly agreed they were able to access services or support when they needed it, 37% disagreed or strongly disagreed:

"I can always access support from A&E, however there will always be a waiting list and a long time to wait the same as mental health teams and CAMHS. I feel that with my past experience before I would never attend a and e for support again and I didn't as a second time this occurred I refused to go as I had such a bad experience before."

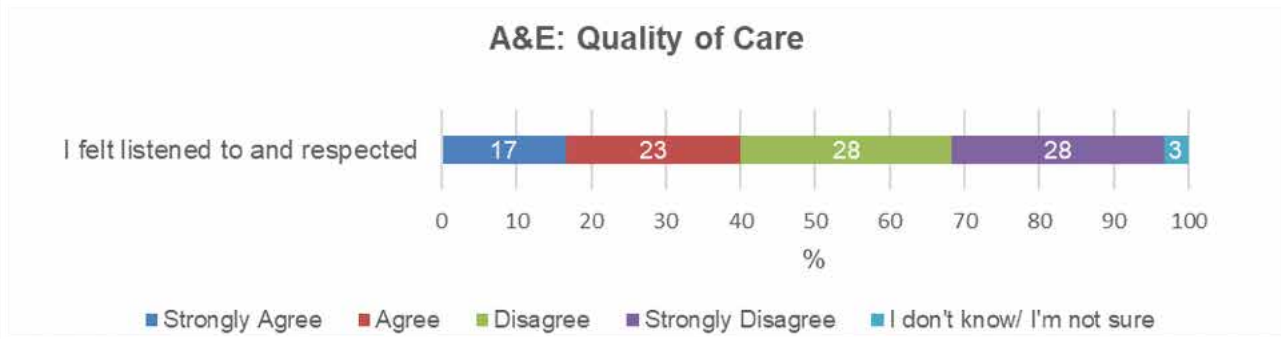
"After being rushed to A&E I had to wait 8 hours for a bed and had to wait until the next morning to speak to the crisis team."

"Having somewhere to go in an emergency situation would be a starting point, not A&E to be sent home because they have no mental health teams on at weekends."

Quality of Care

In terms of the statements that related to quality of care, a significant proportion of young people disagreed or strongly disagreed with them.

Figure 4.65: A&E: I felt listened to and respected



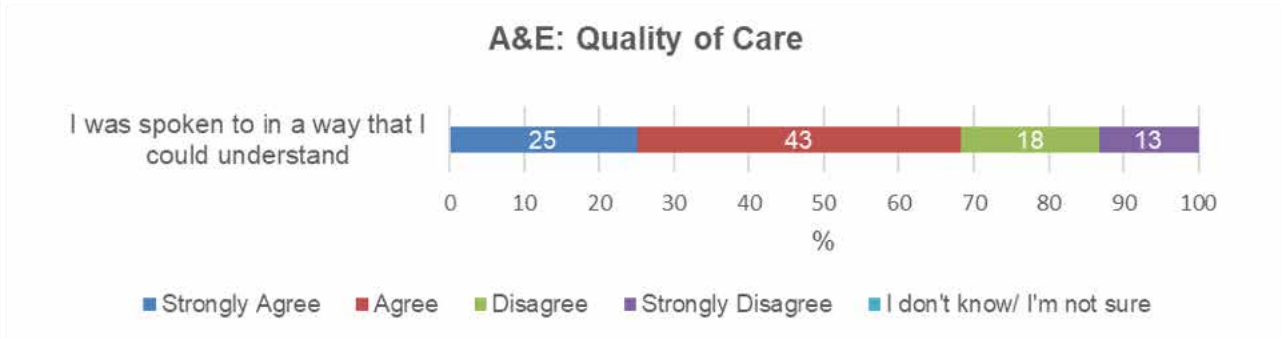
Base:61

Over half the young people disagreed or strongly disagreed they were listened to and respected by staff they met in A&E (56%). 40% of the young people did feel they were listened to and respected:

"The doctor spoke down to me and told me I should not have been in A&E as I was taking up time that other more serious patients needed."

"Found A&E staff helpful and nice."

Figure 4.66: A&E: I was spoken to in a way that I could understand

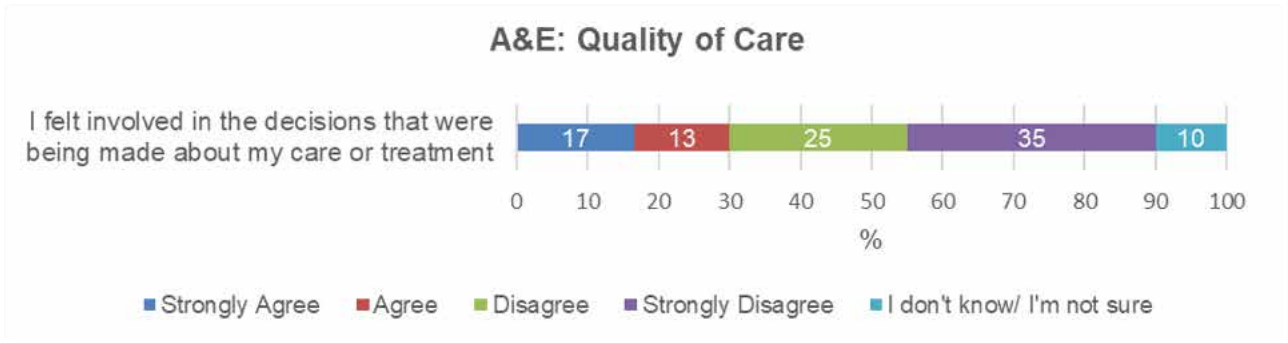


Base:61

The majority of young people (68%) agreed or strongly agreed they were spoken to in a way they could understand, and 31% disagreed or strongly disagreed:

"The doctors didn't speak to me in a way I could understand so I knew what was going on. I found this quite hard and very hard to understand."

Figure 4.67: A&E: I felt involved in the decisions that were being made about my care or treatment

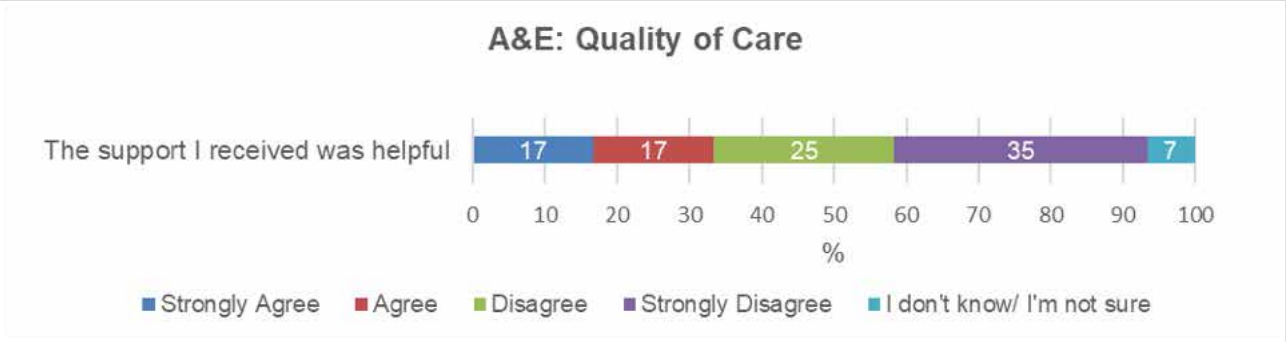


Base:61

60% of young people disagreed or strongly disagreed they felt involved in decisions that were being made about their care or treatment:

"I wasn't involved in any of the decisions about what support and plan of action that would be occurring, this made me feel even worse because I don't know what was going to happen. The help I received wasn't the best and really did make me feel worse as I felt like nothing and didn't understand why things were happening to me."

Figure 4.68: A&E: The support I received was helpful



Base:61

60% of young people disagreed or strongly disagreed the support they received was helpful and 34% agreed or strongly agreed:

"No support at all, in hospital for suicide attempt, discharged in the morning and sent home with no support whatsoever or any form of help."

"I felt like I was a 'problem', that my problem wasn't as important as the people with physical problems who may seem to have needed it more."

"Went to hospital after self-harming and they really helped."

Parent / Carer Survey (n=10)
Four parents/carers agreed or strongly agree the support their child received was helpful, five disagreed or strongly disagreed and one didn't know or was unsure.

Lack of Immediate Follow-on Support after Discharge from A&E

One of the key issues raised by young people with regard to their experience of attending A&E, was a lack of follow-on support after being discharged, this includes whilst suicidal and after attempting suicide:

"Many suicide attempts self-harming and drug overdoses - I just got released back on to the streets, no one even informed my family."

"I was told to go home by A&E despite being suicidal."

"They let a suicidal person with a plan leave after making them wait 5 hours to see crisis then crisis seeing them for 20 mins to be told "you're fine"."

Delays in Specialist Mental Health Support

Some young people mentioned the delays in being seen by a specialist mental health professional after presenting to A&E, which unnecessarily lengthened the time they spent there:

"Having to wait and see a doctor in A&E before you see crisis team is ridiculous. You could be sitting in the middle of a complete breakdown and they don't care, they just leave you sitting there."

"I was brought to A&E after a suicide attempt and I was made to feel like a nuisance. I had to wait a full day for a CAMHS counsellor to talk to me and over-heard nurses saying I was 'taking up a bed'."

Onward Referral not Processed

A further issue raised by young people was being told a referral had been made to a service, but not receiving a follow-up appointment:

"Some of the (A&E) staff were lovely, however after seeing the mental health advisor, the aftercare team failed to set me up with SHIP (Self Harm Intervention Programme)."

Young people also talked about the lack of training of A&E staff on caring for young people with mental health problems:

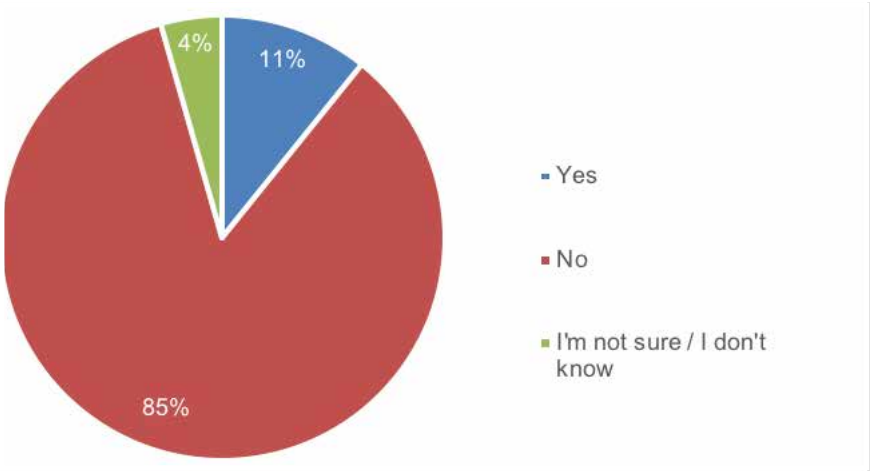
"As a daughter of a nurse I know first-hand that A&E staff are not trained to deal with children with mental health issues. They have an old fashioned view that children cannot suffer from mental health issues. My own mum believed that I could not possibly suffer from mental health issues when I told her at age 12. It wasn't until age 17 she realised I could. This is because of the older generations lack of understanding. Also A&E staff call the police to handle people in a crisis which is unacceptable. We are not dangerous. We are just misunderstood."

Young people also recognised that part of the poor response from A&E staff is due to staff being under pressure to see patients quickly, and do not have the time needed for young people with mental health problems:

"They (A&E staff) are overworked and under staffed, no one has time for self-harming teenagers, they just want you to leave."

4.13 Inpatient Care

Figure 4.69: Have you experience of receiving care in a hospital for your mental health?



Base: 315

Of the young people surveyed, 11% had experience of being admitted to hospital for their mental health. Of these 35 young people, 16 had been admitted to Beechcroft. A similar number said they had been admitted to a general hospital ward for their mental health (n=15). Eight young people stated they had been admitted to an adult mental health ward and two were admitted to a hospital outside of Northern Ireland.

Table 4.7: Where did you receive help for your mental health? (multiple response question)

	%	Freq
Children's mental health hospital (Beechcroft)	46%	16
A hospital ward for physical health	43%	15
Adult mental health unit	23%	8
A hospital outside of Northern Ireland	6%	2

Base: 35

Table 4.8: Which of the following best describes your experience as an in-patient? (multiple response question)

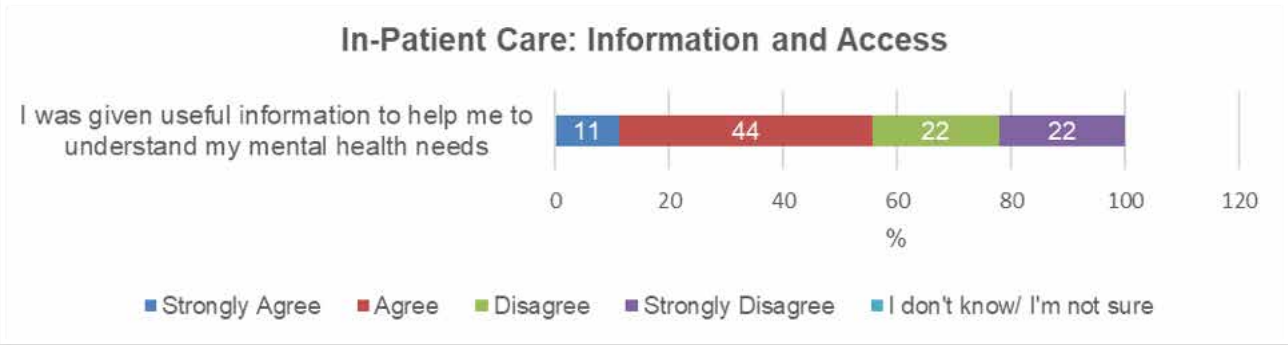
	%	Freq
Voluntary Patient	47%	16
Detained Patient	21%	7
Period(s) of observation	32%	11
I don't know / I'm not sure	15%	5
I'd rather not say	9%	3

Base: 34

Of the young people surveyed, it was most common for them to have been admitted as a voluntary patient (n=16), followed by periods of observation (n=11). Also seven of the young people surveyed had been formally detained under the Mental Health (NI) Order 1986 at some point during their hospital stay. A further 5 young people didn't know, or were unsure, about the status of their stay in hospital.

Information and Access

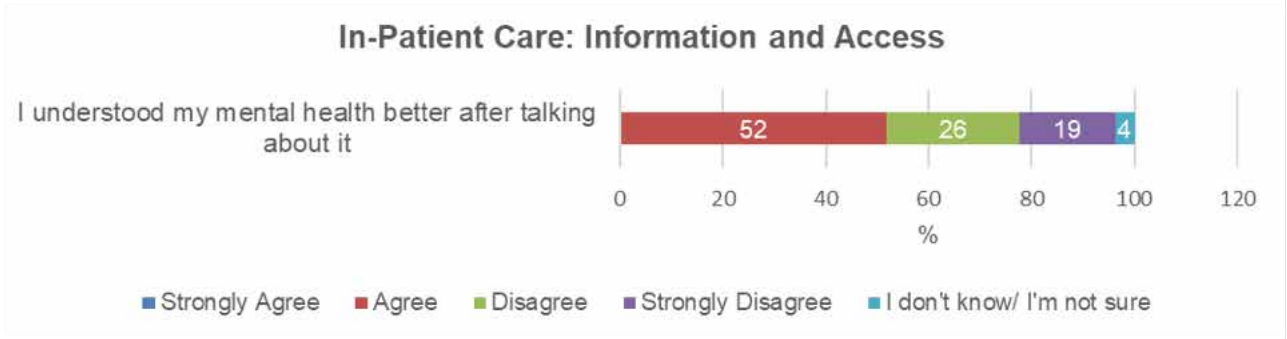
Figure 4.70: In-Patient Care: I was given useful information to help me to understand my mental health needs



Base: 26

Just over half of the young people (55%) with experience as a mental health in-patient, either agreed or strongly agreed that they were given useful information to help them to understand their mental health needs. A further 44% disagreed or strongly disagreed that this was the case.

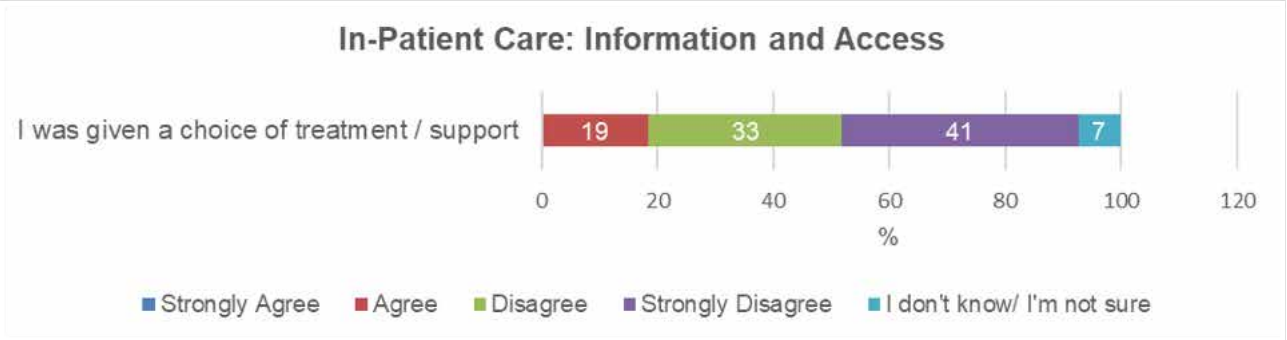
Figure 4.71: In-Patient Care: I understood my mental health better after talking about it



Base: 26

Slightly more than half of the young people (52%) agreed or strongly agreed that they understood their mental health better after talking about it, 45% disagreed or strongly disagreed that this was the case.

Figure 4.72: In-Patient Care: I was given a choice of treatment / support



Base: 26

The vast majority of young people surveyed (74%) disagreed or strongly disagreed they had been given a choice of treatment or support, when they were admitted as an Inpatient. 19% agreed that this was the case.

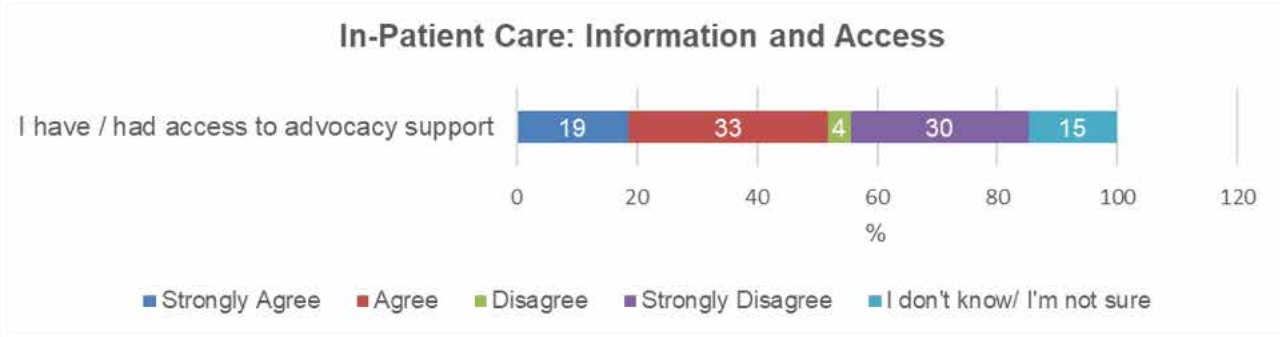
The following quotes provide some further detail which helps to explain the reasons why young people rated the Inpatient service in the way that they did. A number of the quotes describe the experiences of young people with eating disorders who didn't believe that Beechcroft or a paediatric medical ward was appropriate for meeting their needs:

"There isn't a choice of treatment. Although Beechcroft staff very good this is not really the right place for a child with Anorexia. What I saw and witnessed in there will never leave me. When in holywell again not a specialised ED unit and kept my medical health under control did nothing for my mental health and not the right place. We need even an out-patient specialised unit in NI where they can offer staff who are all trained and want to be there as have an interest in the illness and therapies throughout the day that would be of help. I feel because there is nowhere like this we are put anywhere and expected to get ourselves better."

"I was in a children's medical ward - the treatment I received was more for my physical needs instead of mental health needs."

"I was forced medication by a consultant when a voluntary patient and Gillick competent."

Figure 4.73: In-Patient Care: I have/had access to advocacy support



Base: 26

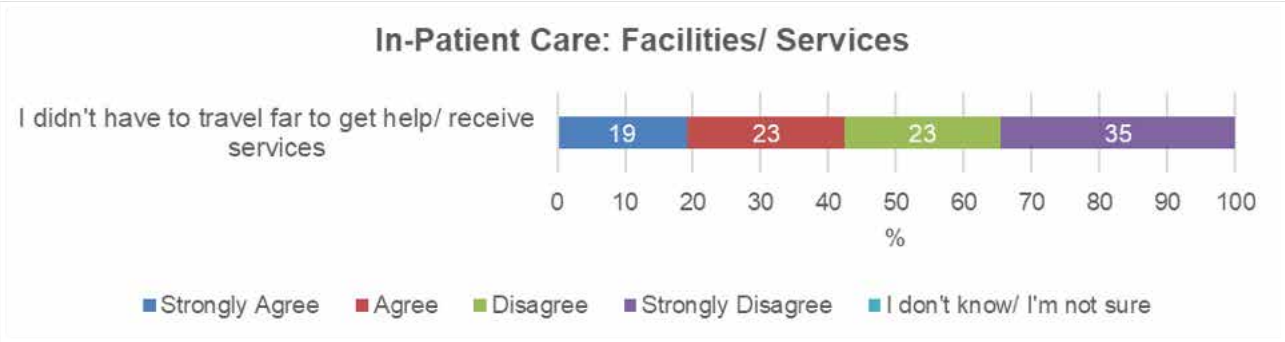
Half (52%) of young people agreed or strongly agreed they had been given access to advocacy support as an in-patient and 34% disagreed or strongly disagreed.

Facilities/Services

43% of young people who had in-patient experience said the place they received support in, made them feel comfortable and safe, and a further 54% disagreed or strongly disagreed that this was the case:

"Beechcroft felt safe but that was it none of the other services did and the staff weren't even welcoming or friendly except Beechcroft."

Figure 4.74: In-Patient Care: I didn't have to travel far to get help or receive services

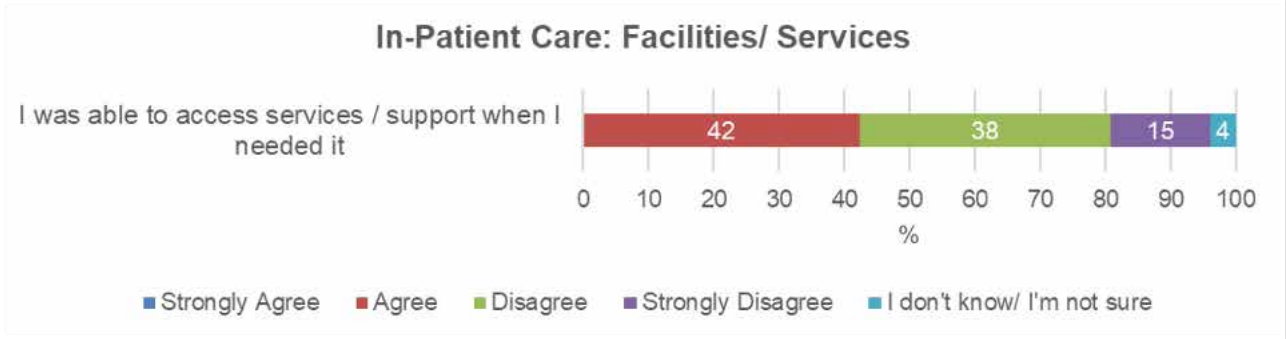


Base: 26

58% disagreed or strongly disagreed they didn't have to travel far to get help or receive services. 42% agreed or strongly agreed that this was the case.

"Beechcroft is 90 miles away from my home. It was a lot of travelling for my family to come and see me."

Figure 4.75: In-Patient Care: I was able to access services or support when they needed it

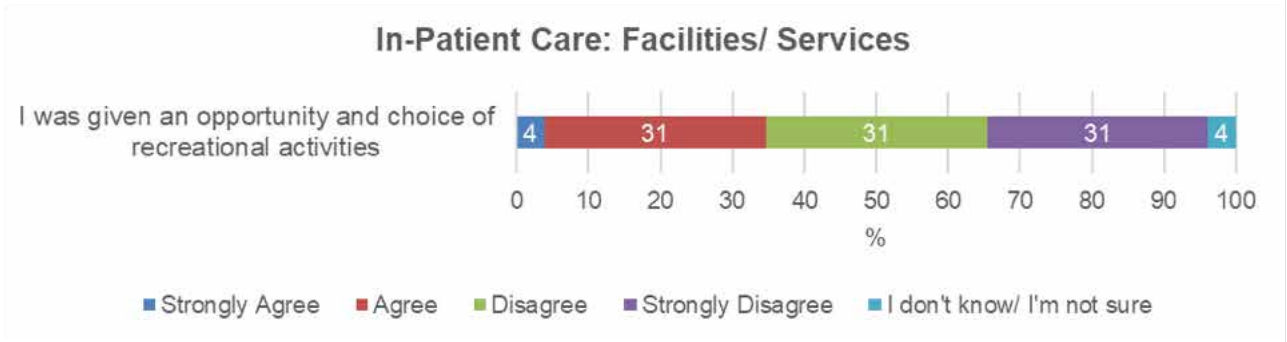


Base: 26

Approximately half (53%) of young people disagreed or strongly disagreed they were able to access services or support when they needed it, and 42% of young people agreed this was the case:

"I was able to access the medical inpatient help when I needed it. I wasn't able to access the mental health inpatient (help) when I needed it."

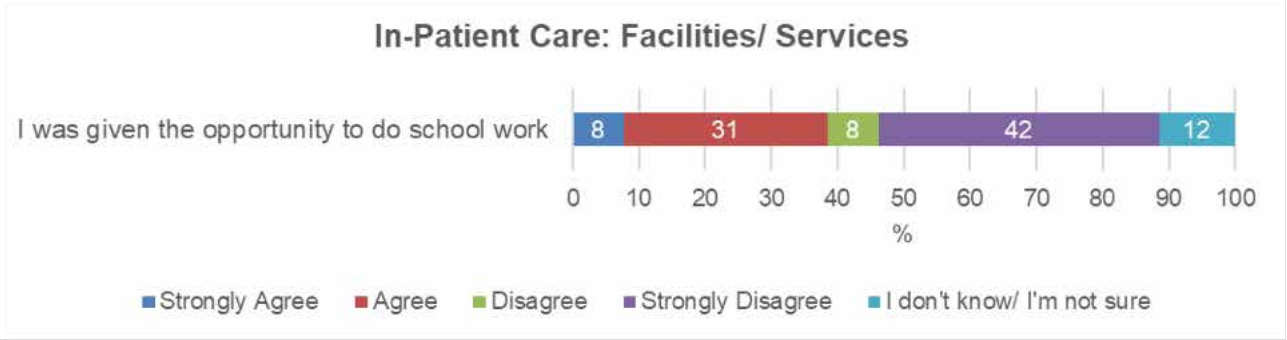
Figure 4.76: In-Patient Care: I was given an opportunity and choice of recreational activities



Base: 26

The majority (62%) of young people disagreed or strongly disagreed they were given an opportunity and choice of recreational activities, whilst they were an inpatient. 35% agreed or strongly agreed that this was the case.

Figure 4.77: In-Patient Care: I was given the opportunity to do school work



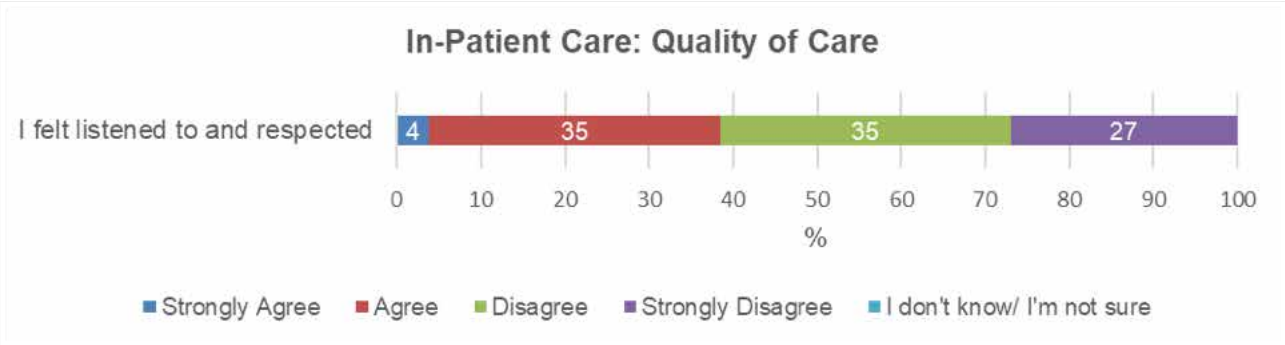
Base: 26

Half of young people surveyed disagreed or strongly disagreed they were given the opportunity to do school work whilst they were in hospital. 39% agreed or strongly agreed that this was the case:

"I was not given the chance to continue my studies due to being in tech and Beechcroft not working with them."

Quality of Care

Figure 4.78: In-Patient Care: I felt listened to and respected



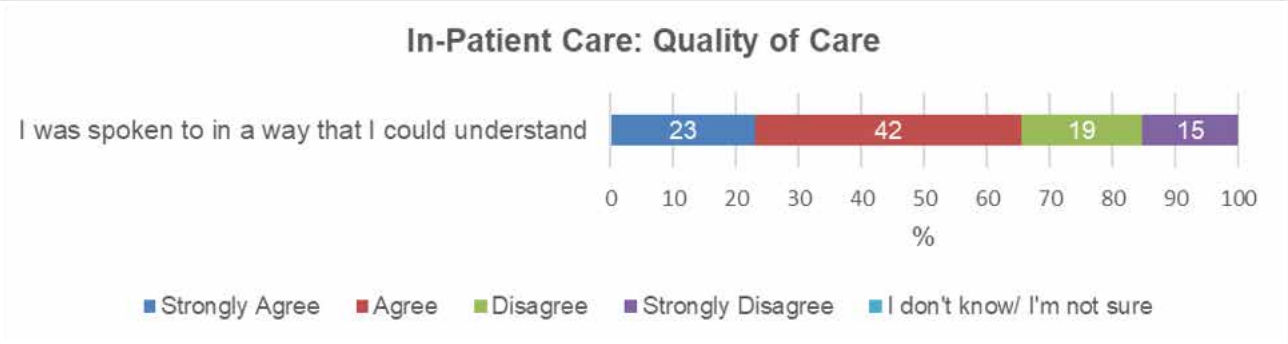
Base: 26

62% of young people surveyed disagreed or strongly disagreed they felt listened to and respected. 39% agreed or strongly agreed with this statement:

"Some of the time I felt listened to but others I didn't. On two occasions when I was speaking to the emergency CAMHS worker who comes to talk to u before being discharged from hospital I told them I was going to over dose again and they discharged me anyway and I did overdose. It hurt that I wasn't listened to. Most times the support was helpful but sometimes professionals communicate between themselves without informing me and this annoys me as I like to know who knows my business therefore often I wasn't included within my care plans. Also there was a mix up with my medication and there was a two week delay in me getting it. And they wouldn't listen to me when I said I couldn't take capsules."

"I really feel medical staff in medical wards should be better trained in illnesses like EDS. I had some bad experiences while in the medical ward. The majority of staff there weren't aware of how to treat someone with an eating disorder. I would love to see better training in this area and including experts by experience e.g. youth advisors in that training could be really helpful."

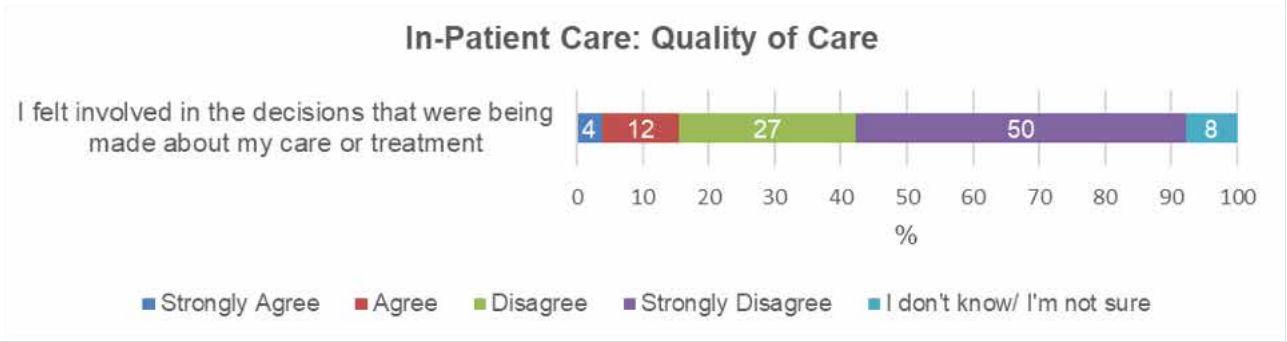
Figure 4.79: In-Patient Care: I was spoken to in a way that I could understand



Base: 26

65% of young people agreed or strongly agreed they had been spoken to in a way that they could understand. 34% disagreed or strongly disagreed that this was the case.

Figure 4.80: In-Patient Care: I felt involved in the decisions being made about my care or treatment



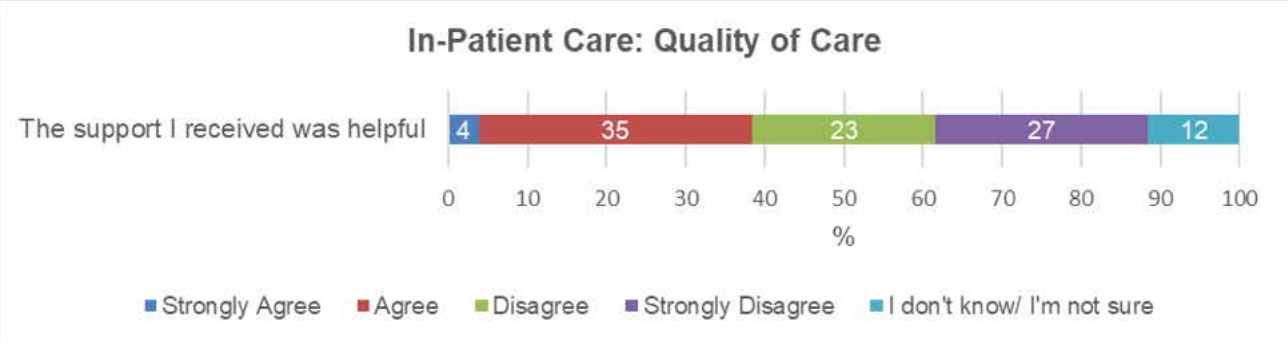
Base: 26

The vast majority of young people didn't feel involved in the decisions that were being made about their care or treatment (77%), 16% agreed or strongly agreed with this statement. This included decisions that were being made about whether hospital treatment was required and whether a hospital stay was benefiting them:

"Assess before discharge but also if a person is getting worse because they are in hospital doesn't mean they have to stay there even if they are sectioned."

"I wanted to stay to get better and I was told to leave the next day."

Figure 4.81: In-Patient Care: The support I received was helpful



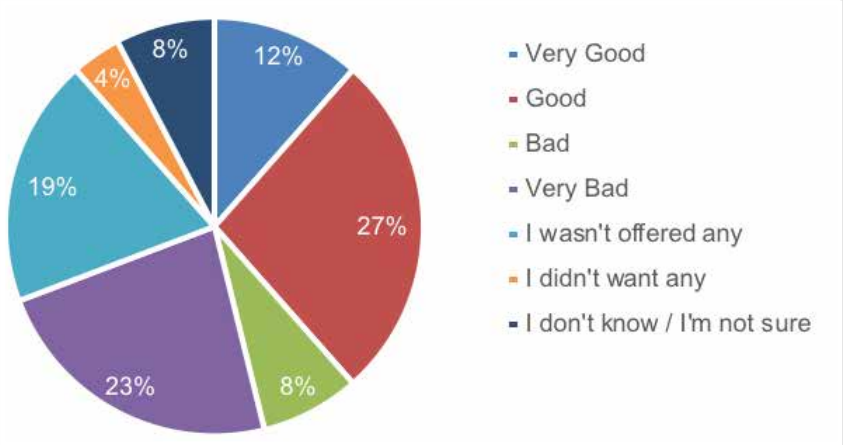
Base: 26

Exactly half (50%) of young people either disagreed or strongly disagreed that the support they had received as an inpatient was helpful. And 39% agreed or strongly agreed that it had been helpful.

Parent / Carer Survey (n=9)
Four parents / carers agreed or strongly agreed that the support their child received was helpful, four disagreed or strongly disagreed and one didn't know or was unsure.

Support Available on Leaving Hospital

Figure 4.82: How would you describe the support that was available to you when you left hospital?



Base: n=26

There were very mixed experiences in terms of the quality of support young people were given when discharged from hospital. 39% agreed the support was good or very good. A further 31% said it was bad or very bad, 19% said they were not offered any, 4% said they had not wanted any and 8% were unsure or did not know.

Do You Think You Would have Benefited from More Support When You Left Hospital?

The majority (20 out of 35) of young people who had experience of Inpatient Care for their mental health, said they would have benefited from more support when they left hospital. They also highlighted a range of supports hey thought would have helped them, these included more regular out-patient appointments and also having some support that helps to bridge the gap between inpatient and outpatient care:

"I would have benefited from a stepped down service, or a day patient unit to bridge the service gap."

"More regular meetings with CAMHS and IIT (Intensive Intervention Team)"

"Someone to check up on how I was doing etc."

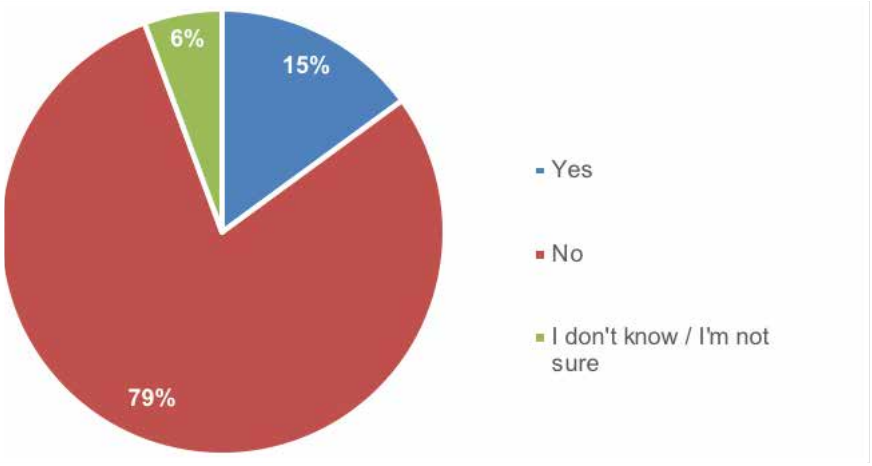
"I honestly think on two occasions I shouldn't have been discharged as I ended up back in the same day."

"As I was supposed to be an inpatient at Beechcroft at this stage, I received intense support from my EDY's outpatient team. However, I really think that I would have benefited a lot from an eating disorder day treatment programme – more intense than community, less intense than in-patient."

Parent / Carer Survey (n=9)
Eight of the nine parents / carers surveyed agreed or strongly agreed that their child would have benefited from more support when they left hospital

4.14 Transition

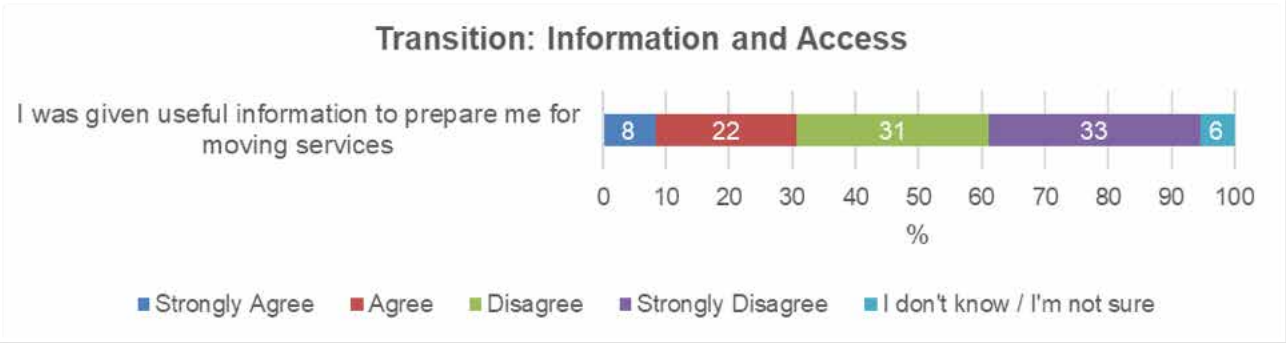
Figure 4.83: Have you experience of moving from child to adult mental health services?



Base: 301

Information and Access

Figure 4.84: Transition: I was given useful information to prepare me for moving services



Base: 36

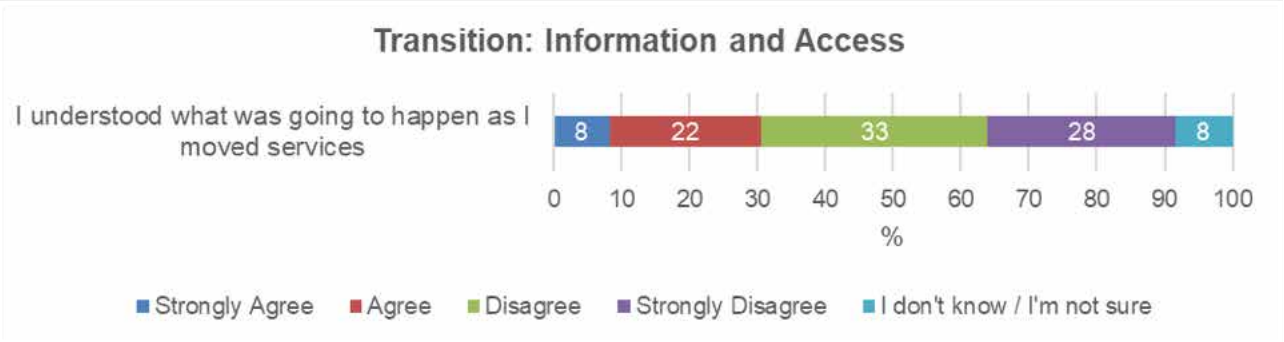
Of the young people who had experience of transitioning between CAMHS and AMHS, 64% disagreed or strongly disagreed they had access to information that would prepare them for moving services. 30% agreed or strongly agreed that the information was useful:

"CAMHS had been so helpful and aware the transition would be stressful and kept me with them as long as they could."

"Zero communication was left to my own devices for a long time was put off therapy because of the situation."

"I had no input or useful information with regards to my transition. I've been over 18 for a year and still haven't met with adult mental health services due to cancelled appointments on their behalf (although it must be said that I've been out of the country at uni for the past two months, but even before that I've been waiting for 10 months for an appointment)."

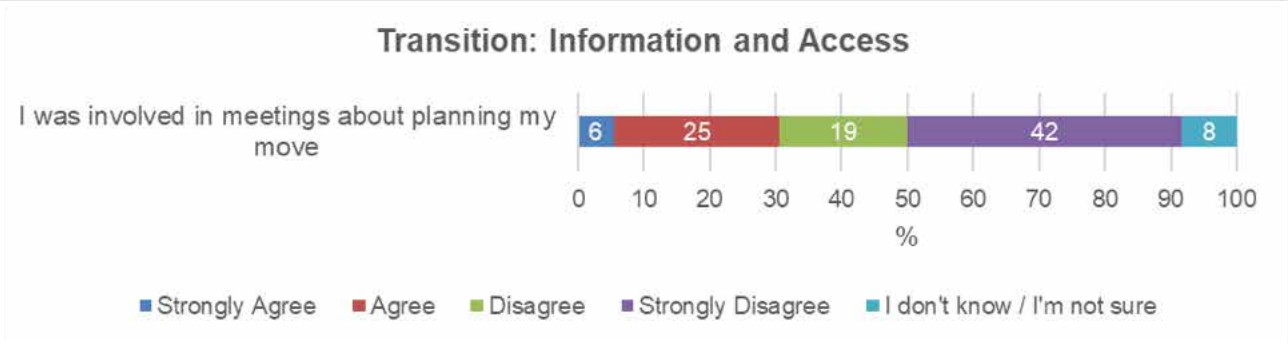
Figure 4.85: Transition: I understood what was going to happen as I moved services



Base: 36

61% of young people disagreed or strongly disagreed they understood what was going to happen to them as they moved services. 30% agreed or strongly agreed this was the case.

Figure 4.86: Transition: I was involved in meetings about planning my move



Base: 36

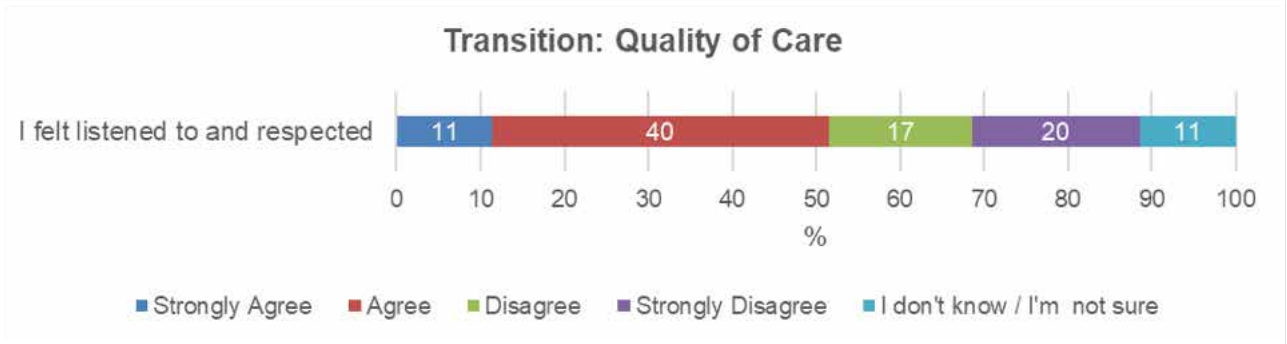
61% of young people disagreed or strongly disagreed they were involved in meetings about planning their move. 31% agreed or strongly agreed that this was the case:

"Very good experience. CAMHS was kind enough to let me stay after I turned 18 to ensure I had some place to go before moving to adult services."

"I was never given the option to plan my move, turned 18 and was discharged and that was it."

Quality of Care

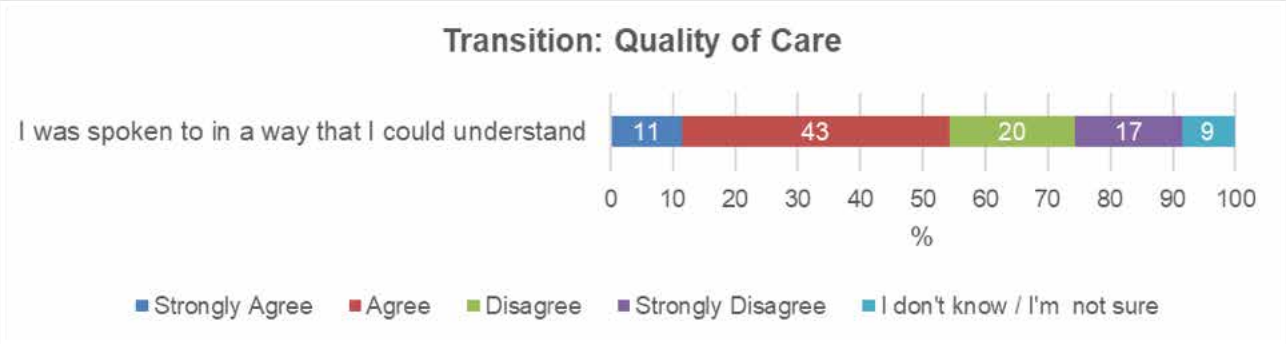
Figure 4.87: Transition: I felt listened to and respected



Base: 36

Half of young people who had experience of moving between CAMHS and AMHS reported they felt listened to and respected, 51% agreeing or strongly agreeing with this statement. 37% disagreed or strongly disagreed with it.

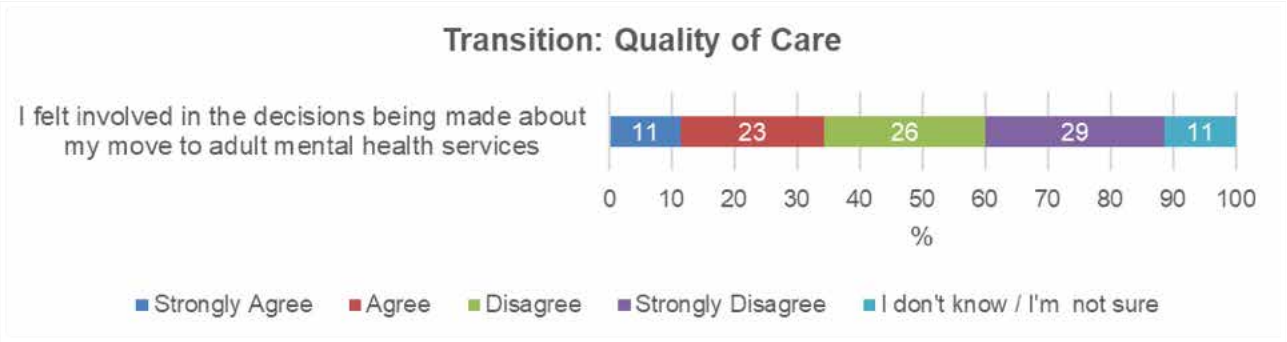
Figure 4.88: Transition: I was spoken to in a way that I could understand



Base: 36

Just over half (54%) of young people surveyed agreed or strongly agreed they had been spoken to in a way they could understand during the transition process. 37% disagreed or strongly disagreed this had been their experience.

Figure 4.89: Transition: I felt involved in the decisions that were being made about my move to adult mental health services

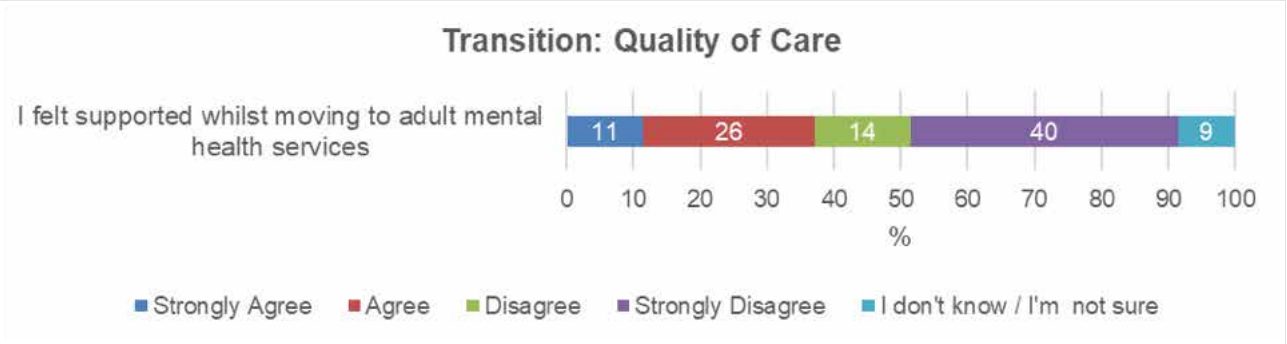


Base: 36

55% of young people disagreed or strongly disagreed they felt involved in the decisions being made about their move to adult mental health services. 34% agreed or strongly agreed this had been their experience:

"I never actually got to say goodbye to the child mental health service. After my last appointment with them I just stopped receiving appointments and was then informed I was too old."

Figure 4.90: Transition: I felt supported whilst moving to adult mental health services



Base: 36

Over half of young people surveyed (54%) either disagreed or strongly disagreed they felt supported whilst moving to adult mental health services. 37% agreed or strongly agreed this had been their experience:

"There was a three month time gap where I had no support from either service as I moved from CAMHS to adults services."

"Make sure people are actually moved as when i turned 18 i was just discharged and never heard from them again or got help moving."

The following two quotes demonstrate the mixed experience young people are having when it comes to transitioning between CAMHS and AMHS:

"My CAMHS team supported me and cared for me when I was being discharged."

"Really bad experience, no support."

Additional Comments about Transitions

Young people were asked to provide any further comments on their experience of transitioning between CAMHS and AMHS, including anything that would have made their experience easier.

More Preparation for Moving between CAMHS and AMHS

A common point made by young people was they felt transferring to adult mental health services at 18 years old can be very difficult. Young people said it would have been better if there was a longer transition period for those aged 16–25 years old, to gradually move them into adult services, in order to get used to the different ways adult services work, and gradually build up relationships with new staff:

"You do not go from being a child to an adult overnight and services do not reflect this; they see you as a child one day and are very involved to an adult the next and not caring and "we'll see you in 3 weeks". Appalling service. Need to have a transition service or a young people service from 18–25."

"I was in CAMHS till the age of 17 and found it very helpful I just wish they didn't have to transfer you at 18 and it continued till aged 25."

More Joint Working Between CAMHS and AMHS
Young people also said it would be useful for CAMHS and AMHS to work more closely together:

"It would also be more helpful if they worked closer to adult mental health."

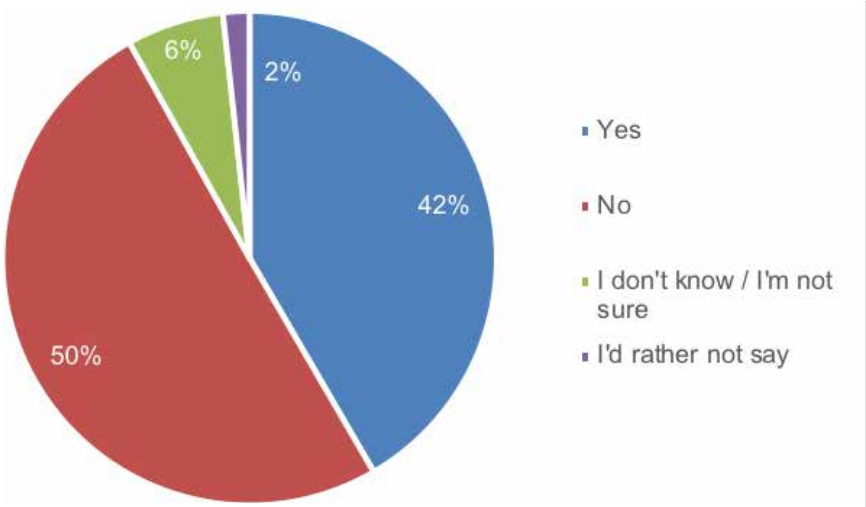
Young people reflected on the fact that moving to adult services had negatively affected their treatment and recovery, as they had to end the relationship with their CAMHS therapist:

"The adult team work very different to the CAMHS and the transition is difficult. I don't know why you can't continue with CAMHS after 18, especially considering you have been with them and built a good relationship and they know you well! The transition can also makes things worse with illness if you not in a great place."

"I wish the transition was phased, it annoyed me that I just started connecting with one person and they then abandoned me and the next person wasn't interested."

4.15 Mental Health Appointments

Figure 4.91: Have you had to cancel or been unable to attend a mental health appointment?



Base: 173

Of the young people surveyed, 42% had cancelled or been unable to attend an appointment about their mental health, 50% had not had this experience and the remaining 8% didn't know, were unsure or would rather not say.

Parent / Carer Survey (n=14)
35% of parents/ carers reported that their child had to cancel or been unable to attend a mental health appointment.

Reasons for Cancelling or Being Unable to Attend an Appointment

As outlined below, there are a wide range of reasons for young people having to cancel or being unable to attend appointments. The most common reasons given by young people were that the appointment time given did not suit (51%), they did not feel well enough on the day of the appointment (51%) and they forgot they had an appointment (31%). Many talked about how their mental health problems made it difficult for them to attend appointments. For some this led to them becoming disengaged with services and their mental health worsening.

Table 4.9: What are the reasons for having to cancel or being unable to attend an appointment? (Multiple choice question)

	%	Freq
The appointment time I was given didn't suit	51	36
I didn't feel well enough on the day of my appointment	51	36
I forgot that I had an appointment	31	22
I didn't find the health professional(s) helpful	18	13
The appointment time I was given came at too short notice	17	12
I couldn't get a lift / organise transport to the appointment	11	8
I'd rather not say	4	3
I didn't need it anymore	1	1
Other (please specify)	1	1

Base: 71

Challenges with being able to attend appointments with services was a general issue raised by young people during the Review, that related to a range of services i.e. GP, School/College/ University, CAMHS out-patient appointments, and Voluntary and Community Sector services.

Anything that Could Help Make Attending their Appointments Easier?

Young people were asked if there was anything that could help make attending their appointments easier. A range of ideas were raised by young people as outlined below.

Flexibility in the Time and Location of Appointments
More flexibility in the time and location of appointments. Young people would like to have more choice in the time of appointments to make it easier for them to attend. This includes appointments that are not during the school day. Young people ideally would like appointments to be closer to home, and include home appointments when they feel too unwell to attend a clinic:

"***If they (appointments) were closer by."***

"If they (appointments) were closer to home and were not arranged when I was in school or my parents were working."

Different Options for Making an Appointment
Young people talked about having a range of ways of making appointments that did not require telephoning an office. Young people mentioned online booking and getting reminder texts about appointments, to make sure they did not forget about it:

"If the appointment is weeks away, to receive a reminder coming up to the time."

"Not having to phone to make an appointment."

More Regular Appointments/Contact with Services
Young people also mentioned that it can be difficult to fully engage with a service when there are a long gaps between appointments, and that it would be better if they had appointments that were more regular, or at least have some contact with the service between face to face appointments:

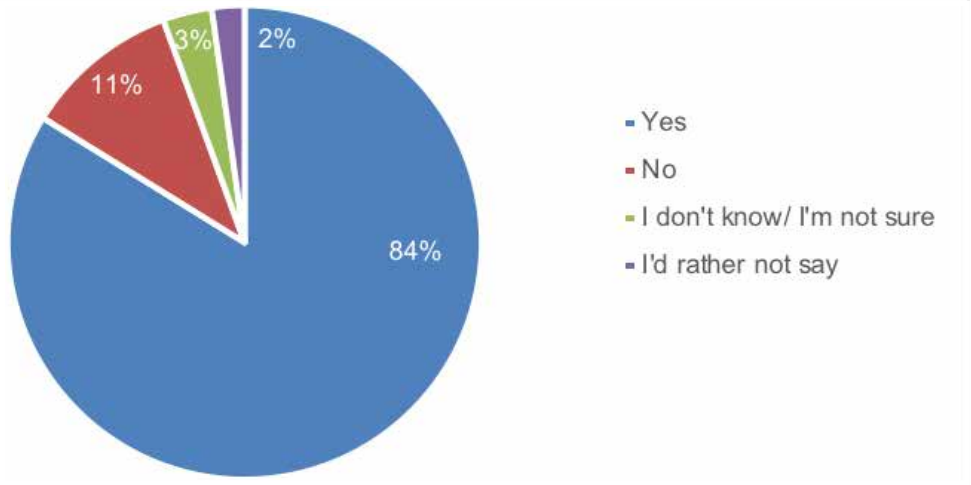
"I wish I had of had more control over the appointment dates and also while waiting for my next appointment I'd of liked some sort of connection with my counsellor in case I need support instead of having to wait weeks to a month to get it."

"Making the appointments more regular as a 3-4 week or longer wait is a very long time."

"A wrap around service would help."

4.16 Waiting for an Appointment

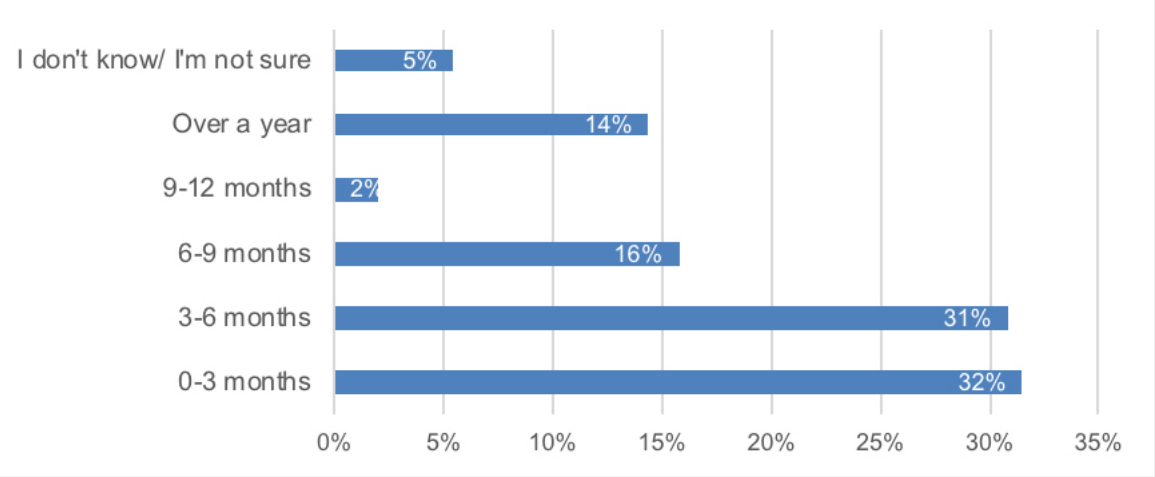
Figure 4.92: Have you had to wait for an appointment to see someone about your mental health?



Base: 179

The vast majority (84%) of young people surveyed have experience of having to wait for an appointment to see someone about their mental health. 11% had not had to wait, and 5% said they did not know or would rather not say.

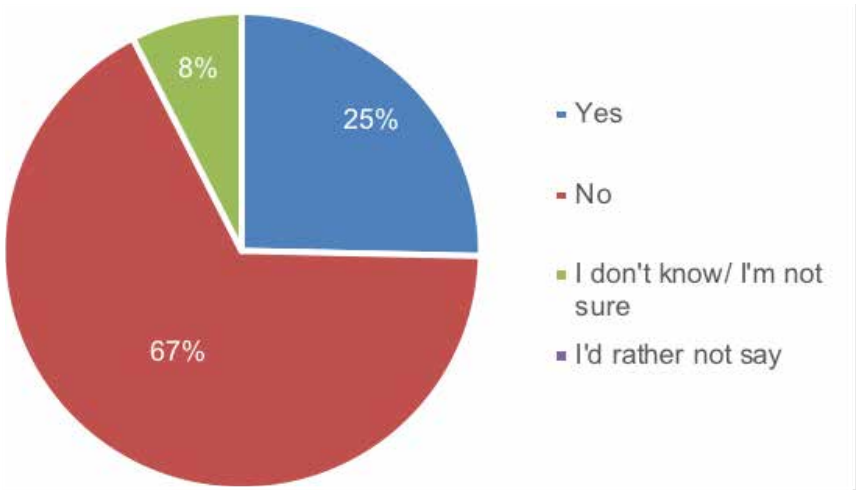
Figure 4.93: What is the longest time that you have had to wait to attend an appointment?



Base: 146

Young people described having to wait a considerable length of time to receive an appointment with a mental health specialist. 31% reported the longest time they had to wait for an appointment was between 3–6 months. 32% had to wait 6 months or more to attend an appointment, and of these 14% had to wait over a year.

Figure 4.94: Did you receive any other help while you were waiting to see someone about your mental health?



Base: 146

Young people were asked about the help they had received while they were waiting to see someone about their mental health. 67% reported they had not received any help, and a quarter (25%) reported they had received help.

Parent / Carer Survey (n=29)
86% of parents / carers reported that their child had not received any other help while they were waiting to see someone about their mental health.

Young people were asked to outline what type of help they would have found useful whilst waiting for an appointment. It is clear they felt they would have benefited from some form of online or face-to-face support. The examples provided included: access to additional support from a range of professionals that include GP services, school/College/University, teachers/ school counsellors and Community and Voluntary based services:

"I think while waiting for an appointment it would have been good to have extra support rather than just be handed anxiety medication."

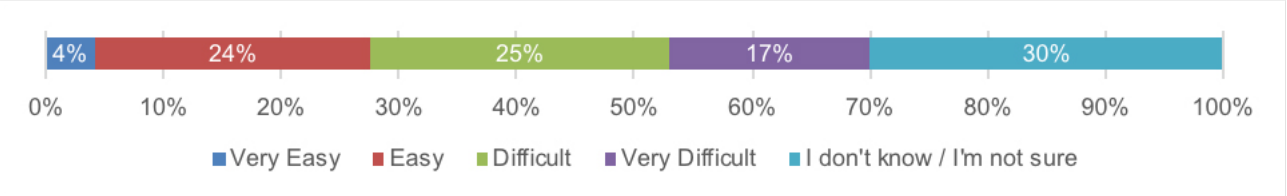
"It would have been good to have a weekly meeting or a phone number to ring in crisis rather than going back to A&E and starting from square 1."

"I would of liked to receive information about online help for mental health while waiting for an appointment."

"Whilst waiting on the support from the mental health team I had support from a community organisation, although this was short term and was only there to help me while I waited on the mental health team it was some form of support. I received one to one support and mentoring everyday from my youth worker, this was a great support however there was only so much she could do as a youth worker at one point she was my only support system I had in place."

4.17 Complaints

Figure 4.95: Have you or your parent / carer ever made a complaint about a mental health service?



Base: 170

Almost a quarter of young people (24%) had experience of making a complaint about a mental health service. 62% reported that neither they nor their parent or carer had made a complaint about a mental health service, and 14% stated that they did not know or were unsure.

Figure 4.98: How easy or difficult was it / do you think it would be to make a complaint?

Base: 170

There was a mixed view from young people in terms of how easy or difficult they would find making a complaint. A significant percentage of the young people surveyed reported that it was/would be difficult, or very difficult, to make a complaint about a mental health service (42%). However, well over a quarter thought it was/would be easy to make a complaint (28%). A further 30% said they did not know or were unsure.

Parent / Carer Survey (n=40)
80% of parents / carers had never made a complaint about a mental health service.
70% didn't know how easy or difficult it would be.

Across the range of mental health services and supports young people were asked to comment on, a number described very unhelpful and inappropriate comments being made by professionals they had spoken to about their mental health. Some of these unhelpful or inappropriate comments are outlined below. Although this Review has not been able to determine how common these sorts of experiences are, they sit against a backdrop of a small proportion of young people, or parents or carers surveyed, who have made a complaint or knowing how to go about it, as the graph above demonstrates.

School

"It was bad, my school counsellor told me I was stupid and didn't know what I was talking about, then when I was told it was anxiety and depression she refused to take me on."

"I had a male counsellor who told me that I was attractive and he was surprised I did not have a boyfriend. It made me feel uncomfortable."

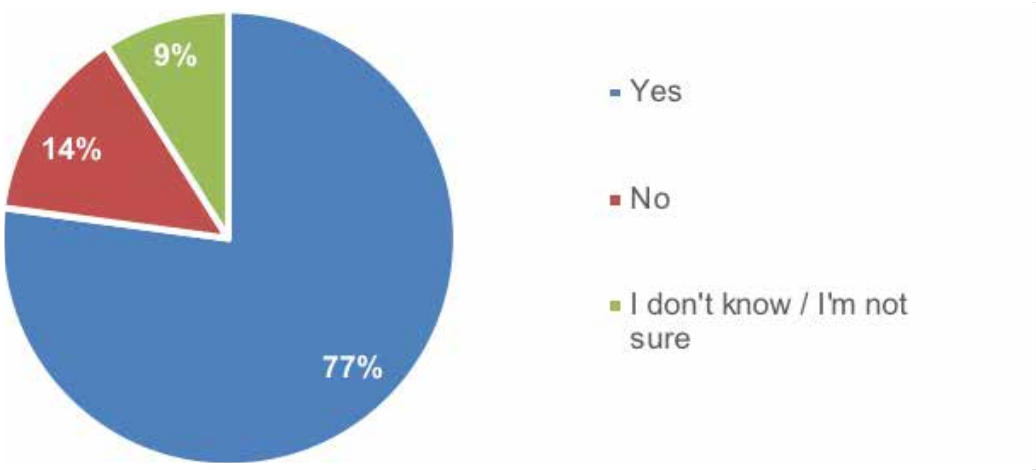
"I said that I wanted to kill myself in front of the same teacher, who did nothing to help me."

CAMHS

"I saw two counsellors both of which were no help and made me feel worse - one told me to 'fake being happy until I became it' and the other advised me to start drinking wine to calm my nerves."

"There was one occasion I felt like complaining but the process seemed a nightmare so I didn't bother."

Figure 4.96: Would you advise friends or family to look for help from mental health services if they had emotional or mental health problems?



Base: 289

The vast majority of the young people surveyed (77%) said that they would advise friends or family to look for help from mental health services, if they had emotional or mental health problems. Only 14% stated that they would not advise friends or family to look for help and 9% didn't know or were unsure.

Parent / Carer Survey (n=49)
92% of parents / carers would advise others to look for help from mental health services if their child had emotional or mental health problems.

4.18 Overarching Issues

Two key overarching issues were raised by young people at the end of the survey. These are relevant to all services and support and were the need for better communication between services involved in the young people's life, and for help/treatment options to be more person centred and age appropriate.

Communication Between Services
Young people talked about the importance of services involved in a young person's life, working together. For example in relation to school and CAMHS, and GP and specialist mental health services:

"Better communication between services about me to save me having to answer the same questions over and over."

"If the school and CAMHS were in contact with each other then I would feel more safe and secure in school."

Young people described how draining and difficult it can be, to have to repeat themselves over and over again with different people/services, before getting any help:

"…With the mental health team it gets confusing as your GP refers you there and then the mental health team then refer you in to another organisation again it can all get very confusing and repetitive."

"(..) having to answer the same questions all the time about your past etc is annoying when the information could be on a system ready to be viewed to save the time taken telling them your life story every time you have a new appointment, not much information given about how to deal with mental illness."

Need for Person Centred Support

It was the experience of some young people that the mental health support was not effective or did not help. Young people also referred to the fact that some programmes or treatments only lasted 4–6 weeks, which was not long enough to deal with their problems:

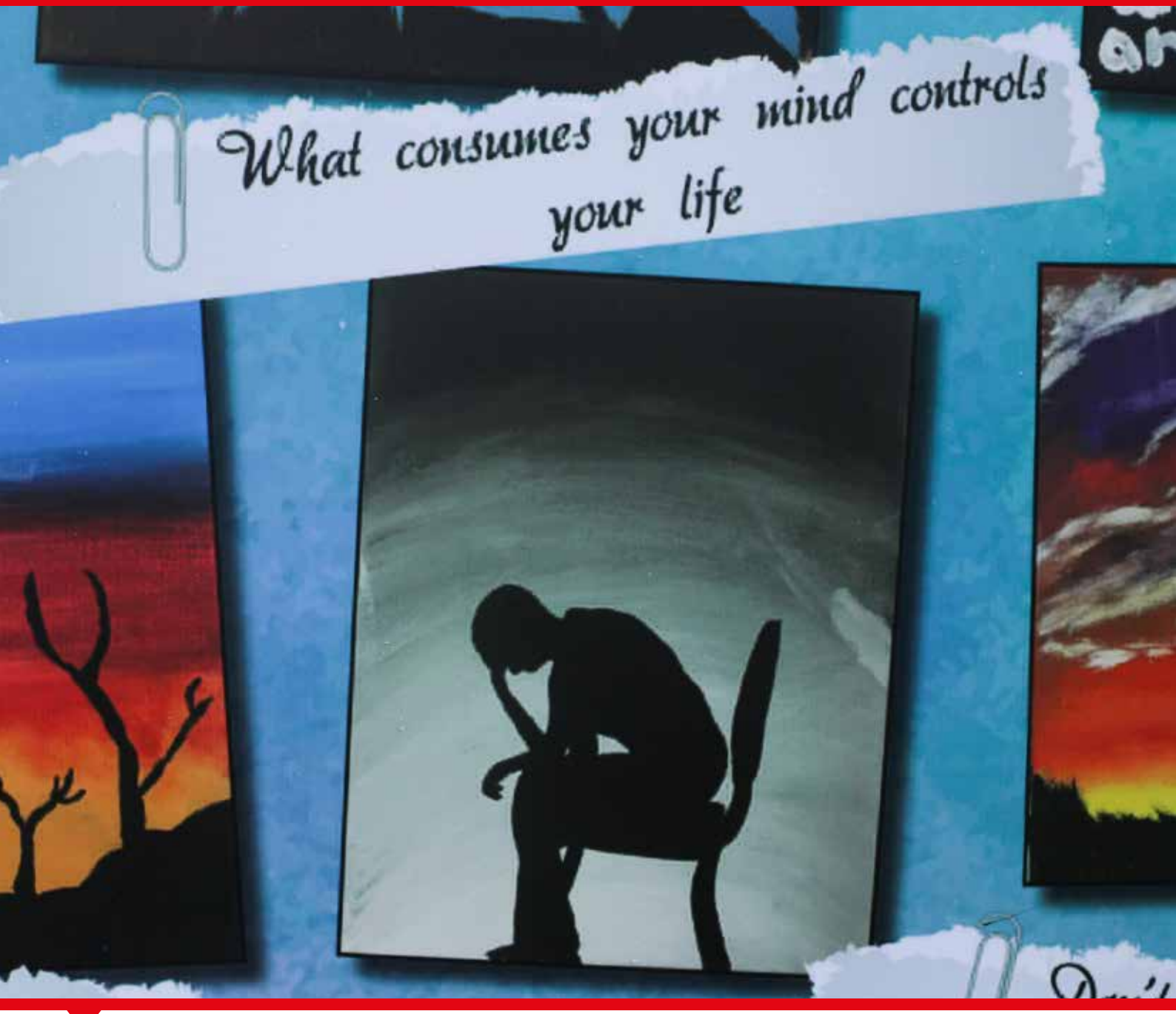
"It was good to discuss how I could in the future improve. However, I feel that for this benefit to be long term then discussion should have been had about my past and what caused my current problems because this was never discussed and perhaps if it had of been then the treatment would have benefited me for longer." (Counselling services)

"I found it very intimidating going to my doctor it was very abrupt I couldn't deal with things gradually at my own pace, they took my wrists and pulled up my sleeves while I struggled to stop them."

"I feel the support I got from the charity organisation was geared more towards a child I had to do exercises like choose an animal or shape and was never really explained the purpose of them or how they were supposed to help me as a 17 year old I felt it was silly."

"I think services need to look more into how best to relate to a young adult and help them deal with their feeling and emotions so they find the balance between treating us like children that don't understand anything and talk to us more like adults letting us deal in our own time."

"Receiving the initial referral was easy, however the waiting list was long and the help given was not an appropriate level for the severity of the problem."



SECTION 5

YOUNG PEOPLE WITH A LEARNING DISABILITY AND MENTAL HEALTH PROBLEMS: INTERVIEW FINDINGS

5.1 Prevalence of Mental Health Problems

There is no universally accepted definition for the term 'learning disability', in the same way there are different definitions used for the terms 'mental health' and 'mental health problems'.

For the purposes of the Review, NICCY chose to use the term 'learning disability', rather than 'intellectual disability', as this is the terminology used by the key partner organisation that supported NICCY to identify young people for interview.

The following is a rights based definition of disability:

'A learning disability includes the presence of a significantly reduced ability to understand new or complex information or to learn new skills; with a reduced ability to cope independently, which started before adulthood with a lasting effect in development and which in interaction with various barriers may hinder full effective participation in society on an equal basis with others' (Lundy et al., 2012).

A learning disability can be categorised as mild, moderate, severe or profound. However, those with the same diagnostic 'label' can be very different with respect to their needs, and the range of barriers they face.

There is no accurate register of the number of people with a learning disability in Northern Ireland, but it has been estimated that 42,000 people have a learning disability, and 11,000 are aged between 0–17 years old. These figures are based on an estimate that 2.16% of adults and 2.5% of children have a learning disability (Mencap, 2018).

Young people with a learning disability are much more likely to experience mental health problems, compared to their peers without a learning disability. It has been reported that nearly 40% of this group will experience a significant psychiatric disorder, compared to less than 10% of those without a learning disability (Emerson and Hatton, 2008). Furthermore, the likelihood of mental health problems are higher for those with the most severe learning disability (Pote and Goodhan, 2007). Mental health problems in children with a learning disability can often start earlier in life and show considerable persistence in the population, especially if interventions are not introduced early enough (Emerson and Einfeld, 2010).

Research shows people with a learning disability are more likely to experience poorer health outcomes, and have shorter life expectancies than the general population (Black, 2013). The higher prevalence of mental health problems within this group has been connected with a range of factors that include an innate vulnerability and co-existing physical, neuro-developmental conditions (Lenehan, 2017). From a rights based perspective, it is important to consider the higher prevalence of mental health problems using a social model of disability.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) requires the UK government to promote, protect and ensure the rights of disabled people. Areas covered include: health, education, employment, access to justice, personal security, independent living and access to information. The Equality Commission and the Northern Ireland Human Rights Commission are jointly responsible for monitoring its implementation in Northern Ireland. In the preamble statement of the UNCRPD, it is recognised that disability is an evolving concept and that disability results from: *'the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.'* (UNCRPD, 2006 para. 5).

In a similar vein, the Committee on Rights of the Child draws attention to the impact that discrimination and inequality can have on the ability of disabled children to enjoy the full range of rights, as enshrined in the UNCRC.

In particular, it has stated that: *'the barrier is not the disability itself but rather a combination of social, cultural, attitudinal and physical obstacles which children with disabilities encounter in their daily lives.'* (UN, 2006 para. 5).

Both the UNCRPD and UNCRC emphasise the fact there are a wide range of socio-economic and environmental factors that can lead to poor mental health in children and young people, and those who have experienced multiple adversities or discrimination in the realisation and enjoyment of their rights, are at much higher risk of experiencing poor mental health.

The UNCRC's Preamble recognises that: *'in all countries in the world, there are children living in exceptionally difficult conditions, and that such children need special consideration'*. Inevitably, the category of children living in exceptionally difficult conditions includes children with widely different problems requiring a wide range of different remedies. The situation of such children is best defined in terms of discrimination in the realisation and enjoyment of various rights contained in the UNCRC. The Committee on the Rights of the Child has consistently commented on the need to identify the most vulnerable and disadvantaged children in a State, has expressed concern about their situation, and has recommended action to ensure that such children have equal access to the realisation and enjoyment of their rights.

5.2 Access to Mental Health Services for Those with a Learning Disability

Under Article 24(1) of the UNCRC, young people with a learning disability have a right to access healthcare services in the same way as everyone else.

Article 1 of the UNCRC is very clear that: *"for the purposes of the present Convention, a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier."*

In recognition of the particular difficulties young people with a learning disability face when trying to exercise their rights, including rights to access to good quality healthcare services, Article 2(1) of the UNCRC emphasises that: *"State Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status."*

A range of inquiries conducted elsewhere in the UK have stated that healthcare services are failing to meet the needs of people with learning disabilities, resulting in poor health outcomes (Lenehan, 2017). There are issues with generic services not having the specialist skills and knowledge to provide health care to this group. There are also problems with a lack of 'reasonable adjustments' being made by services, such as providing longer appointment times, making psychological therapies accessible to young people with a learning disability, and joined up working practices with other parts of the healthcare system (Lenehan, 2017; Burke, 2014).

The Bamford Review of Mental Health and Learning Disability recommended that specialist mental health services for children and adolescents with learning disabilities should be commissioned as part of specialist mental health teams for all children, although recognising the need for specialist skills, training and joint working with existing intellectual disability services (Bamford, 2006).

More recently, mental health service provision for young people with a learning disability in Northern Ireland has been considered by the Royal College of Psychiatrists who have stated that: 'there has been some service development and commissioner investment since Bamford, but access to specialist, multi-disciplinary and therapeutic community services for this group remain limited.' (RCP, 2016).

Research has estimated that between 72% and 76% of learning disabled children with mental health problems had not accessed specialist mental health services in the previous 12 months, suggesting low levels of mental health support being accessed by this group of young people (Toms et al., 2015).

In general, people with learning disabilities and their families have much greater difficulty accessing mental health services, than other groups in society. This is partly because in order to access mental health services they have to show that their mental health is unrelated to their learning disability. This problem is described as 'diagnostic overshadowing', where the symptoms being presented are often considered as part of the learning disability (Burke, 2014). Diagnostic over-shadowing is particularly problematic for young people with the most severe learning disability for whom interventions are generally focused on managing a behaviour rather than an underlying mental health problem.

Young people with a learning disability can display any of the full range of psychiatric disorders, this includes Autism Spectrum Disorder (ASD), Attention Deficient Hyperactivity Disorder (ADHD), emotional disorders and behavioural disorders. These mental health problems frequently co-occur with other physical or sensory impairments (RCP, 2016). There is also often a wide range of other 'nuanced' issues that young people may present with, including loneliness, grief, anger management, behaviour that puts them at risk, and sleep deprivation (Burke, 2014).

The often multiple and complex factors that can affect a young learning disabled child's mental health, means that a person centred approach to care is essential. A person centred approach requires professionals from different disciplines and sectors working together on a shared care plan (Lundy et al., 2012). An over-reliance on 'silo working' and one service meeting the heterogeneous needs of children with disabilities inevitably leads to issues not being addressed and is not conducive to person centred care in which multiple needs are addressed at the same time (Kelly et al., 2016). When the system does not meet the needs of children and young people with a learning disability, there is a greater risk of social exclusion, prolonged admission to hospital, deprivation, physical harm, abuse, misdiagnosis, exposure to ineffective interventions and failure to access evidence based interventions (McGill and Poynter, 2012).

Due to the range of issues faced by young people with a learning disability and their families, it is not surprising that they make far less use of the health system beyond what is made available through learning disability teams. Significant delays in being diagnosed with a learning disability and/or mental health problems means that access to essential support services and specialist advice is often crisis driven rather than offered as a form of early intervention. Chronic lack of funding in specialist

mental health and disability services is widely understood as contributing to the unacceptably long waiting times for assessments and lack of access to services. Although there have been important developments in specialist community based services by some Trusts, these services generally continue to be under-resourced resulting in inappropriate admissions to hospital and delayed discharges (Rees et al., 2014).

Medication and restrictive practices are overused with respect to young people with a learning disability. There are a range of reasons for this which include the fact that people are not aware of alternatives, or there are not enough professionals trained to be able to offer young people and their parents/carers a choice of alternative interventions (Bamford, 2006).

The National Institute for Health and Care Excellence (NICE) developed guidelines on the prevention, assessment and management of mental health problems of people with a learning disability in 2016. It reported that young people with a learning disability are a hugely neglected group, in terms of an evidence base of how to identify mental health problems, and how to support their mental health. It also found no evidence of specific psychological therapies that have been clinically trialled, to be effective for young people with a learning disability. However, it went on to say that there is enough evidence to demonstrate the potential life changing impact that alternative therapies such as psychotherapy and counselling can have for people with a learning disability; this includes improved confidence, self-esteem and behaviour, increased daily living skills and more success in finding employment (NICE, 2016:1).

The Committee on the Rights of the Child expressed specific concerns about discrimination in access to services and in particular, the potential discrimination in access to quality services for young children, especially where health, education, welfare and other services are not universally available and are provided through a combination of state, private, and charitable organizations. The Committee encourages State Parties to monitor the availability of, and access to, quality services that contribute to young people's survival and development, including through systematic data collection, disaggregated in terms of major variables related to children's and families' background and circumstances (UN, 2005, para. 12).

It is important for young people themselves to be facilitated and supported to provide their own opinion on the services they use, as these can be different to the perspective given by parents/carers and professionals. Having a valued role in the decisions being made about their future and the support they require is important to young people, and a lack of autonomy has been linked to poorer mental and emotional well-being (CYPSP, 2011).

In the most recent examination of the UK and Northern Ireland's compliance with its obligations under the UNCRC, the Committee on the Rights of the Child stated that: *'a lack of co-ordination and integration of services was evident when young people are transitioning from children's services to adult services.'* This was described as 'often neither sufficient, timely nor well co-ordinated, and does not ensure fully-informed decisions by children with disabilities' (UN 2016:2, para. 55 (a) and (c)).

A UK study that compared the views of families versus service users of all ages found major differences in familial opinions about mental health services, compared to their relative with a learning disability. Family members tended to be much more satisfied with services than the person with a learning disability. For example, the report found that 90% of families agreed that their loved one was treated with respect, however 100% of young people felt they were not respected or listened to (Burke, 2014). The research also found families were much more accepting of the mental health service that was provided to their relative, than the professionals

that were working with them. On average it found that 65% of families agreed the service provided to their relative was adequate, compared to 14% of the professionals surveyed (Burke, 2014).

In Northern Ireland, the introduction of anti-discrimination legislation, including the Disability Discrimination Act 1995 and Equality Duties under Section 75 of the Northern Ireland Act 1998, have been necessary legislative advancements to address the issue of health inequalities and disability. In policy terms, The Bamford Review set out a series of recommendations to improve the lives of people with a learning disability and address unmet health care needs. Despite two Bamford Action Plans and a Service Framework for Learning Disability, progress to reduce the health inequalities faced by people with a learning disability, whilst commendable, has been slow. At times, it appears that details of actions have been vague and targets have not always been met (Black, 2013).

5.3 Service Profile

The ongoing implementation of a Regional Model for the delivery of CAMHS includes a commitment to the development of a regional specialist service model for young people with a learning disability (DoH, 2016:2).[30] However, currently the mental health services available for children and young people with a learning disability vary across Health and Social Care Trusts (HSCTs). There are a range of factors that have influenced the design and configuration of child and adolescent mental health services at a Trust level. The current Health and Social Care system is made up of five HSCTs, the current configuration of services came from merging a greater number of smaller Trusts, which are often referred to as 'Legacy Trusts'. The historical arrangement of services continue to influence budgets, planning and policy decisions today. Although all HSCTs recognise the need to ensure that children and young people with a learning disability can access a comprehensive range of services for their emotional/mental health, there are different views on the best way of doing this.

Community CAMHS (Step 3 Services)

As already stated, there is currently no single regional approach for providing mental health services to children and young people with a learning disability, and each HSCT is structured differently. This makes it very difficult to fully understand the system as a whole and the range of services being delivered to young people.

The Southern Health and Social Care Trust have developed a specific mental health service for those aged under 18 year old called ID-CAMHS (Intellectual Disability-CAMHS), this service is fully integrated into generic CAMHS. Within the other four HSCTs, young people with a learning disability and mental health problems are cared for by one of two services, these are Children's Learning Disability Services or generic CAMHS. The referral pathway young people in these Trusts go through tends to be determined by their assessed IQ level. There is no regional policy on this, and each HSCT varies in terms of the IQ cut-off for access to generic services, however, it tends to sit around 50-60.[31] Typically young people with mild learning disability are seen by generic CAMHS.

30 An outline of the Regional Stepped Care Model of CAMHS is included in Section 1: Background.

31 Bamford Review 2006 reported that some HSCTs were applying IQ cut off points as 55–65 for access to generic CAMHS. This Review has spoken to Clinicians who have confirmed that currently the service they work in has a cut off point that sits between 50–60. Also note, the HSCB have informed us that there is regional confusion on the scores for categorisation of learning disability.

Young people must have an IQ of 50–60 or more (mild learning disability) to be seen by generic CAMHS. The main specialism of the staff working within these services tends to be mental health and not learning disability.

Generic CAMHS is not generally accessible to young people with a more severe learning disability. Those with an IQ of 50 or less (severe learning disability) will be referred to a specialist learning disability team, in which the main specialism of the staff will often be learning disability and not mental health. Some will be referred to adult learning disability services where the specialism is adult and not children, and in other HSCTs children with a learning disability will sit within Children's Disability Services. In other HSCTs, children with a learning disability sit within Children's Disability Services.

Children's Learning Disability Services often adopt a more behavioural approach to children's needs, in which access to specific talking therapies is likely to be limited. Generic Learning Disability Services are generally not as multi-disciplinary as CAMHS. This means they may be missing key specialisms such as psychiatry, occupational therapy and speech and language services, that are essential for providing comprehensive, and person centred care.[32]

Children's Disability Services provide a more generic range of services for children with disability and additional needs. This includes supporting parents with the demands of raising a child with a disability, and provides a means for families to access a range of information, assessments and services.

Young people with moderate/severe/profound learning disability or borderline IQ may have been referred to a wide range of professionals for mental health support. These include a paediatrician or other health professional, a community nurse in learning disability, or someone from a Behaviour or Autism Spectrum Disorder Team. They may have been in contact with a psychiatrist or a psychologist, but this may have been a life span professional that works across all ages. Some of these services will not necessarily have children and young people's mental health as part of their service specification, and the professionals working within them will not always be trained in assessing or addressing children and young people's mental health.

The segregation of mental health and learning disability services means there are a lack of professionals trained and experienced in working with children that have a learning disability and a mental health problem (Lundy et al., 2012).

The IQ based referral criteria means that children and young people with learning disability that sit around the 'cut off point' between services, are more likely to have difficulty accessing appropriate mental health services within either learning disability services or CAMHS due to ambiguities that occur regarding referral criteria (Bamford, 2006).

The Royal College of Psychiatrists report (CR 200) has set out some of the inherent flaws in determining eligibility of access to mental health services solely on the basis of IQ:

"Poor functional ability is often the result of a mix of underlying neurodevelopmental disabilities, it is inappropriate to use intellectual disability alone to determine the best service for an individual. Services

32 Information gathered at meetings with clinicians during the process of this Review.

should avoid arbitrary assignment by IQ, and instead take into account the nature of the young person's difficulties and the disturbances arising from them." (RCP, 2016)

The provision of specialist mental health services (generic CAMHS) only to young people who are assessed above a certain IQ level, should be urgently reviewed. NICCY is extremely concerned that access to CAMHS on this basis, without the provision of an equivalent service, could be construed as discrimination.

Early intervention to identify and support children presenting with early signs of emotional health or behavioural problems should happen from as early as 18 months. It has been reported that this group of young people are particularly poorly catered for in the early years (Mencap, 2018). Concerns have also been raised with NICCY about the ability of services to respond to the needs of young children (4–5 years old) with moderate/severe learning disability, who are presenting with complex behavioural and mental health needs.[33]

5.4 Budgeting Data on Services for Young People with a Learning Disability

During the Review it became evident that young people with a learning disability are not clearly visible in the mental health system. This lack of visibility and integration of mental health and learning disability services is apparent in the commissioning and management structures, including Programmes of Care. Within Healthcare in Northern Ireland, there are seven Programme of Care (POC) which are divisions of healthcare, into which activity and financial data are assigned. They are used to plan and monitor health services and are not defined by age.

POC 5 is a defined division of healthcare that focuses on Mental Health Services for all ages and excludes learning disability services. POC 6 is the division of healthcare for Learning Disability Services and includes the Iveagh Centre (HSCB, 2018:1). The Iveagh Centre is explained in more detail below, however, the facility is an assessment and treatment centre for young people with a learning disability, who have a range of support needs that includes mental health.

This fragmentation of services can make it more difficult to ensure that planning and investment in mental health services is done adequately and equitably. The lack of integration of mental health and learning disability services within the commissioning and financial planning part of the system, has obvious implications for other parts of the system, which includes service delivery and monitoring. It can also negatively affect innovation in these services, as commissioning processes become more difficult.

The challenge of providing a cross system, integrated approach for this group of young people, is not unique to Northern Ireland. Other countries face similar challenges and it is recognised that system structure and commissioning processes are the basis for ensuring there is fair and practical leadership and accountability.

For example, in a recent review of services for children and young people with learning disability in England, commissioned by the Department for Health, it was stated that: *'there currently appears to be no line of sight for our group of children through the system. The way the system is structured reinforces the status quo. The fragmentation across three statutory agencies builds inertia within them and breeds a lack of ownership.'* Further on in the report, it is stated that: 'our children

33 Meeting between clinicians and NICCY- 27.06.16.

cry out for a cross government, cross system approach. They should sit at the heart of joint commissioning and yet they don't.' (Lenehan, 2017)

5.5 Operational Data on Services for Young People with a Disability

The operational statistics available for generic CAMHS are not disaggregated by 'disability', so young people with mild to moderate learning disability that meet the eligibility criteria for this service, are invisible in data. There are no plans to include disability as a demographic indicator in the new CAMHS dataset.[34] The HSCB has informed NICCY there is no suitable definition of disability that could be used.[35] This is a wholly unacceptable position for the service commissioners to take, and runs counter with the requirements set out under Section 75 (1) of the Northern Ireland Act 1998 for public authorities to meet equality of opportunity obligations. The legislation outlines nine categories/groups against which public authorities are required to monitor to eliminate discrimination. This includes between persons of different age and between persons with a disability.[36]

It is also contrary to the advice provided by the Committee on the Rights of the Child on the actions required by State Parties to implement the UNCRC. This includes a child's right to be protected from all forms of discrimination, as set out under Article 2 of the UNCRC, and the need for data collection to be disaggregated to enable discrimination or potential discrimination to be identified (UN, 2003, para. 12).

5.6 Iveagh Centre

The Iveagh Centre is an eight bed, acute (Step 4 – 5), short term, multidisciplinary inpatient assessment and treatment service for children and young people up to the age of 18, who have a learning disability, additional mental health difficulties, and who may display associated complex patterns of behaviour. The service is commissioned to cover all HSCT areas. Until recently, the Western Trust had their own facility called Crannog Lodge in the Lakewood Hospital in Derry/Londonderry. The Iveagh Centre is managed by the Belfast Trust and replaced services provided at Muckamore Abbey Hospital for under 18s. Muckamore Abbey Hospital provides inpatient, assessment and treatment facilities for people with severe learning disabilities and mental health needs, forensic needs or challenging behaviour. It currently provides services for over 18s, and some young people who turn 18 whilst in the Iveagh Centre, are transferred to Muckamore due to a lack of adult community placements.

In terms of commissioning and management, the Iveagh Centre sits apart from generic CAMHS, in that planning and delivery sit within the learning disability programme of care, and not the mental health programme of care. This disconnection between Iveagh and other mental health services is evident in the lack of visibility this group of young people have within mental health budgeting, operational data collection, including the CAMHS dataset, and the Stepped Care Model for CAMHS.

The survey and interview engagement carried out as part of this Review, did not include young people with severe or profound learning disability. The operational

34 CAMHS Dataset (HSCB, 2018:1)

35 Included in email correspondence from HSCB to NICCY, 19.10.2017.

36 https://www.legislation.gov.uk/ukpga/1998/47/section/75

data phase of the Review provided some useful information, which is included in the tables below. Available budgetary data related to the Iveagh Centre is included in Section 8.

However, NICCY has carried out previous relevant policy and research work, and sourced information that has been useful in understanding the pressure points faced by Iveagh, and the system more generally, in responding to the emotional and mental health needs of children and young people with severe learning and highly complex needs.

The Iveagh Centre has a very challenging role in responding to the needs of children and young people with severe and highly complex needs. Often the pressures faced within Iveagh are due to gaps in services or provisions in other parts of the system, most notably the lack of sufficient and specialist community infrastructure to work alongside the Iveagh Centre, to ensure that admissions are appropriate and planned, that re-admissions are kept to a minimum, and that discharges are not delayed. Unplanned admissions, delayed discharges and the lack of clear interfaces with community services, including crisis intervention and respite support makes it very difficult for the Iveagh Centre to run the facility in the way intended, because it is plugging gaps in other parts of the system and dealing with the impact from that. Service Commissioners acknowledge that community based care is under-developed (Rees et al, 2014). Professionals we have engaged with through this Review have also raised concerns about the lack of investment in infrastructure and services required to provide early diagnosis and intervention for children with a learning disability and to plan ahead with identifying and preparing to meet young people's support needs as they get older. An advocacy service is in place for young people and parents / carers of children in Iveagh Centre[37], however, further improvements could be made in terms of accessibility of advocates, including their involvement at key meetings relating to care planning.

A range of positive changes have been made at the Iveagh Centre in the last number of years, including addressing very concerning issues raised by RQIA inspection processes in 2014-15. More recent RQIA inspections have reported that young people's access to therapeutic services has improved, and use of physical interventions/restricted practices has reduced (RQIA Inspection Reports- (including 30 May '14; 3 June '14; 14 July '14; 13 August '14; 20-22 February '17 and 12 February '18). There has also been investment in a new sensory room for young people to use, education provision provided on site and consistency in the staff team working at the Centre.

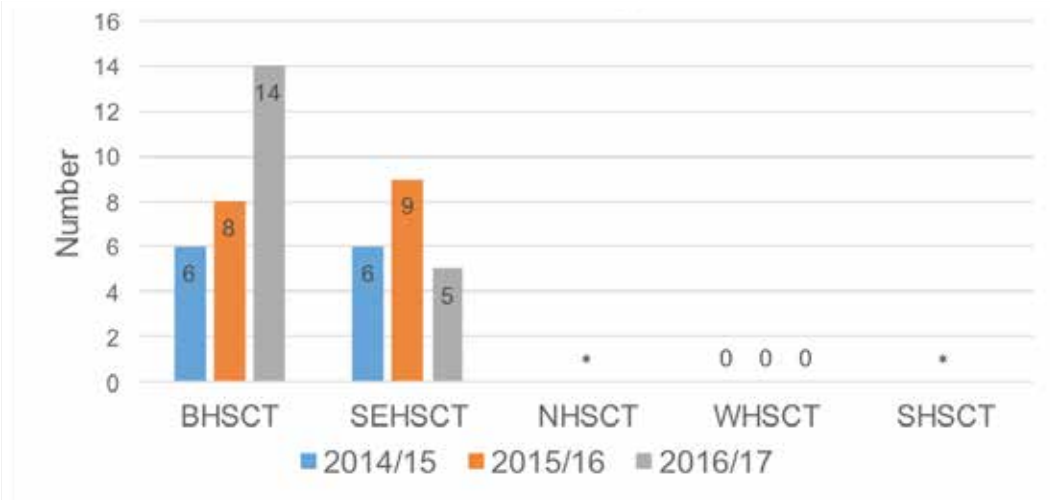
Operational Data on the Iveagh Centre

NICCY received inpatient statistics from the BHSCT, on young people admitted to the Iveagh Centre, for the period 2014/15 to 2016/17 and these have been set out below. The information provided includes the Trust of Residence of the Patients in Iveagh, gender and age breakdown of in-patients, status on admission i.e. voluntary or detained, and length of detention and delays.

37 Since 2017/18 Bryson has been providing advocacy service in Iveagh - nine hours to carers and nine hours to young people each month. (Information provided to NICCY by RQIA via email 23.06.18).

Demographic Profile

Figure 5.1: Resident Trust of Iveagh Patients



*Figures for NHSCT and SHSCT are under 5
Note 1: During the reporting period, the Western Trust had their own facility called Crannog Lodge.
Note 2: Admission rates for BHSCT may be affected by greater outreach work.

Although the Iveagh Centre is a 'regional' facility, there is a disproportionate number of young people admitted to the facility from the Belfast and South Eastern Trusts, as illustrated in the table above. The data provided shows a year-on-year increase in the number of young people being assessed or treated in the Iveagh Centre. In 2014/15 there were 14; in 2015/16 there were 20; and in 2016/17 there were 22.

NICCY has become aware through its legal casework of admissions to Beechcroft because a suitable bed was not available in the Iveagh Centre.[38] The RQIA have confirmed that to their knowledge this is a rare occurrence. There is no statutory obligation for a HSCT to inform RQIA when a young person is assessed as requiring admission to the Iveagh Centre but due to lack of beds is admitted to Beechcroft.[39]

Gender Breakdown

Over the last 3 years, there were a higher number of males than females admitted to the facility, and the proportional difference increased over the reporting period.

38 Information shared with Legal Team at NICCY, June 2018.

39 Email correspondence between NICCY and RQIA,18.06.18.

Figure 5.2: Gender Breakdown: Iveagh Patients

Age on Admission to Iveagh

The age of young people admitted to Iveagh over the reporting period ranged between 10 and 17 years old, with an average age of 14–15 years old.

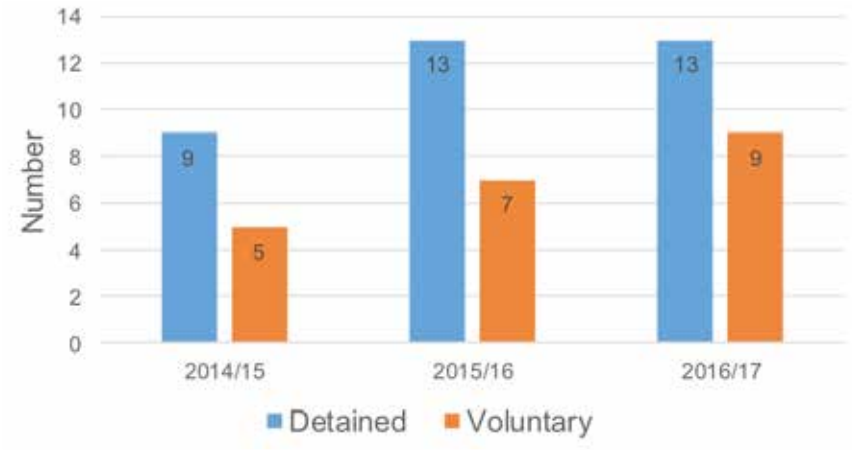
Table 5.1: Age on admission to Iveagh

	2014/15	2015/16	2016/17
Range	11-17	12-16	10-17
Average	15	15	14

Status on Admission to Iveagh

The table below shows the breakdown of the status of young people admitted to the Iveagh Centre across the reporting period. A larger number of admissions to the Iveagh Centre were detentions under the Mental Health (NI) Order 1986. This is not the case for admissions to Beechcroft, the general Regional Mental Health Inpatient Unit for under 18s, where a small proportion of all admissions were detentions over the same period.

Figure 5.3: Status of Admission to Iveagh



Note: The figures are based on patients resident at the beginning of each financial year, plus admissions during that year.

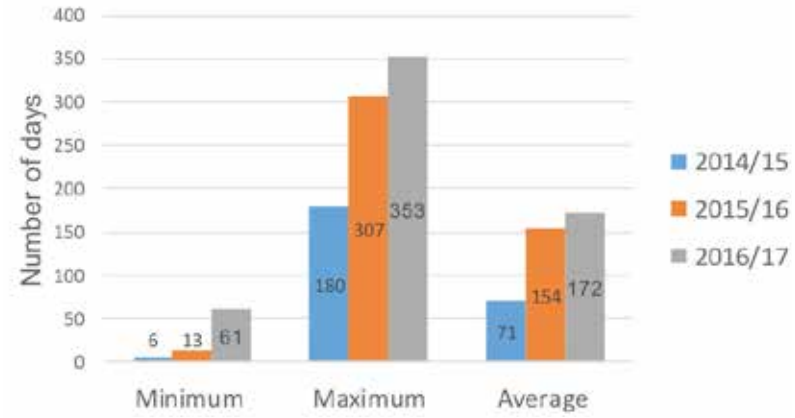
Length of Detentions

The legal limits for periods of assessment and detention for Beechcroft and Iveagh come from the Mental Health (NI) Order 1986, which states that the maximum length of time that you can be detained in hospital to have your mental health assessed is 14 days (under Article 12 of the Mental Health (NI) Order 1986). After the assessment process has been completed, a young person can be discharged from hospital or detained for treatment of a mental health condition in a hospital, if a psychiatrist believes that:

(1) The young person is suffering from a mental illness of a nature or degree that warrants their detention in hospital for treatment; and
(2) If they were not detained, there would be a substantial likelihood of serious physical harm to themselves or to others.

Where the conditions for admission for treatment have been met, a young person can be detained for a period of 6 months, and this can then be renewed for a further 6 months (under Article 12 of the Mental Health (NI) Order 1986).

Figure 5.4: Length of Detention in Iveagh



On average, it should take 6 months for a young person to be assessed and receive treatment (180 days). However, as the graphs above shows, some young people are remaining in Iveagh much longer than this. The minimum, maximum and average length of detention in the Iveagh Centre have all increased between 2014/15 and 2016/17. It is notable that the average length of stay in Iveagh has more than doubled between 2014/15 and 2016/17, from 71 days in 2014/15 to 172 days in 2016/17. During 2015/16 and 2016/17 the maximum length of stay for patients was close to a year, with the maximum length of stay being recorded as 307 days in 2015/16, and 353 days in 2016/17.

Table 5.2: Number, Length and Reasons for Delayed Discharge

Year of Admission	Number of delayed discharges	Minimum and Maximum Length of delayed discharge (days)	Reasons for delay
2014–2017	5	45-171	Residential Home – No Bed Other Complex Delay Reason

Across each of the 3 years that data is provided, there have been young people whose discharge from Iveagh has been delayed. The table above shows that between 2014–17, five young people had experienced delayed discharge. The length of delayed discharge over the reporting period ranged from 45 days to 171 days. The main reason for the delay in discharge have been due to a lack of suitable provision in the community i.e. no bed in a residential home, and difficulties with setting up care packages in the community, that meet complex needs.

The issue of delayed discharge of young people from Iveagh, who are otherwise 'medically fit', provides a stark illustration of the pressure within the system. Helping young people leave hospital when they are ready is a crucial part of promoting recovery. However, the need to arrange suitable accommodation, social care and follow-up support can prevent this from happening at an appropriate time. Delayed discharge can also lead to delayed admission for other young people requiring assessment or treatment, a deterioration in young people's condition whilst they wait, and further pressure on parents/carers and community based services that are attempting to 'manage', while they wait for a bed to become available.

5.7 Feedback on Mental Health Support and Access to Services for Young People with a Learning Disability

NICCY partnered with Mencap to engage with young people and their parents/carers for interviews. Identifying key partner organisations was agreed as part of the Review's ethical review process. It was also agreed the target age group for the interviews should be 16–21 years old. Efforts were made to engage with parents/carers for a focus group, unfortunately no suitable participants were identified to take part. However, parents/carers were given the opportunity to participate in the Review by completing an online survey (see the Methodology section of the report for more details on this).

The challenges of engaging with young people with a learning disability and mental health problems, and their parents and carers, for interview or focus group is discussed further on in this section of the report. However, from a very early stage in the recruitment process it became clear that neither young people nor their parents/carers were identifying their child as having emotional or mental health problem, or accessing mental health services or support.

In addition to engagement with young people and parents/carers, a focus group was also held with staff from Mencap. As a key partner organisation, Mencap had a central role in making initial contact and facilitating NICCY's engagement with suitable young people and their parents/carers.

Mencap Staff Focus Group

A focus group was held with 10 staff working directly with young people with a learning disability or difficulty, through one of Mencap's key services i.e. employment services, youth services. The staff focus group was an opportunity to share some of the key themes coming from the interviews with young people, and for them to raise any additional issues about young people's access to mental health services, or support that wasn't covered as part of the key themes. It was also a chance to review the engagement process with young people and parents/carers, as it was much more difficult than anticipated to engage with young people for the interviews.

Profile of Young People Involved in Interviews

One-to-one interviews were conducted with 15 young people across 5 locations. Eight participants were male and 7 female, and they were aged between 17–25 years old, the average age was 21 years old. All the young people interviewed had been diagnosed with a mild learning disability or learning difficulty.

Table 5.3 Profile of young people involved in Learning Disability interviews

Location	Response	Male	Female
Carrickfergus	3	1	2
Newry	1	1	0
Magherafelt	3	3	0
Fermanagh	3	1	2
L/Derry	5	2	3
Overall	**15**	**8**	**7**

Parent / Carer Views Through the Online Survey

The online survey was open to all parents/carers that had experience of supporting their child to access mental health services or support.

5.8 Overview of Themes Coming from the Interviews

Recruitment Process for Interviews

It was recognised at the beginning of this Review that additional planning and capacity building was required in order to engage with young people with a learning disability. A great deal of preparation was carried out to make this process as meaningful as possible. This included working with a key partner organisation known to the young people who could provide wrap around support before, during and after the interviews. In advance of the interviews, it was planned to carry out a series of workshops. These had two aims: (1) provide mental health awareness training; and (2) introduce the Review which included the researchers involved, explain the review, and identify suitable young people for interviews (the Methodology section of the report includes a full outline of how this part of the review was carried out).

It was much more difficult than expected to get young people with a learning disability to speak about their mental health, and the services they had used. This is very surprising and disconcerting when set within a context where it is known that there is a much higher prevalence of poor mental health within the population of children and young people with a learning disability (40%) compared to their peers without a learning disability (10%) (Emerson and Hatton, 2008).

During the interviews, young people mentioned a range of barriers making it more difficult for them to access mental health support. These are set out in more detail below and include: a lack of mental health awareness or literacy in young people with respect to mental health, stigma and fear of talking about mental health problems, and a sense that mental health services are not relevant to them.

Mental Health Awareness and Literacy

One of the overriding issues raised during the recruitment for interviews was the lack of understanding of what mental health is, a lack of awareness of the young people's own mental health and emotional well-being, including how to recognise poor mental health in themselves or having a knowledge of what support is available.

The young people that took part in interviews highlighted the need for greater mental health education and mental health awareness within their peer group. One young person talked about this issue by stating it is important for adults to support young people to express their feelings:

"(…) a child to express their mental well-being and get understanding themselves, and actually express their feelings, so if they are getting bullied how they can let them know that..." (YP B)

The ability to express emotions is also an important baseline that young people need in order to engage in counselling and other forms of support:

"(…) talking to a shrink I don't think helped just 'cos at the time I was like I didn't understand it and I didn't understand what he was trying to do for me." (YP B)

A lack of mental health literacy was also one of the main issues raised during the staff focus group. Staff talked about some of young people they work with not having the self-awareness or words to verbalise or describe what they are feeling:

"(…) some of our young people, they don't even recognise that what they have is a mental health condition or that they're spiralling into poor mental health, because they don't have that self-awareness often." (Staff)

This need to educate young people around mental health and to normalise conversations about it was mentioned by staff and is very important in the context of early intervention:

"It's not just about managing when times are bad but also educating beforehand." (Staff)

Staff highlighted the important role of schools in providing the space and opportunity for young people to talk about mental well-being and mental health problems:

"I think school is definitely where it needs to start in terms of making it normal for those conversations and making it normal for young people just to be able to articulate and have the words, cos I think that's where your young people struggle is just to articulate what it is they're feeling" (Staff)

Stigma

There was a strong sense from young people we spoke to that they find it hard to talk about their feelings or mental health. Some young people talked about being worried they would not be understood or taken seriously:

"It's really hard for me to talk. I don't like talking about things like this." (YP C)

When asked the reason for delaying asking for help, this young person said:

"Cos I thought nobody would kind of listen to me if I said anything about it or that it wasn't that important." (YP D)

Young people also raised concerns about being discriminated against or stigmatised for having mental health problems or needing help. Many of the young people interviewed were in their late teens or early 20s, and referred to a lack of awareness of mental health and learning disability in the workplace:

"(…) employers especially should be getting trained in the basics of mental health – I don't think employers are trained to see the signs of mental – like I think they have some training but it's not enough in my opinion." (YP B)

Like other young people, there is a desire to not want to 'bother' or 'upset' parents by opening up about how they are feeling:

"(…) my mum hasn't been well herself (…) so it's harder for me to [talk about my mental health] 'cos I don't want to put too much stress on my mum you know." (YP B)

During the staff focus group, staff made a number of reflections on the barriers to parents/carers and young people looking for mental health support, and these are listed below:

- Parents / carers of children with a learning disability are sensitive to the fact that their child has been 'labelled' with a condition from a very early age, and they do not want to have to deal with anything else;
- A poor response from 'services' can lead parents / carers feeling that the best approach is to try and deal with their child's needs, by themselves, within the home; and
- Young people with a learning disability face double stigma about their learning disability and their mental health problem.

The engagement with young people with a learning disability, and staff who work with them, showed that the personal or internal barriers to seeking help by young people with a learning disability, are often similar to those faced by young people more generally i.e. difficulty describing feelings, fear and stigma of talking about mental health problems. However, what is different for young people with a learning disability is that they face these barriers in the context of broader systemic discrimination because of

their disability, alongside greater challenges in expressing feelings, and less confidence in talking about mental health or seeking help.

Diagnostic Overshadowing Leading to Unidentified Mental Health Problems

Unsurprisingly, 'diagnostic overshadowing', which describes the tendency to attribute signs and symptoms to the child's learning disability rather other causes, was raised as a major factor that can lead to mental health problems in children with a learning disability not being picked up by health professionals or parents and carers:

"I think it's the blur as well sometimes it's what is a learning disability need and what is a mental health need? And a lot of people would fob off a mental health need as 'naw it's just their learning disability." (Staff)

"(..) even the young people themselves you know they obviously have a learning disability and there's issues around their understanding of things in general. So the understanding that they might have a mental health issue is another barrier." (Staff)

Language Used by Services

A blurring or lack of distinction between a learning disability and mental health problems is also reflected in the language that is used to describe emotional and mental health problems in this group of children and young people. During the staff discussion there was a conversation about services for young people with a learning disability being called 'behaviour support' or 'challenging behaviour services', and that these labels imply the symptoms are the focus for the professionals and not the underlying problem. Of course, behaviour therapy can be a very effective treatment option. However, to some of the professionals taking part in the NICCY focus group, it appears there is a much greater emphasis on 'behaviour' within the context of mental health support for young people with a learning disability, compared to their peers without a learning disability:

"I'm talking about young people who are under eighteen, (...) where there's behaviours of concern, they're being seen by a behavioural nurse and maybe not a mental health professional. Now I'm not saying that those behavioural nurses don't have a good understanding of mental health issues but they are treating it very much 'as a behaviour'." (Staff)

"Yeah they're dealing with the behaviours and not the underlying kind of issues sometimes." (Staff)

CASE STUDY

This case study is a summary of one of the interviews carried out for this Review. It highlights some of the underlying causes of mental health problems in children and young people with a learning disability.

John* is 24 years old and has been diagnosed with a learning disability and autism. He currently lives with his parents.

John experienced bullying when he was in a mainstream primary school. In P7 John tried to take his own life twice and was referred to psychology services.

Things improved when he got diagnosed with special needs and he was placed in a special school. He felt safer there and the staff understood how to support him.

John did not realise he needed to look for help for his mental health until he was 19–20 years old:

"I think it's because as a kid you're not aware of mental health in a sense."

As a young adult, John found it much easier to access the support that he needed:

"It's nice to be able to get that support to work out how to do the self-help – my issue was – I knew what the issue was I just didn't know how to deal with it which he [counsellor] was able to give me the steps "

John felt very strongly that there should be much more support at primary school level for young people. The support should help young people to understand their disability and their mental health: *"I think also that there needs to be more support and help for people who have certain disabilities, how to deal with the disability, as well as tackle mental health…"*

(*Name has been changed to protect the identity of the young person)

Root Causes of Poor Mental Health

Young people talked about a range of issues they directly connected to having poor emotional or mental well-being. A number of young people talked about mental health problems being caused or exacerbated by barriers or discrimination they faced in day to day to life. Issues young people raised were: bullying because of their disability or disabilities, discrimination in the workplace, worry/anxiety and stress about a range of 'life issues' i.e. physical health, financial situation:

" (..) my sister knows I've been bullied – her sons got autism she doesn't want it to happen again (…) 'cos if it did ever happen I think I would lose control and they would actually send me off – it would actually really distress me because I don't want my nephew turning the way I did 'cos I have no social life – it cost me my life – my social life like even now I struggle – I'm slowly getting back into the social way but its harder for me." (YP B)

One young person talked about being bullied and discriminated in the workplace, by being treated differently to the other workers and not being given the same opportunities. They talked about the impact this had on their mental health:

"I was told I wasn't as good as the other workers"… "Aww it was bad after I left the job it took me like a year to – from a very strong person mentally cos of what I went through but it's still took me a very long time to push through that." (YP F)

Young people with a learning disability, face the same issues as their peers without a learning disability, when it comes to the pressures of growing up and moving into young adulthood, although these issues tend to appear slightly later than a typically developing young person. For example, staff mentioned the value of social media for young people with a learning disability, as it helps them to keep connected to friends, where independent travelling is more difficult. Staff also mentioned how young people's lack of understanding around safety and boundaries, when using social media, can be a problem and can contribute to anxiety and other mental health problems:

"(..) it sort of reduces isolation and you know people can get access to friends without jumping into a car or whatever it is but they have access 24 hours a day. And it is very hard for them to understand when they can say no or you know they want to be seen as to be part of the crowd and all that type of thing and they just don't understand relationships, they don't understand their own boundaries, and it's just causing huge, huge issues." (Staff)

Staff talked about the need for young people to be supported to deal with some of the root causes of their poor mental health. They also mentioned that although services should be in place to help young people explore

their feelings, this should be done alongside supporting young people to address the practical issues that are directly contributing to this i.e. relationships, employment, financial independence:

"(..) young people want to speak to a mental health professional that can give them hope. (…) some might feel its all well and good talking about feelings, but if its because ' I cant get a relationship' or 'I cant get a job' (..) this person can't actually help me do that, they're not going to help me get a relationship or get a job so where do I go (…)?" (Staff)

Meaningful Activities as a Way of Looking After and Managing Mental Health

The young people we spoke to recognised that meaningful activities such as training/ employment, socialising and exercising brings a lot of benefits to their mental health:

"Doing physical activities like swimming's a brilliant stress reliever I do it as well and its really just good stress reliever." (YP F)

"– that's why I want to get a job; cos getting a job actually helps my mental health because I can then get out and meet people and sort of forget my problems." (YP B)

However, for some young people mental health problems make it more difficult for them to feel well enough, or confident enough, to leave the house. They need support to build confidence and motivation to do that:

"It helps so it does, if you don't go for help, you're gonna end up like in the house, and doing nothing then 'cos you need help – everybody needs help." (YP E)

When asked in what way seeking support helped them, one participant said:

"My depression, my depression. I don't lie in on my bed anymore as much as I did. 'Cos I used to do it like every day." (YP E)

Professionals illustrated how difficult social interaction is for young people with a learning disability and mental health problems, and how they face a range of barriers, which when unaddressed, can lead into a spiral of social isolation that is difficult to rectify:

"(..) their life experience doesn't afford them many opportunities to get out of that spiral so if they're socially isolated being able to fix that is an issue because it's not easily fixed." (Staff)

Social isolation, discrimination in accessing social activities, employment opportunities, challenges in school life, including a lack of education around relationships and sexual health, are some of the pressures that young people with a learning disability face as they move into adulthood:

"I think too for that age group (..) it's a big time for them with relationships and stuff and maybe if there was a wee bit more education on relationships and how to deal with those it would reduce maybe some of the mental health issues that your finding because that's particularly what we're having at the minute isn't it? There's a real lack of understanding there. And they're going through big changes at that age bracket." (Staff)

Service Experiences – Availability and Accessibility of Services

The Role of the Family Unit

Not all young people with a learning disability live at home with their biological families. However, all of the young people we engaged with to inform the Review, were living at home with their family. It was very clear from the interviews that family were key in identifying poor mental health, and

supporting young people to seek help. Young people talked about being very nervous about going to a health professional to talk about their mental health problems, and that many need to bring a family member or other trusted adult to these appointments. Young people also talked about relying on family to remind them about appointments, and to provide support between appointments.

Staff highlighted the critical role parents and carers have in supporting their child to seek help for their mental health, and to support them to engage with services. However, where parents or carers have needs of their own, this can lead to greater difficulty in young people being supported to access the support they need:

"And then another thing we would find a lot is needs at home, parents with maybe learning difficulty a learning disability themselves or their own mental health needs and not always learned behaviour but there's a pattern in the household and there's not always reinforcement of treating your mental health in a positive way and you know young people are shadowing maybe the behaviours of parents or other siblings in the household and things like that which is re-enforcing the needs." (Staff)

Poor experiences with health professionals can put young people and their parents/carers off seeking help in the future. As the below example suggests, services that do not have mental health as part of the specialism, are not always responding to young people's mental health problems:

"I supported an individual to a doctor's appointment for a physical need but while she was there she said she wanted to start talking about mental health need and the doctor actually fobbed it off and said that wasn't booked for today. And kind of brushed it off so you know, somebody might want to book and think, 'I'll go and book and get me knee seen to but really this is what I want to talk about', GPs need to pick up on that (...)." (Staff)

Routine and familiarity are important for young people with a learning disability, and this is even more important when they also have a mental health problem. Staff believe that parents can be afraid and reluctant to involve young people in services, unless they know that they are going to be tailored to meet their child's learning disability needs:

"Yeah its very concerning isn't it really because all of the literature would tell you that mental health need within the learning disability population is higher than within the average group of children and young people and they're clearly just not getting [the support]. There's a range of different issues – one that there is a huge amount of unidentified mental health need, not enough literacy or understanding (...) and a huge fear within parents and carers as well because a lot of it is because of past experience." (Staff)

Choice and Decision Making

Staff reflected on the fact that parents/carers are anxious about talking about their child's mental health, which is highlighting another 'problem' for their child, that services may not be available to support them with:

"(...) from [the perspective of] parents of young people with a learning disability there's a need to be sensitive. (...) [they are] having lots of conversations about what is wrong with their child, that it just send hairs raising sometimes and (...) some people kind of pull back against that (...)." (Staff)

Young people with a learning disability are not used to being given choices or opportunities to be involved in decisions being

made about their own health but it is clear that young people are more likely to benefit and engage with services when they do.

"I think the young people need to feel it's about me not my parent or no it's me making the decision here and they're talking to me, they're not talking over me you know so that's important as well." (Staff)

Health Professional Competency: Understanding Disability and Mental Health

During the staff focus group, there were concerns raised that, in general, health professionals are not sufficiently trained in understanding young people's needs, when they have a learning disability and mental health problems. Often young people with a learning disability acquiesce, or have a strong desire to please people, and therefore it can take time and patience to explore issues and determine what their issues are:

"(…) you know that people with a learning disability tend to say the things that they think is what the person wants to hear. So they're always very agreeable and sort of digging in below that you know and asking the questions that's actually going to get to the heart of it rather than sort of sometimes you know are you okay? Yes I'm fine you know there's nothing wrong with me type thing." (Staff)

During the focus group, staff also highlighted that young people with a learning disability often have a range of health and social care needs, and statutory services are not available for some of the young people they work with, or waiting lists are so long that some parents are reverting to paying for private services. There was a discussion about allied health services, and the fact that small private businesses are being set up to provide speech and language therapy or sensory integration therapy, and families are paying for these services. The staff were aware of families that had got into debt, or had to sell belongings, in order to pay for these services:

"(..) even in terms of early years services, we have speech and language therapists setting themselves up in business providing speech and language therapy and parents buying it, (…) Occupational Therapist's setting themselves up and parents are forking out a lot of money, well those that can afford it, but someone that can't afford it, are selling their TVs to pay for a course (…)." (Staff)

A parent who responded to the online survey provided the following information:

"I had to pay privately to get help for my daughter otherwise her health and well-being would of deteriorated and the lengthy wait was just too long. I felt it was like playing Russian roulette with a child's life...it was taking a toll on my child and family." (Parent)

Criteria for Services

This Review found that children and young people with a learning disability do not have access to generic mental health services in the same way as their peers, who do not have a learning disability.

Staff made some specific comments about Step 2 and 3 services which have been highlighted below.

Early Intervention - Step 2 Support

Under the Stepped Care Model for CAMHS,[40] Step 2 services are early intervention services for young people experiencing mild to moderate developmental/behavioural difficulties and or mental health/emotional problems.

40 See Background section for information on the CAMHS Stepped Care Model.

Reference was made by staff, to the limited availability of Step 2 emotional and mental health services for young people with a learning disability, that are withdrawn and not presenting with problematic or challenging behaviour. This was felt to be particularly the case for young people who cannot access generic services, because their IQ is below the 68–70 cut off point:

"if a young person isn't acting out with a lower IQ but is just withdrawn they don't really get access to anything, there's nothing left for them. It's only if there is problematic behaviour." (Staff)

Staff reported there has been a reduction in funding for Step 2 services. Due to this, professionals fear this pushes emotional and mental health problems in children and young people with a learning disability further 'downstream'. So issues have to develop into 'problem behaviour' before they are responded to, by which time young people are much more distressed, and issues are harder to address. This practice is contrary to the government policy intention of targeting support as a prevention and early intervention measure.

"(…) I'd like to be proved wrong but I think just in terms of the in the last two years the retraction in the pulling away from some of those investments in Step 2 services I think means that what your getting in the statutory side is that they are prioritising services for people who are really at acute level of being really unwell." (Staff)

One young person specifically mentioned how they have found it difficult to get support because their symptoms didn't seem to be severe enough:

"It's trying to find the right help I can't seem to get it. And me granny has tried and the school and the tech's been helping but the only help is kind of about more severe stuff I think." (YP C)

On a related point, during the staff discussion, it was raised that it is more likely young people will receive support or services such as social services, behavioural or mental health support, if they are presenting with challenging behaviour, physical health issues or where broader family support has been identified. Staff were concerned this sometimes means that young people who have problems that are 'less visible' or challenging, and who are not engaging with services, go under the radar, even though they may require the support:

"Whereas non-engagement as we know is maybe a sign of issues you know not resolved or whatever." (Staff)

Community CAMHS - Step 3 Referrals

Under the Stepped Care Model for CAMHS,[41] Step 3 services are specialist intervention services, for children and young people experiencing moderate to severe mental health or emotional difficulties.

As discussed, in most HSCTs there are two referral pathways for young people with a learning disability, who have an emotional, behavioural or mental health problem. One referral pathway is to behavioural support teams based in learning disability services, and the other is to generic CAMHS, referred to in the Step Care Model as 'Elective CAMHS'. The decision on which service young people are referred to is based on their assessed IQ level, as outlined above. There is no regional policy on this and therefore each HSCT policy varies in terms of the cut off for generic services, but it tends to sit around 68–70. Young people with an IQ above 68–70 will be referred to a psychiatrist or psychologist who sits within learning disability services, and not

generic Step 3 CAMHS. This criteria setting is sometimes informally referred to as the '68–72 rule':

"If you're over 70 you're excluded and if you're under the IQ of 70 – in some Trusts its 68–72 we call it. If you're 68 you get service and if you're 72 IQ you don't." (Staff)

CASE STUDY
This case study is a summary of one of the interviews carried out for this Review. It demonstrates how access to services on the basis of IQ can lead to unnecessary long referral pathways for young people.

Philip* is 25 years old and has a mild learning disability.

He has been working in a factory since he was 15 years old; he started on work experience and then moved to getting a small cash in hand salary for working 16 hours per week. At the age of 21, and after 5 years of working with the same employer, Philip applied for a full time permanent job. He was told that he was not good enough for the job, even though he felt very strongly that he was as capable as the other workers. Relationships with the employer got very strained, Philip's hours were cut and he left his job as a result.

The discrimination Philip experienced, and the void that employment has left in his daily routine, resulted in him developing depression that has had a significant impact on his life:

"Yeah I was down for about a year after that and then never got any help during that whole period."

He was referred to a psychologist/psychiatrist in his local learning disability team, but he had to wait 6 months to get an assessment, and was told that he did not meet the criteria for the service because his IQ was too high:

"I went for an assessment and they said I was too smart to use their services!"

It was a year after first starting to look for help, by the time he received an appointment from generic mental health services, and at that point he felt he had almost recovered from his depression. The mental health service team advised him that a mental health charity with activities would be the best support for him and that he did not need to see statutory mental health services.

In hindsight, Philip thought that it might have been better if he had been referred to the learning disability team rather than the mental health team, because they would have taken his learning disability into account:

"(..) it would've been probably better using the learning disability than the normal ones."

During the year that he was waiting to meet with statutory services, he said that he had relied on the: 'support of family and just staggering through it by myself'.

(* Name has been changed to protect the identity of the young person)

Practicalities of Accessing Services

Both staff and young people talked about the practical difficulties for young people who are unable to get out and about independently. Young people will often be reliant on others to bring them to appointments or social events. Also the costs of using public transport and taxis can be a significant barrier to independent travel:

"Getting help is free but getting there and stuff, it's costing you something." (YP B)

"(For A…) to get into (Town) from his house was £20 return in a taxis so he just used to avoid everything, (…) the community transport bus could only come at a certain time. He had physical disability needs too; there was no option of walking to a bus-stop or anything so that's the kind of level of money that you're talking about." (Staff)

Staff highlighted that because young people with a learning disability find it challenging to deal with new situations, they can require greater preparation before doing new things. Young people with a learning disability engage much more positively when they are introduced to new places, people and experiences, at a slower pace and when ongoing support is available to maintain engagement:

"And they do have anxieties about doing new things you know so even introducing something new, sometimes takes a lot of lead in then as well." (Staff)

Staff talked about the difficulties young people have with picking up voicemails that are left by professionals, regarding appointments and test results. They also talked about how signposting young people to services needs to be more than providing young people with a list of contact numbers. Some young people with a learning disability will require intensive and ongoing support to access services. Currently the onus is placed on parents or carers to organise appointments, however as already discussed, they are often ill equipped, confused and not fully informed about what to do.

Staff had a positive view of health and well-being centres, in which a range of health services are available under the one roof. However, they also explained the difficulty for some of their clients in navigating through multi-purpose facilities like this. It can be very difficult if a young person does not have a trusted adult, either parent/carer or support workers that can help them, or if the structures are not in place to make it easy for young people with a learning disability to do this on their own:

"And if you've someone who needs help – if they don't have a social worker and they're waiting for a GP referral which can take a couple of weeks. You know, two weeks can be a long time whereas maybe if there was something there like a drop in or something, a helpline or something that they can call just for that wee bit of support." (Staff)

There was also a conversation with staff and young people, which reflected on the need for greater flexibility in relation to where services are delivered, and the need to bring services to the young people:

"It's proper brokering (that is needed) where even if you don't actually physically bring the person to you, you bring that service to the person which is often much easier and you broker those first few conversations and make sure that the persons comfortable before you walk away. And then you follow up. And you follow up again and you follow up again because its like when we do inclusion with mainstream services, its great as long as the funding's in place and we have capacity to do the follow up and everything else as once the funding goes and we no longer have the capacity it falls apart very quickly. So that real time brokering I think is good." (Staff)

"I suppose in tech, it would be easier if it was inside tech, so I don't have to like travel to a hospital or anything I just can go up to the wee like interview room in tech and just like have a chat in there." (YP A)

Family Support Hubs

Family support hubs are multi-agency networks of statutory, community and voluntary organisations that either provide early intervention services, or work with families who need early intervention services. Family Support Hubs were mentioned as an example of effective inter-agency working, where a multi-disciplinary team reviews individual cases together, to determine which services are best placed to work with that young person and their families. However, as outlined below, it was raised that young people with a learning disability don't seem to be coming through this network:

"One of the things that works fairly well (..) is our family hub. Early intervention, but, for me there's never any young people coming through say with learning disabilities or spectrum disorder (SD), maybe more so SD. But you've got CAMHS and Social worker and health visitors and agencies like ourselves in the one room (…) And it works really well. But a young person with a learning disability doesn't really come through a lot." (Staff)

Staff also talked about the pressure on voluntary and community sector organisations, responding to families who are unable to get support from statutory services, and that these organisations are doing this with reduced funding:

"(…) I kind of feel like part of that process has been decanted away from the gateway teams into family support hubs and family support hubs are doing a wee bit of the job of the Gateway teams. But - which is fair enough, but I think there's a pressure now on being able to respond to some of those referrals coming through because the community based services (…) just aren't there anymore to respond, or (are) not there at the same levels." (Staff)

What Does a Good Mental Health Service look Like?

At the end of the interviews, young people were asked to describe in their own words, what a good mental health service or support looked like. This exercise was an opportunity to summarise some of the things they mentioned during the interviews, and to distil down what they thought a young person friendly mental health service looks like. They were asked to talk about the physical place, the people in it and how the people made them feel.

Physical Space

Young people described going to speak to someone in a place that was familiar to them. For example, some of young people who were attending FE colleges said they would prefer for a health professional to come there. There were mixed views about a health professional coming to their home. Some liked this idea, others did not, and some also said they wouldn't have the confidence to ask for alternative arrangements to be made for them. Staff also said the physical space was important, stating that the environment should be very informal, relaxed, welcoming, really visual, using lots of easy read documents and pictures, and that services should be available 24 hours a day, 7 days a week.

Professional Approach

In terms of what good mental health looks like, the professional approach was the most important aspect of a service for the young people interviewed. They felt it is important that professionals are friendly and they feel they are being listened to:

"A lot feel that they're not listened to and that really frustrates them." (YP F)

Young people also talked about wanting to speak to a mental health professional who can give them hope that there is help out there, and that things can get better. They said it was important for a health professional to adapt how they speak, so that they can understand them:

"They should talk like in plain English as I call it, that kind of thing – don't really use like big words that I probably won't know the meaning of." (YP A)

Staff also talked about the importance of services being tailored to the needs of the young people, including going at a pace that is comfortable for the young person, and recognition that some young people, particularly those living in rural communities, have a considerable distance to travel in order to get to the place the appointment is held.

"(…) I think for some young people actually getting there (is a challenge) and you know just because they don't attend or they don't take up an appointment – then that's the back of the queue again, and I think that – a bit of flexibility is needed" (Staff)

Choice in How Support is Delivered

During the interviews young people had lots of ideas about the type of support that would help their mental health and emotional well-being. There was considerable interest in 'group support', for example, employability/ skill building or training courses which have a mental health element added to them. However, as already outlined, a significant barrier to engaging with social events or programmes, even if they are free events, is the expense of things such as transport and lunch.

"Yeah that's probably the biggest part of getting help, mental health is having the activities and meeting people who's the same as you. That you can actually go and talk to a stranger that is and knows what you're going through." (YP F)

Frequency of Support

A number of young people were having such infrequent meetings with a psychiatrist that they described finding it hard to open up and relax in the sessions. Young people did not seem to have any clear support from mental health professionals in-between yearly, or very infrequent, check-ups. When they were asked about this they tended to state that family were their main support between appointments. This raises obvious issues for young people without adequate family support. It also highlights the importance of good quality and accessible support for family members, who are managing most of the time on their own.

5.9 Conclusion

Placing a focus on young people with a learning disability, and their access to mental health services, has been a very important part of this Review. Statistics show there is a much higher prevalence of mental health problems in young people with a learning disability, compared to their peers without a learning disability. There is also evidence this group of young people and their families have much greater difficulty in accessing services.

The Review has found that access to specialist multi-disciplinary and therapeutic mental health services for this group of young people is wholly inadequate, and needs to improve as a matter of urgency.

Young people with a learning disability are an extremely diverse group in terms of their levels of functioning. The types of support which are likely to be most effective are therefore equally diverse. A person centred approach to promoting and responding to mental health is important.

In Northern Ireland, the use of an IQ based referral system to determine the services that young people with a learning disability and mental health problems can access, is too crude a measure to be the sole basis for making decisions regarding access to services (RCP, 2016; Lenehan, 2017). The segregation of mental health and learning disability services means there are a lack of professionals trained and experienced in working with children with a learning disability and a mental health problem (Lundy et al. 2012). All children and young people, regardless of their IQ level, should have access to the full range of specialist CAMHS (Bamford 2006; RCP 2016). The range of professionals that a young person may have come into contact with about their mental health, and the variation in the level of specialist support, is affecting learning disabled children's access to services. This inequality in access to specialist mental health services, should be immediately rectified.

SECTION 6

YOUNG PEOPLE WITH MENTAL HEALTH AND ALCOHOL AND/OR DRUG PROBLEMS: INTERVIEW FINDINGS

Section 6: Young People with Mental Health and Alcohol and/or Drug Problems: Interview Findings

6.1 Prevalence of Mental Health and Alcohol and Drug Problems

Increasing numbers of young people are reporting that they have never used alcohol or drugs (DoH, 2017:1). However, there are significant numbers of vulnerable young people for whom substance use is problematic. It has been reported that the age of onset of young people experimenting with drugs is dropping and that rates of homelessness linked to drug use is increasing when drug use begins at an early age and involves females.[42]

The most recent statistics available from the Young Person's Drug and Alcohol Treatment/ Aftercare services recorded 489 clients using services. The average age of clients was 16 years old (DHSSPS, 2015).[43] Overall, 31% of all clients were female while 68% were male. The majority of all clients seen were of a white ethnic background (97%). Of these clients, 10% were receiving treatment for alcohol misuse only, 29% were receiving treatment for drug misuse only and 32% for a combination of alcohol and drug misuse. Prior to starting treatment nearly three-fifths (58%) of all clients had a family history of alcohol/drug misuse, 63% were engaged with other agencies, 30% had mental health problems, 30% were involved with the criminal justice system and 13% did not have stable accommodation. Half of all clients received mentoring as their main intervention, and counselling was received by two-fifths of all clients (DHSSPS, 2015).

As of 1 March 2017 there were 5,969 people in treatment for misuse of alcohol and/ or drugs in Northern Ireland. Three times as many male clients under 18 (9%) were receiving treatment than female clients under 18 (3%) (DoH, 2017:2).

In 2015–16 there were a total of 221 children and young people from Northern Ireland admitted to hospital with an alcohol related diagnoses (CYPSP, 2017). Data on the number of young people aged under 16 years old who received treatment for excessive alcohol consumption in emergency care departments is not available (AQW 2307/16–21 answered 11/07/16).

Alcohol and drug related indicators continue to show some of the largest health inequalities monitored in Northern Ireland, with drug related and alcohol specific mortality in the most deprived areas around five times the rates seen in the least deprived (DoH, 2018). In the last 10 years official figures report 102 deaths of under 25s due to drug misuse in Northern Ireland and the rates have tripled from 5 in 2006 to 17 in 2016. During the same period there were a further 152 drug related deaths and rates had doubled during that period from 9 to 20 (NISRA, 2017). There is also growing concern about the misuse of prescription drugs in Northern Ireland, including misuse by under 18s (BBC Online, 2017).

The National Confidential Inquiry into Suicide and Homicide by People with Mental Illness (NCISH) is a UK wide body that monitors and analyses suicide and homicide and makes recommendations on how risks can be reduced. A report by the NCISH in 2011 found that of those with a history of mental illness who took their own life in Northern Ireland under the age of 25, 70% had a

42 Information provided to NICCY by DACT Co-ordinator.

43 Although generally these services are for young people aged under 18 years old, the oldest client in the 2013 /14 impact report was reported as 29 years old. This is problematic when wanting to focus on services provided to under 18s, however, the mean client age was 16 years old.

history of substance misuse. This report also found that the most common response from clinician's on the cause of suicide were use of alcohol and drugs (38%), the patient's mental illness (32%), and social factors (20%).The most common factors that clinicians stated may have made the suicide less likely was closer contact with the patient's family (11%), closer supervision of the patient (10%), and adherence with treatment (8%) (NCISH, 2017).

Studies have shown that there are some particular connections between drug and alcohol use and mental health problems in young people. These issues include:

- Misusing drugs can increase the risks of a young person experiencing psychosis, feeling depressed or suffering from anxiety;
- If a young person already has a mental health disorder, using drugs can lead to their symptoms getting worse;
- In families where there is a history of mental illness, using drugs can act as a 'trigger' for the young person developing mental ill health; and
- Children exposed to alcohol in the home are at risk of developing mental health and/or substance misuse problems.

Substance misuse among young people can often be a sign that they are 'self-medicating' as a way of coping with trauma and a way of blocking emotionally distressing thoughts. We know that children who have had a difficult start in life are far more likely to develop long-term mental health problems, and drug and alcohol misuse may often play a role in this. The greater the intensity of the drug and the more frequently it is used, the higher the likelihood that it will have an adverse impact on young people's mental health (Aynsley et al., 2017). In addition to the physiological and psychological impact, substance misuse can have far-reaching impacts on a young person's relationship with family and friends, their ability to learn and participate in school or college and the chances of them getting involved in risk taking or criminal activities.

There is growing awareness of the impact of negative childhood experiences like poverty, neglect, abuse, violence within the family or substance abuse on the well-being of individuals across their lifespan. The development of mental health and alcohol and drug problems can also be transgenerational. There are currently a range of initiatives and interventions which have a whole family focus, which can improve outcomes for children and young people. For instance the HSCB is incorporating the 'Think Family' Model into all practices, but in particular mental health services. The PHA has adopted this for its youth treatment services. There is also a focus on the need for children's services to take a trauma informed approach to the work they do.

Children and young people who use drugs and alcohol, and those with mental health problems, are overrepresented in the criminal justice system and within custody in particular. Successive inspection reports carried out by Criminal Justice Inspection Northern Ireland (CJINI) of the Juvenile Justice Centre (JJC) in Northern Ireland have highlighted the range of complex mental health problems and substance misuse issues being experienced by the young people resident there. Most recently CJINI found many of the children in the JJC were vulnerable due to complex alcohol, drugs and mental health problems. It also highlighted a reliance on the use of psychotropic medication in the treatment of children in the JJC and limited indication of it being evidence-based. NICE recommended individual therapies being provided. It noted that some of the children admitted to the JJC were already being prescribed high doses of anti-psychotic and anti-depressant medication, when living in the community (CJINI, 2018).

Similarly, children in the secure care facility in Northern Ireland also report high rates of drug and/or alcohol use and mental health

problems (CLC, 2016). A lack of expedient access to CAMHS in the community for children in secure care has been highlighted (CLC, 2016), as well as the continuous movement of young people between the care, justice and mental health systems in Northern Ireland (NICCY, 2017:1). The DoH directed the HSCB to undertake a review, to look holistically at the provision offered by these regional facilities and the relationship between them in an effort to more effectively address the complex needs of children in these facilities, this report is yet to be published.

"This [Review of Regional Facilities – unpublished] would be by far the most strategic development to affect the JJC since it opened in 2007. It broadly accords with the thinking in the DoJ's scoping study into Children in the Justice System regarding the development of a closely aligned Health and Justice facility to provide support to children with psychiatric, substance misuse and behavioural problems, encompassing step-up and step-down intensive units" (CJINI, 2018).

6.2 Access to Mental Health Services

Whilst all rights under the UNCRC will be relevant to children and young people with alcohol and substance misuse issues, the UNCRC specifically provides at Article 33 that:

"State Parties shall take all appropriate measures, including legislative, administrative, social and educational measures, to protect children from the illicit use of narcotic drugs and psychotropic substances as defined in the relevant international treaties, and to prevent the use of children in the illicit production and trafficking of such substances."

Article 24 of the UNCRC provides children and young people with a right to the highest attainable standard of health and to facilities for the treatment of illness and the rehabilitation of health. In examining the UK Government's compliance with its obligations under the UNCRC in 2008, the Committee on the Rights of the Child stated that:

''The Committee is concerned at the incidence of alcohol, drugs and other toxic substance use by adolescents in the State party, including its Overseas Territories.

"The Committee recommends that the State party continue to address the issue of substance use by adolescents across the State party, including by:

(a) Studying the root causes of these problems in order to provide targeted prevented measures;
(b) Strengthening mental health and counselling services, ensuring that they are accessible and sensitive to adolescents in all jurisdictions, including the Overseas Territories; and
(c) Providing children with accurate and objective information on toxic substances, as well as support to those attempting to abandon their use or dependency." (UN, 2008)

There are a range of alcohol and drug education, early intervention, and treatment and support services across all five Health and Social Care Trust areas, commissioned mainly by the Public Health Agency. A number of these services are targeted specifically at children, young people and their families. These include the Drug and Alcohol Intervention Service for Young People (DAISY), and the Dunlewey Addiction Service.

One Stop Shop Drop-In Centres provide Step 1 and 2 services and operate across Northern Ireland. They provide information, education, sign posting and referrals, particularly in relation to alcohol and drug misuse (PHA, 2009). An evaluation of the service in 2009 recommended that as substance misuse is often one of a range of underlying issues

that include self-harm, suicide and mental ill health, that such services should also be able to provide information advice and signposting to other services (PHA, 2009).

The Public Health Agency (PHA) has also funded a Drugs and Alcohol Co-ordination Team (DACT) Connections Service in each HSCT locality, that acts as the operational arm of the local DACT. Its role is to assist with taking forward priority actions and to work with other stakeholder organisations and partnerships in the area to develop and deliver drug and/or alcohol-related projects, events and initiatives.

Drugs and Alcohol Mental Health Services (DAMHS) is a specialist service for children and young people under 18 years who have a co-morbid presentation i.e. a significant substance misuse problem in conjunction with a mental health difficulty. There is a DAMHS service in each HSCT, and as a Step 3 service it offers talking therapies and medication, but does not offer out of hours support. Referral to DAMHS must be done through a GP or other health professional i.e. Health Visitor, Social Worker or Hospital. Self-referrals or family/carer referrals are not accepted. Youth treatment services like DAISY can also directly refer to DAMHS.

Many people receive mental health care and treatment in the community. However, sometimes admission to hospital for assessment and treatment is necessary. Young people entering Beechcroft are admitted either as a voluntary patient i.e. agree to their admission voluntarily or are formally detained under the Mental Health (NI) Order 1986 (MHO). The legislation sets out parameters regarding the length of time that a young person can be detained for assessment and the length of time a young person can be detained without review.

In Northern Ireland, the assessment, treatment and rights of persons with mental health issues are covered by the Mental Health (Northern Ireland) Order 1986 (MHO). Under this law a mental disorder is defined:

3.(1) In this Order "mental disorder" means mental illness, mental handicap and any other disorder or disability of mind; (2) No person shall be treated under this Order as suffering from mental disorder, or from any form of mental disorder, by reason only of personality disorder, promiscuity or other immoral conduct, sexual deviancy or dependence on alcohol or drugs. (NIHRC, 2015:1)

Failing to meet the criteria or to follow the correct procedures may mean that the detention is not legal. Under the MHO, mental health treatment under detention, requires the individual to be assessed as suffering from a recognised mental disorder; dependency on alcohol or drugs alone is not sufficient grounds for detention for assessment.

A Mental State Assessment (MSA) is always required for admission to a mental health hospital to ensure that admission is appropriate even if the MHO is not used. The criteria used for this is risk to self which is assessed from the MSA and previous history. Health professionals cannot complete a Mental State Assessment (MSA) whilst a young person is under the influence of substances because it may not be accurate and any subsequent risk assessment cannot be stood over professionally. As an MSA is required for young people to be admitted to Beechcroft this can preclude young people from receiving in-patient care.

Generally, as young people under the influence of substances are not medically fit for assessment, the current practice would be to ask relatives to take them to A&E as a place of safety and they can be assessed when medically fit. A subsequent decision on intervention that can be based upon the MSA may include in-patient treatment where co-occurring substance misuse is present.

There is no rehabilitation centre or safe place for young people with co-occurring mental health and drug and alcohol problems, and this creates a vicious cycle for the small group of young people in this situation. Statutory Drug and Alcohol Mental Health Teams (DAMHS) or specialist voluntary and community sector organisations (DAISY) are the main community based services available, however as they are Step 2-3 services, they cannot provide the specialist intensive support required by young people with the most complex and serious problems. Social Services are able to offer limited support in such circumstances. Often parents and carers feel like they are left on their own with limited support. There have been a number of high profile cases reported through the media, which have highlighted the problems with lack of services (BBC Online, August 2016).

Addiction and mental health services do not always work in an integrated way when it comes to young people with mental ill health and alcohol and/or drug problems. This is despite the fact that best practice guidance states that a greater focus on alcohol and drug misuse is required as a key component of risk management in mental health care, with specialist substance misuse and mental health services working closely together (NCISH, 2017).

A wide range of stakeholders, including families, Voluntary and Community Sector organisations, and elected representatives have raised questions about the adequacy of current provision in meeting the demand for drug and alcohol support services among children and young people.[44] One significant gap in provision is the lack of a secure alcohol and drug treatment unit for under 18 year olds in Northern Ireland.

The former Health Minister Michelle O'Neill MLA, acknowledged that more needed to be done to improve the response to young people in crisis, and that the priority for the future would be to strengthen existing provision in early intervention and intensive community based support, rather than on the creation of a specialist secure unit. Furthermore, the Minister in a press release from 24 September 2017 in the North Belfast News indicated that she was committed to exploring the issue of addiction and mental health services. She referred to the fact that she had been in discussions with the Northern Ireland Commissioner for Children and Young People about this issue, and children's mental health service provision more generally.

Government Policy

Preventing young people misusing alcohol and drugs, and intervening at an early stage, are key priorities in the cross-departmental Substance Misuse Strategy for Northern Ireland called the New Strategic Direction for Alcohol and Drugs. More recently, the Northern Ireland Government has been considering the Icelandic Prevention Model on tackling drug and alcohol misuse in young people to see how elements of it could be rolled out here (PHA, 2017). This model places a significant emphasis on early intervention, reducing known risk factors for substance use, while strengthening a broad range of parental, school and community protective factors (Sigfusdottir et. al., 2008).

44 There has been a number of high profile cases in the media, and it was also raised as an area of major concern during the stakeholder workshops held as part of the Mental Health Review.

6.3 Young People's Feedback

To inform this part of the Review, one to one interviews were conducted with 17 young people across 4 locations. There were 10 males and 7 females aged between 14–25 years old, the average age being 19 years old.

Profile of Young People Involved in Interviews
In line with the ethics process agreed for this Review, two key partner organisations were identified to engage young people and to be available to support the young people before, during and after the interviews took place. All of the young people spoken to as part of the Review were engaged through Start 360 or Dunlewey Addiction Services. It was important to reach out to young people from across Northern Ireland, therefore organisations were identified that had services across all of the five HSCT areas. Start 360 is a delivery partner for the DAISY service (The Drug and Alcohol Intervention Service for Young People). It runs services in the BHSCT, SEHSCT, WHSCT and the NHSCT. DAISY is a Public Health Agency funded service for young people aged 11 – 25 years old whose substance use is impacting on them, their families or communities. The support offered includes therapeutic mentoring, individual counselling, therapeutic group work and family based interventions. Dunlewey Addiction Services provides youth support and substance use counselling in the SHSCT area. All youth treatment services use a harm reduction approach in their work, and work in partnership with the young person to set goals that are realistic for them. They also have family focused approach and highlight strengths and potential.

Table 6.1 Profile of young people involved in Alcohol and Drug Problem interviews

Location	Response	Male	Female
Portadown	5	3	2
Ballymena	3	2	1
Belfast	4	3	1
L/Derry	5	2	3
Overall	**17**	**10**	**7**

6.4 Overview of Key Themes Coming from the Interviews

A pattern started to emerge very quickly from the interviews with this group of young people, of considerable time lags between mental health and substance use problems presenting themselves, and accessing support. Young people talked about mental health issues presenting themselves at around the age of 13–16 years old, they talked about it taking a long time before seeking help. This was followed by long delays in getting access to services once they had sought help.

Early Adverse Childhood Experiences

During each of the interviews, young people described having dealt with difficult issues and challenges during their early childhood. Young people described a range of physical, psychological and emotional trauma that they had experienced directly or indirectly from a very young age. The following quotes provide a summary of some of the trauma that young people had faced:

Child sexual exploitation and abuse
"I (14 years old) was goin' with him for two years, two and half years so I finished with him I was coming sixteen, or was sixteen I think and he tried to end up killing me at the end of it locked in a house to it was two in the morning to half seven the next morning and it was just putting belts around me neck tablets in me throat, battering me do other stuff to me. And then I was rushed to hospital then." (YP G)

Physical Abuse by Parent / Carer
"I started getting kickings, you know as well. It's hard to explain cos my mum and da's a good mum and daddy but (...) the way they were reared they were rearing us." (YP I)

Gun violence
"My da pulled a gun out and fired it at me, and it bullet jammed, he put it point blank range right through my eyes and fired it and the bullet jammed and he went out and beat it with a hammer to try and fix it and it done it again the bullet jammed know what I mean?" (YP P)

Substance use and mental health problems in the family
There is very strong research evidence of the intergenerational nature of substance use and mental health problems. In the following examples, young people talked about being brought up in a home where they were exposed to substance misuse or mental health problems:

"Yeah alcohol problems and drug problems run in my family so it is. (..) And me cousins, me other family members they were hard on drugs, so I just like followed them uns – And so she (mum) took a nervous breakdown and we all like two other kids, there was two wee sisters and we both got we all got took into care and from then I just took drugs." (YP M)

"When my sister took sick and was away down to Foster Green in Belfast and then my ma would be going down to stay with her at the weekends so I could get away wherever I wanted. So I thought I'd take a few pills and then couldn't stop then. (..) I've a lot of anger about my sister and all and I feel like a c**t for it but I had to let it out sometimes." (YP K)

Bereavement
A number of young people talked about adults lack of understanding about the impact of bereavement on children and young people. However, as this young person highlights, the death of an uncle marked a significant point in their life:

"Aye I lost my uncle when I was ten and never really coped with it, that's what they think it all stemmed from." (YP P)

Adverse Childhood Experiences not Addressed

For many of the young people interviewed, the impact of these extremely difficult childhood experiences had not been identified or responded to at the time they occurred, and to this day young people have still not been provided with specific and specialist support to deal with their experiences. It was also very clear from the interviews, that the young people participating in the interviews had been physically, psychologically and emotionally damaged by early adverse childhood experiences, and that their use of alcohol and/or drugs was in most cases a way of coping and a form of self- medication. The impact of the adverse experiences that the young people had been subjected to were wide ranging and life changing. One of the most obvious negative impacts was on the young people's school attendance and ability to learn:

"I wasn't afraid of dying I was P6 and suicidal. You know, I found one of mummy's tablets one night going to school, I took it, I was wild drowsy the teacher sent me home thinking I was sick but I was trying to kill myself in Primary School." (YP I)

Awareness Raising on Causes and Impact of Alcohol and Drug Use

Many of the young people interviewed as part of this Review are extremely vulnerable young people who have experienced multiple adverse childhood experiences, developed mental health problems and are using alcohol and/or drugs as a way of masking the symptoms of their mental ill health, in the absence alternative positive coping mechanisms. The young people interviewed talked about falling into a trap of using alcohol and drugs as their main coping mechanism:

"But like mostly my mum would of blamed it on the drugs but I didn't see it that way because I only took drugs to try and block it out." (YP U)

Lack of Knowledge about Mental Health and Services

All the young people who took part in the interviews had a very good understanding of the mental health system. Many of them had experience of using different parts of the system and for some young people, over many years of their life. Young people talked about there being a lack of information provided to them about mental health, and the services and support available. A number of young people talked about having to figure it out for themselves once they were 'in the system', having experienced a range of services and been involved for a significant amount of time.

Young people were very keen that schools did more to educate young people about the dangers of alcohol and drug use, and the impact that it can have on a young person's mental health. They felt that time spent on this, was as important as the academic learning:

"I'd say that they need to have classes in school about this here stuff so there should. There should be warnings - they're learning stuff in school that stupid stuff that's not even important till them when they get out of school stuff like this like mental health this should be in school there should be classes about this here and there should be stuff like highlighting what happens, you know, highlighting about your mental health what drugs do to your mental health and how where to go for help". (YP O)

Young people talked about the lack of focus on mental health in their school, and the information on it being limited to one module in their personal development classes. They also highlighted how they would like to have seen a greater focus on promoting good mental health, and supporting those with mental health issues as part of the daily operation of the school. Young people also emphasised the importance of this sort of education from an early age:

"The only time my school talked about mental health was in like LLW personal development classes and that was about it. And then there was no real concern for student's mental health outside of that so that was a bit rubbish!" (YP S)

"I think that it would be taught about from a younger age in school because you're only actually taught about it whenever its already too late for some people like we didn't really learn about it at all till your like sixteen." (YP N)

Young people talked about the importance of making it as easy as possible to access support for mental ill health and drug and alcohol use. Young people talked about the value of having mental health and drug use support available in schools and Further Education Institutions. They placed emphasis on the familiarity of the surroundings and staff that they feel safe around and trust:

"So two benefits for one – I would've been getting the mental health – the mental health help and the drug abuse, help that I deserved. And I would've also been going to work like I feel like the likes of the Tech or Rutledge they shouldn't just have counsellors, they should have the appropriate people who are put in place to deal with that kind of problem." (YP G)

"I think people should be doing talks in schools because there's a lot of that's where mostly mental health starts from schools and a lot of people don't speak up and all and then no counselling and stuff people might be too embarrassed to get taken out of class to go to a wee counselling session so I had to like people should do wee talks where they go around each classroom and then at the end go look of anybody wants to come up or something came up at their own time, and you know like ?" (YP G)

The young people interviewed highlighted the importance of awareness raising messages around the use of drugs and alcohol. However, as the following quote from a young person explains, if done badly it can reinforce or encourage risk taking behaviour. The experience relates to an education video that the young person was shown in P6 about solvent abuse:

"But all's I took from it was one of the wee boys being asked 'why do you take if you know you die instantly?', And he says well 'I was having a lot of problems at home and if I took solvents they all went away', and I was like oh my God, forget about this boy died and how many people died taking it, I was like I cannot wait to get home to try out this…. and I became addicted." (YP I)

Clear Information about Services

It is also important that children and young people are given clear information about the support available, how they can access it, and what it will involve, as the following quote from one young person illustrates:

"(..) that's what I thought was good about it and that's why I actually agreed to do counselling 'cos before that I would've never said to do it because I didn't really know what way it worked or anything like that there but then see whenever you hear that like they're just going to listen to you and not like judge you or anything, it's more like appealing if you know what I mean?"

One young person described their experience of going to a school counsellor at the age of 13 years old and being very unclear about the process. They went on to explain how this lack of clarity prevented them from fully engaging with the therapy:

"I thought he was just being nosey and then I didn't take no heed of him." (YP R)

Barriers to Seeking Help

During the interviews, young people talked about the barriers which had made it difficult for them to ask for help. There were a wide range of barriers mentioned during the interviews, including: denial and not being

ready to change or accept support, challenges with attending appointments due to financial problems and symptoms of mental ill health i.e. depression, anxiety and low motivation, avoiding services because they were unsure about the boundaries of confidentiality and not wanting parents/carers to know about it.

Denial / Readiness to Change

Many of the young people mentioned that family, friends and youth workers had raised concerns with them about their mental health or their use of alcohol and/or drugs, and tried to encourage them to seek help. Young people talked about the difficulties they faced in becoming ready to accept help:

"I think it's just a personal thing, if the person wants to change they'll change. No amount of people telling them how bad drugs are is going to matter. Somebody wants to do something they are gonna do it and no-one's gonna change anybody unless they are gonna change themselves. It's just how it is." (YP W)

Young people talked about the affect alcohol and drugs had on their readiness to seek help and engage with it. This included anxiety, depression, low motivation and finding it hard to trust people in order to accept help:

" I was always in a bad mood, always, just no motivation to do anything just lazy everything like that there. Would never speak to anyone or anything like that only people I would speak to would be my friends." (YP V)

"(..) it's a bit difficult to find the trust in someone whenever you're in those kind of predicaments, like for example, I said that that my substance abuse, grass led to me having anxiety and depression. The fact that I had anxiety and depression made it so much harder for me to open up about the problem that's why it took at least a good two and a half years down the line I was sixteen years from fourteen still smoking it at a very young age and I didn't know who to go to." (YP J)

There was clear recognition from the young people interviewed, that it was important to hear the concerns and worries about their behaviour from people they loved and respected, even when they weren't ready to accept help. A very striking message from young people was that they were glad that people didn't stop offering help and support, because eventually they realised they wanted things to change and needed support:

"Well I didn't really start realising that I needed help until it was way down the line. There was a wild lot of struggles that I had to go through first a wild lot of different people saying to me that you know you do need assistance you do but I wasn't listening at all." (YP J)

Practicalities of Accessing Support

Young people talked about the practicalities of accessing support, as being a significant barrier to seeking out support and sticking with it. The practical challenges young people mentioned included: not knowing where to look for help, not having money to pay for the transport or fee to attend a course, difficulty with working within a 9-5 service model, not wanting to worry family, being unsure about the boundaries of confidentiality and having their confidentiality broken by services:

Not knowing where to go

Many of the young people reported that they were unclear about the services available in their local communities when they were ready to accept help:

"I really hadn't a clue where to go I knew there was places like the Samaritans, but or say ChildLine but they weren't

the places that I was looking for that's somewhere you can go you can talk about your problems, like a counsellors, sort of place but whenever it came to drug abuse I hadn't a clue." (YP J)

Finances

One young person talked about how not having taxi money to get to a group counselling session knocked her momentum in attending these sessions:

"(..) the only reason why I stopped going was it was a bad week and stopped getting money and I couldn't get over and then on that week too there was a whole pile of stuff about the house and me loosing me head and stuff so I just haven't got back to it yet but –" (YP G)

Difficulty in Working Within a Week Day 9-5 Service Model

Many young people also talked about the challenges they faced in being able to engage with a 9–5 week day service model. Many services, particularly statutory services, work to a 9am – 5pm system that are appointment based and require young people to attend the building were the professional/practitioner is based. Young people talked about the fact that their mental health problems alongside the symptoms of the drug and alcohol intake makes it hard for them to be in busy public spaces. They also mentioned that young people with mental health problems who are using alcohol and/or drugs as a form of self- medication, often need to be on alcohol and drugs to attend meetings or appointments which then becomes a vicious cycle:

"(..) actually need to be on the stuff to be have the confidence to socialise to go to those places." (YP J)

Not wanting to worry family

One of the most common barriers to seeking help was not wanting to worry their parents, carers or family. For many of the young people there were a range of problems or issues happening in the family home already, and they didn't want to add to the stress:

"I would say I didn't actually talk to anyone about it is because I hate burdening other people with my own problems." (YP Q)

"I couldn't talk to my Ma with all that going on, I couldn't give her more stress." (YP K)

Unsure of boundaries of confidentiality with services

Young people talked about their reluctance to seek out counselling in school because they were unsure about the boundaries of confidentiality. One common concern was being afraid that their parents would have to be informed:

"I feel like if you're the person getting help then that should be consent from that person cos like my Dad doesn't exactly know about everything that's wrong with me. He knows I go to counselling and I have issues but we don't tell him about what they are and it works better that way cos some people can't deal with it, like maybe there is a problem at home, that it's best if the parents don't know." (YP L)

As the following quote illustrates confidentiality is something that can be a concern for young people from a very young age:

"Well I remember like whenever I was in primary school I remember like wanting to get counselling, but then they made you get your parent's permission to get counselling. (…) And then so I didn't want my parents knowing that I wanted counselling so then I didn't do it." (YP N)

Confidence broken by Counsellor
A young person talked in very strong terms about their experience of having information passed on from a counsellor to their foster parents. From the young person's perspective, this was unnecessary and didn't meet the threshold for breaking confidentiality. There were far reaching consequences for the young person of this breach in confidentiality, which included destabilising their care placement. It also led to the young person disengaging with counselling services and losing trust in the Health and Social Care system overall:

"(..) my foster parents sat me down in my own room and was asking me question after question. (..) I had a meeting the next week with her [the counsellor] and I said to her this is the last time you will see me and I will not be talking about anything today I just want to sit here in silence for this whole hour." (YP R)

Significant Adults as Key Enablers to Seeking Help

Family support is key to supporting young people to get help. Young people who do not have a reliable and consistent adult support are particularly vulnerable, and it is likely to take much longer before they get the help they need.

The following young person talked about how supportive they found having their mother attend appointments with them:

"Yeah a lot of the time she would sit in the room with me while I was having the interviews like I would keep her in the loop and then she could answer questions as well especially when I was getting autism assessments and everything done because then she would be able to weigh in on my early life and everything, but there was never any support for her or the family." (YP L)

The following young person is now 21 years old and grew up in a children's home. She started taking drugs at age 14 years old. She described how difficult it had been growing up without a parental role model:

"I didn't have a parent to tell me what to do or anything - you see when I lived in the children's home, I got expelled for not going into school. Workers they can't make you do anything they just say go into school, you know what I mean? That's not a stabilised childhood like. (..) And I started taking alcohol and drugs when I was fourteen like I had no help at all." (YP H)

Another young person talked about the strong relationship they have with a youth worker and how much they value having someone who cares about their welfare:

"She's always been the one who's asked me if I'm okay. If I'm doing alright." (YP J)

Another young person talked about the key driver for them seeking help, was seeing the impact their behaviour was having on their family:

"Probably lyin in that jail cell crying thinking about me Ma and me Granny and me Granda and just thinking what if they f*n die and I'm in here?"*** (YP R)

Service Experience

Problems with Accessing Services
During the interviews it was very common for young people to describe being passed around different services without getting any clear support. Young people talked about having to repeat their story over and over again before getting support. They described feeling physically and emotionally exhausted by having to repeatedly describe how they were feeling to different people:

"Yeah so then I felt like every time I moved to someone from the first counsellor to the second counsellor, the vice principals and the year head and then to GP and then to the new CAMHS person I was just giving my story all the f**g time 'cos I was ready to hurt someone! (...) I mean it was awful."*** (YP S)

"They need to help them instead of throwing them about the place. They're not a yo-yo like. You know what I mean? There's no point – if you're going to send them to a hospital there's no point throwing them out two days later with no help and no nothing. Like what's the point of even sending them in there like!" (YP H)

"You feel like a freak of nature because they don't know what to do. And you're going f**k am I as mad as you're saying? So you try and end it." (YP P)

Young people consistently and repeatedly talked about the long delays in getting appointments for counselling and statutory mental health support. Some young people talked about having tried to access help for years:

"See when you go to the Mater full of drugs they don't see past the drugs, they see you're a drug addict they don't see why." (YP P)

"Telling the drug addict say you can come back when you're clean that's a joke. Because they can't. (..) It's either they are going to keep doing it or else they're going to end up dead." (YP U)

Signposting to support

Young people talked about the challenges of being signposted from one service to another without sufficient support to make contact with them. This includes the initial signposting from a GP to Step 3 CAMHS, and also signposting by Step 3 CAMHS once the treatment with them had ended. A common theme coming through the Review was of referrals not being processed, so some young people were waiting for a referral to a service that never arrived. Without a clear handover from the GP to the Community CAMHS this can mean that young people fall through the gaps in services, unless they follow-up with their GP about their referral.

Young people described how they were more likely to miss appointments because they needed support to attend. They talked about how there is very limited flexibility when a young person 'Does Not Attend' (DNA's) for a statutory CAMHS appointment. Young people talked about being discharged from Step 3 CAMHS, after missing a number of appointments, leading to the young person having to be referred back to their GP if they wanted to be seen by that service again.

The Role of the GP in the Mental Health Service Pathway

Some of the young people interviewed described feeling forced, and 'resenting' the fact that they had to go to their GP in order to get a referral to CAMHS. Others talked about feeling particularly uncomfortable speaking to their GP. This was especially the case if they had previous bad experiences with them:

"I was seventeen and I was nearly finished with my first year of A Levels and I was in a really bad place I was like self-harming and feeling really suicidal and all that so I sort of knew that I had to go to CAHMS cos that was what they sort of specified but then to do that I had to go to my GP and I hate my GP. I would have felt better not going to the GP at all but I needed that referral so I sort of resented that a lot (..)" (YP S)

One young person talked very passionately during the interviews about the delays in getting access to mental health support because they

are still taking drugs. He talked about his personal experience of going to the GP for help, and being told that he needed to be off alcohol and drugs before he could access mental health support:

"(..) the first thing I told my mum, my mum would've took me down to the doctors every couple of weeks he needs help; and his mental health, suicidal, drugs he's taking, it's scary, all this here, and every time the doctor would just say 'he's to be off everything for a certain amount of time before the mental health people will talk till him' – it shouldn't work like that there, people are taking drugs, because their heads are that messed up they're just trying to take drugs to block out what's wrong with them, (..) I was cutting myself and everything and still I'm getting no help sort of at the time with what was going on in my head so and just – they just delayed me." (YP O)

Some of the young people expressed their disappointment about the lack of alternatives to medication available to them when they asked for help:

"(..) they want to give you all these tranquilisers and sedatives and anti-depressants and all anti-psychotics and all but they do you more harm than good. The side effects are worse than their outcomes (..)" (YP P)

"I just kind of felt that they wanted to get you out as quick as they can and they just prescribe you something and that's it." (YP T)

Harm Reduction approach

Some of the young people suggested a harm reduction approach, where young people can access services whilst still taking alcohol and drugs, as a more practical and useful response to young people in a similar position to themselves. They also stated very clearly the need for mental health support whilst coming off alcohol and drugs:

"(..) I hate talking about it whenever you go to your GP. As soon as you bring up a mental health problem, they are going to ask you do you use any drugs? Do you use alcohol and drugs? The second you say yes, it all comes down to that. That literally is what the doctor says well I cannot give you anything I cannot help you with anything until you stop smoking. What good is that?" (YP J)

Some young people talked about disengaging from services because of the length of time they had to wait to get help:

"I've been trying since I was in school, I've been trying and trying and going to the doctors and trying to get help (..) even while I was in Hydebank, while I was homeless all sorts of different times but –" (YP O)

"I went for three years, at one point! Sitting on a waiting list for three years." (YP P)

Thresholds

A common theme coming through the Review is of young people having to become more unwell before being able to access statutory services, and feeling that they had to prove how unwell they were before getting access to services:

"I went to the doctor and she weighed me and my BMI wasn't low enough to get treatment for an eating disorder. I remember when she said that I just started crying, (..) she basically told me like you need to get more anorexic to get help and so that was horrible, that's like the biggest like problem I've had with like the mental health thing was eating disorder treatment just unless you're like literally dying like they won't give you help for eating disorders." (YP N)

Diagnosis
Some young people described a great sense of relief and validation in being given a diagnosis, and the recognition that what they are feeling is a medical issue. Some young people said that they felt they are not taken seriously or left in limbo without a clear mental health diagnosis:

"Eh it was good for me I liked having a sort of thing to sort of stand back on. You know it sort of gave me a sense of this is what I have or at least what I could have and therefor it's made me feel better about myself cos it's a recognised thing." (YP I)

"(..) its only now that I know a bit more about what's available and you have to ask for things like 'cos I – and especially cos they put off diagnosing you properly. Like cos I've known for like years I've had borderline personality disorder, I remember saying cos I like I just wanted to know what's wrong so I can get the right treatment you know what I mean?" (YP N)

Support for Suicidal Young People
Young people described being discharged from hospital after taking an overdose without any support in the immediate period following the overdose. The following young person talked about attempting suicide again immediately after being discharged from the hospital and ending back in hospital:

"I took an overdose and then got out of hospital and because they wouldn't do anything for me the hospital wouldn't do anything for me, what was in my head they wouldn't, I done that again that night and got rushed back into hospital... So when I got discharged from hospital I went and done it again, because like I was like why are they not helping me?" (YP M)

A number of the young people interviewed talked about feeling that they needed to be admitted as an inpatient but the professional decision being made that admission was not required.

"At one stage I thought I needed to be in Beechcroft and I couldn't get in! I says till the doctor if I don't be brought to somewhere like this I'm going to die! I will take my own life I got till the point where I've blackmailed the doctor and says till him doctor see if I die there is blood on your hands here." (YP P)

"And all's they do is feed you, with medication. They're not really helping you. (..) They're just – they're more or less just taking you out of the community, putting you into a locked environment, for three or four days, fill you with medication and then, on away you go again. (..) That's what they more or less do!" (YP H)

Young people also talked about how difficult it can be to be an inpatient and being placed with young people who are much more unwell than they are:

"Apparently its horrible. Looking back maybe I should've went but I think it would've like scared me cos everyone I know that's went has said that its traumatised them seeing other people and then you don't feel like your crazy enough to be in there you know?" (YP M)

"Whenever you walk into the building you have three different separations that go into different wards. Now the one I was going into I was – I was relatively I don't want to use the wrong words here – ahh it was relatively calm relatively happy with the way it looked the way the TV you know – radio, coffee that sort of thing but it was looking into the other wards while I was waiting for the doctors to come up it made you feel like you know your gonna end up the same way the other people are." (YP J)

While talking about the challenges of accessing help, one young person spoke about assaulting a police officer in order to be placed in custody. For this young person, this was the only secure place of safety that they could access:

"(..) I got till the point where I went down till [X] and hit a cop with a bottle just for safety to save meself from meself and I had a cell for f*n two nights and keep meself clean I said to my solicitor (..) if I don't go to jail get me into Beechcroft or Knockbracken, or whatever the f**k you want to call it, put me somewhere like (..)"*** (YP P)

Another young person talked about having personal experience of young people like them, who were struggling with both substance misuse and mental health problems, and a lack of specialist inpatient support that they needed. The following young person talked about the need for a specialist service to support young people to come off drugs and alcohol:

"There's no services, no detox centres, no place for people with drug problems, they're looked at like they're scumbags, why? I don't understand that when there's so many alcoholics in this town. But that's alright, it's actually acceptable but if someone takes drugs they're scumbags." (YP K)

"I've seen people dyin' (..) trying to get help with their mental health and they didn't get the help and then they end up killing themselves (..) – they could've got offered the help there and then but because they were on drugs, they didn't get the help and now they've lost their lives cos of something they could've talked about. That could've just been sorted out there and then." (YP O)

Qualities of a Good Service

Young people talked about the elements of a mental health service that were important to them and made it easier for them to engage and feel supported. The feedback from young people demonstrates that a non-clinical, youth based service model is the preferred option. Many young people interviewed with alcohol or drug problems described being in a heightened state of panic and anxiety when attending appointments. The young people talked about how the physical environment and the professional approach of the staff working in the services had a big impact on how easily they could relax.

Physical Space

Young people consistently emphasised the importance of the physical environment, and how they find it much easier to relax when the appointments are held in an environment that is non-clinical and informal:

"I remember one time I had to go up to the top room and there was like laptops and computers and they were two people there that – this is when they were trying to sort of know which prescriptions I needed or whatever and then it kind of felt like an interrogation." (YP S)

This same young person went on to say that there is a need for:

"More open space, it was quite a cramped room like I felt like I was so aware of the exit – it was behind me and it was just like 'I think I'll just walk out here'." (YP S)

Relationships and a Connection

All of the young people interviewed as part of the Review have said how important it is to have somebody that they feel understands them, that they can trust, that doesn't judge them, that they can open up to and that they can rely on. Young people have reported clearly that they need someone or a small

group of people who they can ask for help when they need it; who they feel won't judge them.

The following quotes provide examples of where young people were able to connect with the professionals working with them:

"(..) he would talk to me like I was a person like I was, (..) an equal. (..) he'd tell me about like experiences he's had or what he's done in his past or how he copes (..) he told me (..) one of my problems would be alcohol and I like to have a alcohol but I try to stop that so I engage in activities (..), it felt really like he wasn't above me or anything (..) like he was a peer." (YP L)

"It's like meeting a friend. See I like it like that. There was a wee lad worked in here [X] and me and [X] got on really well. [X] was my background I hated see the mental health sectors that go into work in the likes of West Belfast and all of Belfast? East Belfast they're not from working class communities they're heads that come from outside of Belfast or outside Derry that don't have knowledge of what happens in working class communities." (YP P)

During the Review, young people gave a number of examples of where they had been unable to connect with the professionals working with them. The reasons given included young people feeling that there was a lack of empathy, staff having a judgmental attitude or taking a paternalistic approach to their situation:

"The doctors felt like they judged you but in here (youth addiction organisation) and all it was not really a big deal they sort of just said how it was but the doctors went crazy about it in the hospital they were like saying I was going to die of a heart attack and all. They were more age realistic (..)." (YP T)

"Yeah but I was addicted and then that (..) doctor (..) says to me well I don't see how this is an issue because physically can't be addicted to it but I was emotionally (..)" (YP I)

Flexibility and Stability

One finding from this Review is that young people with an alcohol and/or drug problem, because of their chaotic lifestyles and requiring a range of emotional and practical support, can only fully engage with services if they work with them flexibly. As already highlighted, the 9am - 5pm Service Model presents a significant barrier to engagement for this group. It can also be difficult for young people to go to a physical place to make an appointment. Home visits is one example of a flexible way of working young people have identified as really valuable:

"I didn't know that any service did it, it was only whenever I was getting sort of bad at coming to [X] that [X] said like you know we could do home visits and I was like what?! I didn't know that that even existed." (YP N)

There is a wealth of evidence which shows that young people also do much better when there is stability and continuity in the professionals who work with them. It can often take young people a long time to build up trust due to previous poor experiences, which damaged their trust:

"I always had [X] since I was younger as well so I've known her for years (..). I've built up a relationship with her." (YP H)

""(..) me and her got a really strong bond and I was clinging onto her (..) then this person comes in not judging me, really nice, being there for me, all as much as she can do. She'd take me driving around the road, with a MP3 player and just drive and let me listen to music and just chill (..) which is good." (YP I)

Impact of Bad Experience on Engagement with Services

Many of the young people interviewed had very difficult childhoods and faced multiple adversities, and as a result came to services with huge defensiveness and scepticism. Due to their experiences, felt let down by family, friends, professionals and the systems that they work in. In particular, bad experiences with health professionals can lead to problems with establishing trust with health professionals in the future:

"Yeah I really don't like my GP he's very just dismissive of me (..) so I just didn't like him and (..) I started to associate that experience with the whole environment." (YP S)

"(..) if someone goes to me, that their little brother's having problems and (..) thinking of going to CAMHS, I'm like no! Definitely don't. 'Cos your whole family will be put through shit! And everything you say will go back to your mum." (YP R)

"So I know there's no help for people with mental health problems, I seen it first hand wi me sister. My sister had to have a psychosis to be sectioned (..) which aint right. She hurt herself and hurt me ma to be sectioned (..)" (YP K)

The following young person had experience of attending statutory out-patient mental health services and a Community and Voluntary sector service, and described the difference between the two in terms of the flexibility of the services:

"I was getting beatings so there was a lot of times I couldn't go to me appointment (out-patient mental health services). And one day I couldn't turn up and I was actually on me way to it and he ran after me and the cops were there and all and it was just a whole pile of and the next day I rang her and said to her look I'm wild sorry I couldn't turn up to me appointment but can I come in tomorrow? And she discharged me for it – she was all you're kicked out now cos you didn't turn up, but then I tried to explain to her like there's stuff goin on (…), [X] (Community and Voluntary sector service) does hers a lot different. If you cant turn up to your appointment then you just cant turn up, she'll make you another one, where at that place down there (Statutory Services) if you miss an appointment that's you you're kicked out." (YP G)

Choice and Effectiveness of Treatment / Support

Medication

Medication was a very common form of treatment offered to young people with an alcohol and/or drug problems and a mental health problem. Many of the young people interviewed had been reluctant to take medication because of the problems they had with alcohol and drugs, including misuse of prescription drugs. Young people reported that they were not always given information on other possible choices of treatment:

"And then I went I can't remember I think it was just the mental health team and I said till them look I'm sleeping all day and I'm staying up all night. And I want to get out of that. So all they done was give me two types of tablets, one was anti-depressants and two were sleepers and I says I'm not taking tablets. I said simple as that I'm not taking tablets 'cos I don't want to get addicted till them. And he says well come back in about a month and let me know. I says are you having a laugh like! I says like you're just like everybody else you're just like everybody f*n all the other doctors like you just (..) want to give me tablets (..). Like they wouldn't even sit you down and say right well here's such and such, here's play therapy (..)"*** (YP M)

"(..) I didn't want to go on medication but then I was put on Sertraline 100 mg whenever I was like I extreme like anorexic, (..)there was a few reasons that I (..) had the eating disorder but like they just kind of put me on medication and then you know I was gaining weight but I still had the (..) the issue with I hate my body and stuff. (..). It was like two weeks after I started Sertraline or something (..) whenever I took my first overdose and tried to kill myself." (YP N)

Adequacy of Support and Supervision

Some young people admitted they had lied to their GP and told them that they were no longer taking drugs in order to get a prescription for medication. Young people identified the fact that they were very vulnerable to misusing prescription medication and very reluctant to take it. The information shared by young people raises serious concerns about the adequacy of the support and/supervision provided to young people who are prescribed medication and who also have a history of alcohol and/or drug problems.

"And then he got out of jail (..), my dad showed me how to talk till the doctor to get tablets. I was able to go down tell the doctor I'm going to do this I'm going to do that, And then practically just gave me diazepam gave me D20s gave me Tramadol gave me Lyrica. Just gave me everything that I could take (..)" (YP P)

One young person highlighted significant concerns about the reliance by health professionals on medication for treating young people:

"If I'm in desperate need and I'm a young person, and if I'm saying I'm suicidal and all, instead of getting handed depressants cos that's happened before – I said I'm suicidal, they handed me anti-depressants – I went home and hung myself twice. The wires just broke(..)" (YP I)

Lack of Practical Support from Clinical Sessions

Young people talked about the fact that the traditional face to face counselling sessions can be very difficult, and that they don't always find it helpful to talk directly about their problems in this way.

Many young people talked about feeling frustrated with their counselling sessions. This was due to feelings that there was too much talking about feelings, and not enough time spent on practical support, such as coping strategies or techniques they could use to get themselves off alcohol and/or drugs gradually:

"So it's just you sitting down and spilling all this personal stuff which was very hard to keep remembering recalling and there was no kind of positive stuff coming back in terms of building you up and encouraging you?" (YP R)

"(..) the fella was saying to me – "Okay well write down what you believe you would like to do instead of smoking," and I would put down things like I'd like to work or I would like to become more musical. Cos I'm a musical person (..) and it was literally just writing down what I wanted to do, rather than actually doing the things that I was writing down." (YP J)

Young people talked positively about their engagement with Community and Voluntary Sector organisations, which employed a model of therapy which achieved a balance between talking about feelings, working to goals and finding practical coping mechanisms:

"I didn't have a job and stuff and they got me sorted out with a job and all so its just sort of putting in the basics in my life and then after that, I can build up from there." (YP T)

"I kicked the drug habit went down to see [X], [X's] the one who got me off the tablets. Got me sorted and then he gave me a job, my wee volunteering job, (..) that's what's kept me on the straight and narrow, youth work, got my driving lessons , education (..), if not I'd either be lying in Hydebank or IRA or dead." (YP P)

Young people also talked about more regular and longer therapy sessions being useful if needed:

"Yeah I think I think its good but I also think the sessions should be longer for everything like counselling, psychotherapy, just everything I think the sessions should be longer because (..) you have an hour and then that's it and then aww I'll see you next week and then in your head your like I have so much stuff that I need to talk about. " (YP N)

There was a lot of support from young people for more activity based sessions, with activities and talking, rather than just sitting and talking. There were a range of alternative approaches which young people had experience of, which they suggested should be incorporated more into treatment sessions, including: animal therapy, art based therapy, scrap books and peer support. Young people felt this type of engagement was helpful in taking their mind off their problems, giving them a boost, building confidence and self-esteem. The following quotes provide a summary of some of the alternative therapies that young people felt would be beneficial:

Animal Therapy
"(..) aye the wee dog then helped me get off grass I was off grass for six weeks and I was doing really well like I was getting on with things it was just me and her every day." (YP G)

"When I was an in-patient, there was a wee stray kitten – never came near me like but I went about and gave it all my left overs. Went around everybody else's left overs and fed the cat every day and I named it Hope for everybody (..) ever since then I said to all the nurses and doctors, "I think you should actually go up to the pound and get wee dogs every once a week and everyone picks their wee dog and takes a wee walk just to learn how to socialise again" (..) so I thought it was a brilliant idea." (YP G)

Art Therapy
"I have a cousin that went to [X] and he said that he liked it, he said that (..) he was doing like art (..) he was like its counselling, you can do art and all other stuff with it, (..) so I was like "aye that doesn't sound too bad, like I'll do that there one"." (YP V)

Scrap books and day trips
"We did this amazing thing we made a scrapbook about what we did in like they took us out in day trips but yet they were still a counselling service, and you would've write down whatever, whatever day you did this and you would put family photos in your scrapbook and told them about what you felt like you could actually say to them (..). But this picture represented family to me, like I feel like doing something with the young person or the child especially the children, doing something like that asking them to bring their favourite teddy bear, so they don't feel so annoyed and so uptight, its just one of those things I feel that we should have here, especially for the children? In my opinion." (YP R)

Peer support and experts by experience
One young person talked very positively about the day hospitals and the range of activities available:

"I loved it like – its just sitting around with all wee funny quizzes like if you were in a plane crash or if you were on a plane and the plane was about to blow up who would you like to sit beside like you know just wee silly, it was all funny (..) that there really (..) does help and I find that helped a lot of people too because when I first went in I couldn't speak to anybody and wee day hospitals like that you don't even have to speak can sit and listen. But the more you sit and listen the more you might go, right, I feel like I'm gonna speak now and then helps you so I think that's the best part of the whole thing (..) the day hospital." (YP G)

Young people also talked about the specific benefits of peer support. They emphasised that young people have more time to talk than staff, and can relate better to the experience of other young people. The following young person talked about the positive impact of counselling when it was delivered by someone with personal experience of the same issues they were facing:

"So then when I heard about him I went up to him and they were was a group session and I felt like he was amazing, like he's one of the best I've ever been to. Aye he's done anything you can think of, heroine, Meth, everything he's done it all and then has he's lost loads of family members and then his mum was an alcoholic, there was just a wild lot so he's experienced – all of that, and now he helps other people." (YP G)

Wrap around Services
The specialist mental health support or counselling young people receive is often a 1 hour slot every 2–4, or 4–6 weeks, or less for some young people. Young people reported that this isn't always enough, and that they would like to have some support available between appointments. Young people talked about the value of having a range of support and services, which are connected and can provide the wrap around support that they need. Young people also talked about the value of follow-on support after they transition out of a service, so a young person have something to fall back on.

The following young person talked about receiving both statutory counselling and support from a youth organisation, and how this had worked well for them as they felt that there was always somewhere to go to for support in between counselling sessions:

"If I can't make it till then [CAMHS appointment] I can always come here (VCS organisation) ***so I always have a range of support."*** (YP T)

Young people also talked about the challenges they faced in getting the motivation and energy to attend clinical appointments. The following young person was living alone without parent or carer support, and talked about how it would have been helpful if there was support available for them to attend their appointments, especially when they were having a day when they were feeling low:

"(..) even a wee support worker that you can tell anything to, if you get allocated one of them and they help you with appointments and if you're having a bad day and you're not gonna have the will to get up, to have someone to knock on my door, knowin' that I was lying in bed in darkness if I had somebody knock the door and refusing to go away until I got up and went, you know things could've been a bit better. Just the wild lack of support." (YP I)

Support for Young People During a Mental Health Crisis

During the interviews young people described very long waiting times to see a mental health professional during a crisis. There were also examples of A&E discharging young people back into the community, sometimes on their own, after presenting to A&E with serious self-harm or having attempted suicide:

"I was sitting on the Blue Bridge (..) I was in a really bad place. I just wanted to jump off the bridge and they just took me over to AandE; seen a crisis doctor, and he just sent me on again! Like there was me gonna jump a bridge hours before!" (YP H)

"Yeah AandE, I went to a few – I cant remember, a few months ago I was like really suicidal and went to the AandE and was waiting for four hours before I was seen. Before I was even seen by anyone and then I just went home because I was so angry like they were just making me wait and I was the last person in the waiting room and there was people coming in and going and I was just sitting there like and I kept sayin like to one of the nurses like you know do you know why I'm here? Like and she's like yeah we need a specialist doctor to speak to you – in like four hours.." (YP N)

The evidence gathered as part of this Review also raises serious concerns about the suitability of A&E as a place of safety for young people:

"I was just sitting there like, its horrible being in A&E because you feel like everyone can tell that you're there because you've like tried to kill yourself or want to kill yourself (..) these men came up to me and stuff, like these (..) creep like chav guys and they were like tryin to like flirt with me and my friend cos my friend came with me. And they were like trying to talk to us and I was just like this is really the last thing I want right now is anyone to talk to me except a doctor and I had to wait four hours and still didn't get seen and I just think that I don't know you just don't feel like you're being taken seriously and it's just not nice." (YP N)

"Anybody who feels suicidal, anybody whose got mental health should be in a room away from everybody else (..) they put me in (..) a room in AandE like in a wee doctors room it was full of wires and they left me in there for half an hour by me self. I could've hung me self or anything 'cos I was in there for to hanging me self (..) my head was wee bit goin so it was – (..) I used to hear things and stuff and when these wires were sitting there I remember staring at them my head started to go a wee bit and I used to think will I wrap this and put it around me neck now you know?" (YP G)

In general, the young people interviewed often perceived the professional approach taken by A&E staff as being judgemental and disapproving:

"My mum rang the ambulance and then whenever I got to hospital it was like the doctors were a bit mean to me though cos they were like why would you do this? and I was like well because I want to die! Is it not obvious? Why else would you do this like? You know and they were like you know they just try to make you feel guilty for it and its like do you now think I feel guilty enough, already like? Do you not think I've got enough on my plate instead of you's making me feel guilty, cos I had my family trying to make me feel guilty as well." (YP U)

Transitioning from CAMHS to AMHS

Young people with experience of CAMHS talked very positively about it. The following young person was being prepared to move from CAMHS to AMHS, and as part

of the preparation the CAMHS worker provided, was linking the young person to an employment training college:

"I dropped out of college (..) CAMHS brought me to [X] as like they mostly do like training things like that for unemployed people (..) that was the most helpful thing they could've done." (YP S)

"Yeah but I think maybe only just because of who I had a psychotherapy with, you know, I think if I'd had someone else it might not've been as good but she was just really really caring and really did care about me. (..) I've heard about other people just be completely abandoned and like not know what to do and have no kind of transition thing but I think (VCS organisation), (..) kind of took me on, they don't leave you they like will make sure that you have stuff. (..) They really are caring." (YP N)

"It was alright (..) I remember starting about a health centre the time I was – at adult services I bounced around three or four people and that was (..) less than a year." (YP S)

One of the young people interviewed talked about being passed around two different mental health professionals at their local adult mental health service, before being referred back to their GP, who suggested that they ring a peer support group:

"They basically passed me around like a hot potato. And adding that to all the things that happened before with CAHMS and the GP and the counsellors I was just fed up at the time." (YP S)

"Them (GP) going put me to like a group cognitive thing around [A] and I said I would call them and see what's up but I never did there and then I never went back and so that's why I left." (YP S)

Need for Greater Joined-up Working Across Children's Services

One of the young people interviewed stopped going to school at the age of 13/14 years old, in order to look after his mother after her mental breakdown. Social Services were involved at the time, and the young person told them he was attending school when he wasn't, and this lie was undiscovered. This young person's experience demonstrates a serious lack of interagency information sharing:

"I didn't go to school because whenever I was telling you earlier about my mum taking a mental breakdown, she was, she went like it was about eight months went said Id take a breakdown. And I was like I was looking after the kids, feeding them, clothing them and then lookin' after me ma as well. So like I was the parents." (YP M)

They went on to describe how neither social services nor their school communicated with each other, and picked up on the fact that they were not going to school:

"They (social services) ***just didn't help me at all. Like they only came out once a month to see me and it was just like aye I'm going to school. I was lying through me teeth and they didn't even see it – I says that I am going to school like they could've even linked into my school and see if I was going or not."*** (YP M)

Another young person talked about the poor response their parent received from their school, when their school life was becoming affected by the stressful circumstances they were dealing with at home:

"They called my ma and said "eh.. 'X' is such and such he's unhappy and he's not working," and 'me ma said to them, "look he's a lot of stuff going on" and this was when my sister was sick and the head teacher turned around and said, "we're

not social workers, what are we meant to do?" (..) An I never went back to school that day (..)" (YP K)

Approach Taken by Different Services
The young people interviewed had experience of a wide range of services including GP, Community CAMHS, A&E, Voluntary and Community Services and inpatient care.

During the interviews a number of young people described what they understood as being the key differences between the services used. Some of these comparisons reflect the complementary nature between services, and in others it reflects how some services, particularly community based youth services, are much more appealing to young people:

"Yeah. I mean they (school counsellor) talked to me about the emotional side, and that was a different experience to what CAMHS would do cos CAMHS, when I was with them would do things on an addiction and everything, and like how to prevent relapse and all but the school would be like oh so how've you been feeling or what's been on your mind? That sort of thing and then I guess trying to probe it."

This young person described the difference between the Community and Voluntary Sector and the doctor in the hospital:

"The doctors felt like they judged you but in here (youth addiction community service) and all it was not really a big deal they sort of just said how it was but the doctors went crazy about it in the hospital they were like saying I was going to die of a heart attack and all." (YP T)

6.5 Conclusion

There is an urgent need to address the significant gaps in service provision for young people who have co-occurring mental health and alcohol and/or drug problems.

During the Review we found that many young people were using substances as a form of self-medication, or way of coping with the symptoms of their mental health problems. A significant number of those interviewed described having serious mental health problems, including: being highly vulnerable to self-harm, suicidal thoughts and attempted suicides. Many of the young people described having experienced multiple adverse experiences during their childhood, and often the issues causing trauma had never been addressed. It was evident that many had been failed by the system at a number of junctures, where interventions could have changed their life trajectory i.e. social services, education system and health services.

The Review has found young people who have co-occurring mental health and alcohol and drug problems are finding it extremely challenging to get access to the holistic support they need. The typical statutory 9am-5pm service delivery model is extremely challenging to engage with for this group of young people. When young people talked most positively about the support they had received, this was often with reference to support provided by Voluntary and Community Sector (VCS) organisations. Young people also talked very positively about having the support of both statutory CAMHS and VCS organisations at the same time. They valued the complementary nature of the clinical care that statutory CAMHS provides, and the more flexible and practical support that VCS services provide.

Specialist services were not available for many of the young people engaged with in the Review. Medication was a very common form of treatment offered to young people with mental health and alcohol and drug problems. Many of the young people interviewed were reluctant to take medication because of the problems they had with substances, including misuse of prescription drugs. The interviews also raises concerns about the adequacy of the support and supervision available to young people that are prescribed medication who have a history of alcohol and drug misuse.

The lack of specialist services was particularly apparent for young people with more severe problems, that required specialist and intensive community based support, or specialist in-patient admission (Step 4 and 5). The current mental health legislative framework, the Mental Health (NI) Order 1986, prevents young people from being detained for inpatient admission, whilst still under the influence of alcohol or drugs. A Mental State Assessment (MSA) cannot be carried out whilst a young person is under the influence of substances. However, there is no rehabilitation centre or safe place for young people with co-occurring mental health and drug and alcohol problems to go to get support for their complex needs, and this creates a vicious cycle for the small group of young people in this situation.

Due to a lack of highly specialist services, young people with co-occurring mental health and alcohol and/or drug problems struggle to get access to the support they need. A&E has a role in the crisis care of young people for whom medical interventions are required. However, mental health expertise must become embedded into this part of the system, so that young people have seamless and integrated care, at the point when they are most vulnerable.

WAITING FOR MENTAL HEALTH SUPPORT

A Journey from Mental Health Problems Emerging to Accessing Help

*Statutory Specialist Community Support for when mental health is having a 'severe impact on a child's ability to function daily, on relationships or on their education (Step 3).

SECTION 7

OPERATIONAL DATA ON CHILDREN AND YOUNG PEOPLE'S MENTAL HEALTH

This section reports on Strand 2 of the Review: A mapping and analysis of available official statistical information on the operational aspects of mental health services, which relate to services that sit under Step 3–5 of the regional Stepped Care Model. The data was provided from three main sources – the HSCB, HSCTs and RQIA. Unless stated otherwise, the statistics are available for a 3 year period: 2013/14, 2014/15 and 2015/16.

Access to data for Step 1 and 2 services would have required liaising with a wide range of other agencies, which unfortunately, was not possible within the timeframe of this Review.

The remainder of this section will outline 8 different types of data that was requested and the data that was received. This will include an explanation of the data, why the data is important, what the available data tells us, and what is missing from the data being collected.

The data requested and received relates to:

1. **Out Patient Referrals (Step 3 CAMHS);**
2. **Waiting Times for referral to Step 3 CAMHS;**
3. **Attendance at Appointments;**
4. **Inpatient (Beechcroft) Referrals;**
5. **Admissions of Under 18s to Adult Mental Health wards;**
6. **Extra-Contractual Referrals (ECR's);**
7. **Information on Demographic Profile;**
8. **Mental Health Diagnosis or Presenting Need; and**
9. **Additional data from other sources.**

7.1 Out Patient Referrals (Step 3 CAMHS)

Out Patient Referrals relate to the number of young people who are being referred to statutory community based mental health services, these services are also known as Step 3 CAMHS. The vast majority of support young people access for their mental health is based in the community, and does not require inpatient care. Self-referrals are not accepted to Step 3 CAMHS, only qualified professionals can make referrals (HSCB, 2018:2).

The CAMHS Care Pathway document states that when Step 3 CAMHS receive a referral, it will be assessed to determine whether it meets the CAMHS threshold (referral criteria). This process is sometimes referred to as 'triage' or 'screening'. This involves reviewing the information contained on the referral form, to assess whether it meets the threshold for acceptance. When a referral is not accepted, the referral agent will be advised that this is the case (HSCB, 2018:2).

Why is This Information Important?
Referrals to Step 3 CAMHS show the number of young people with mental health problems that are being referred by a health professional for assessment. In the absence of prevalence data, it provides some indication of the scale of mental health problems within the population of children and young people. The number or proportion of young people that are accepted, and not accepted, for referral to Step 3 provides a useful indication of how well the referral process is working.

What Information was Provided from Our Request?

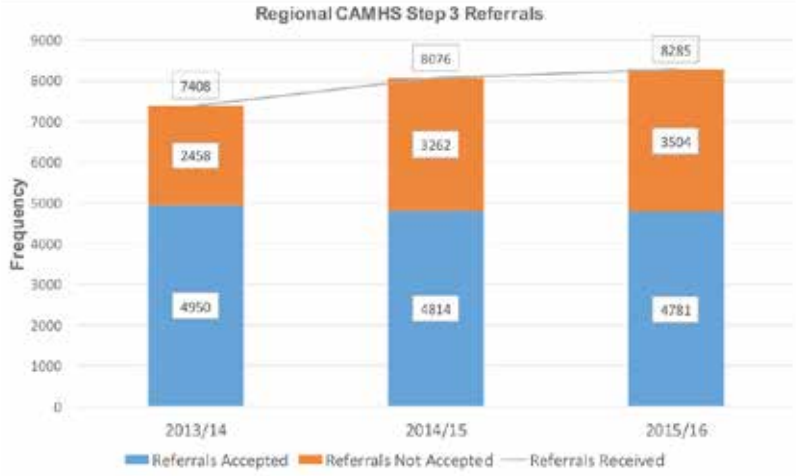
The HSCB provided statistics on the number and percentage of children and young people within each HSCT, and regionally, that were accepted and not accepted for referral to Step 3 CAMHS. They also provided information on the number of young people accessing routine, urgent and emergency referrals within each HSCT and regionally.

The following information was not available as part of our request:

- No data was available from the HSCB on referrals to specific services that sit within Step 3 i.e. addiction services, specialist autism, behavioural support and learning disability services. (Data on a greater range of services are included as data fields in the CAMHS Dataset);
- The reasons for referrals not being accepted are not monitored;
- The system does not monitor or track young people who are not accepted for referral to Step 3 CAMHS, to ensure these young people are successfully referred back to the referral source or on to another, more appropriate service;[45]
- The health professional that refers a young person to Step 3 CAMHS was not being monitored (This person is also referred to as the 'referral source'). (Referral Source is included as a data field in the CAMHS Dataset); and
- Young people that are moving between services within the Stepped Care Model for CAMHS are not tracked. This type of tracking system would help to monitor the length of time, and pathway that young people travel to access support.

Regional CAMHS Step 3 Referrals Received, Accepted and Not Accepted

Figure 7.1: Regional CAMHS Step 3 Referrals



Source: Based on data provided in HSCB report - Oct 2017

The graph above shows a year on year increase in the number of young people being referred to Step 3 CAMHS. Regionally, during 2013/14, 7408 young people were referred to Step 3 CAMHS, compared to 8285 young people in 2015/16. This represents an 11% increase in referrals to Step 3 CAMHS in the 3 year period 2013/14 to 2015/16.

45 The CAMHS pathway document states that these young people should be referred back to the original referral source (HSCB, 2018:2).

The referral figures also show that (during the reporting period) as referrals to Step 3 CAMHS increased, the percentage of young people accepted to Step 3 CAMHS, has decreased.

Table 7.1: Percentage (%) of Referrals not accepted for Step 3 CAMHS

Year	Belfast	Northern	South Eastern	Southern	Western	Regional Average
2013-14	47	23	45	28	26	33
2014-15	53	28	49	36	28	40
2015-16	54	53	50	37	17	42

Source: Based on data provided in HSCB report, Oct 2017

As illustrated above, regionally, the percentage of referrals not accepted by Step 3 CAMHS increased year-on-year between 2013/14 and 2015/16. In 2013/14, the regional percentage of referrals to Step 3 CAMHS that were 'not accepted' was 33% and in 2015/16 it was 42%.

The Table above also shows considerable variation in the percentage of referrals 'not accepted' across the individuals HSCTs, during the reporting period. During 2015/16, the percentage of referrals 'not accepted' ranged between 17% and 54%, depending on the individual HSCT. Three of the five HSCTs did not accept 50% or more of referrals i.e. BHSCT, NHSCT, SEHSCT. The WHSCT did not accept 17% of referrals during 2015/16, which is much lower than the 42% regional average referral 'not accepted' rate, across all the HSCTs.

NICCY has been informed by the HSCB that the system does not collect detailed information about the reasons why young people are not being accepted into Step 3 CAMHS. In addition, there is no information on whether young people are being referred on to other services, and if so, which services.

The HSCB have clarified that: 'a decision not to accept a referral (to Step 3 CAMHS) is a *clinical decision*, and Trusts are expected to follow the regionally agreed Threshold Criteria to inform this decision.'[46]

The SHSCT has also responded by stating that: 'children who do not need these services (Step 3 CAMHS) will be redirected to another service which best meets their individual needs or they will be directed back to the person making the referral.'[47]

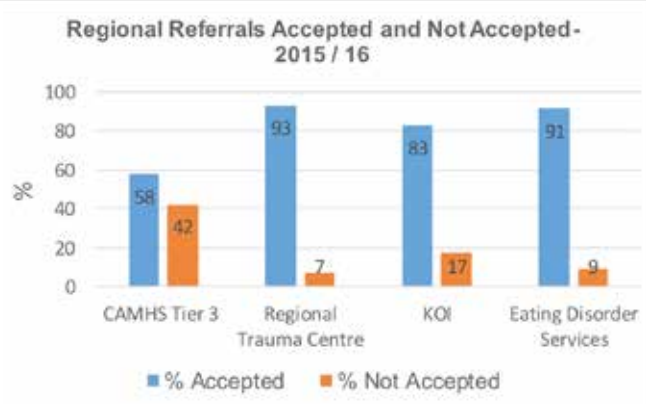
However, as outlined above, the system does not monitor or track young people who are not accepted for referral to Step 3 CAMHS, to ensure they are successfully referred back to the referral source or on to another, more appropriate service.

46 Information provided by HSCB to NICCY, via email 11 October 2017.

47 SHSCT Press Release 24 November 2017.

More information is required to clarify how such a large number of young people, referred by a qualified health professional, are not being accepted to Step 3 CAMHS. This indicates a serious problem with the referral process, which is resulting in many young people being placed on a waiting list for CAMHS, only to be informed after a period of waiting that it is not appropriate for them.

Figure 7.2: Regional Referrals Accepted and Not Accepted- 2015 / 16

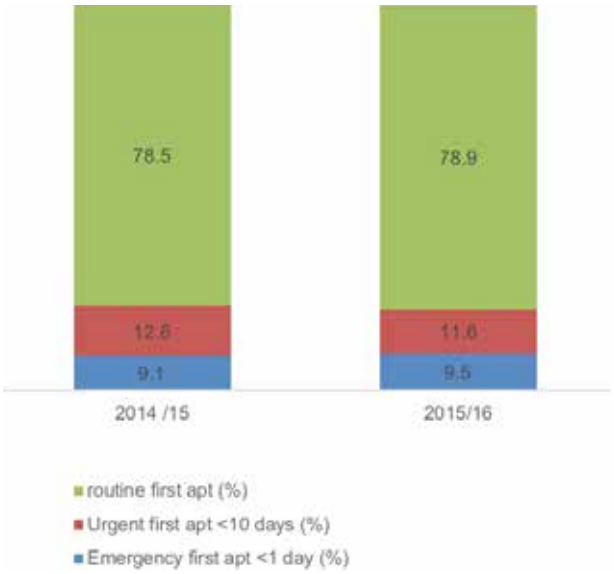


Source: based on data provided in HSCB report - Oct 2017

In contrast to Step 3 CAMHS, in which regionally 42% of referrals are not accepted, referral data for more specialist Step 3 services, such as the Regional Trauma Centre (93%), KOI Gender Identify Service (83%) and the Specialist Step 3 Eating Disorder Service (91%), report that the vast majority of referrals are accepted. These figures highlight a significant difference in the rates of referrals accepted by generic and specialist Step 3 CAMHS.

Referral Type (Emergency, Urgent, Routine)

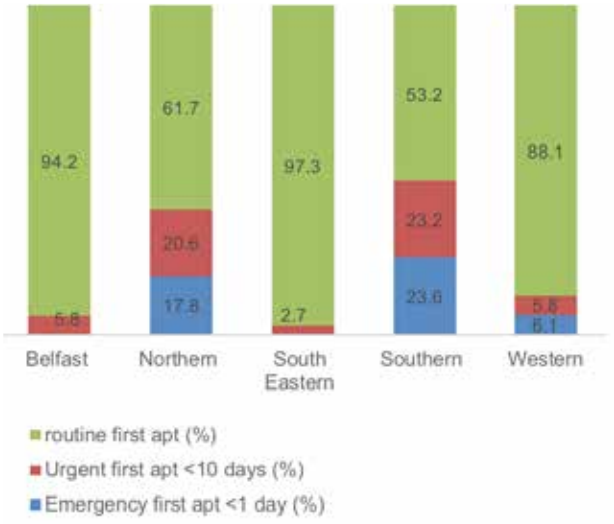
Figure 7.3: Type of Referrals made to Step 3 CAMHS (Emergency, Urgent, Routine)



Source: Based on data provided in HSCB report, Nov 2017

Regionally, routine referrals make up approximately 80% of referrals to Step 3 CAMHS, and urgent and emergency referrals make up approximately 20%.

Figure 7.4: HSCT referrals made to Step 3 CAMHS, 2015 / 16



Source: Based on data provided in HSCB report, Nov 2017

The make-up of referrals varied considerably between HSCTs, during 2014/15 and 2015/16, 40–50% of all referrals to NHSCT and SHSCT were urgent or emergency. There was no emergency referrals, and few urgent referrals, to BHSCT or SEHSCT. This may reflect the difference in availability of crisis response services across the HSCTs.

7.2 Waiting Times for Referral to Step 3 CAMHS

Referrals made to Step 3 CAMHS are subject to a statutory target of 9 weeks.[48] These waiting times are calculated from the date of acceptance of the referral, to the time the patient is seen and assessed at their first appointment.

Why is This Information Important?

Timely access to mental healthcare is a key measure of quality. Early action is more likely to result in full recovery and, in the case of children and young people, will also minimise the impact on other aspects of their development, such as their education.

Article 24, paragraph (1) of the UNCRC places obligations on the Government to ensure

that health and other relevant services are available and accessible to all children. It states that:

"State parties shall strive to ensure that no child is deprived of his or her right of access to such health care services."

What Information was Provided from our Request?

The waiting time statistics for first routine appointments to Step 3 CAMHS were provided by the HSCB.

The following information was not available as part of our request:

- Waiting time statistics were not provided for Step 2, 4 or 5, therefore, for the purposes of this review, data on how long children and young are waiting to access services once referred was not provided for a considerable part of the system;
- Data on waiting times for second appointments to Step 3 CAMHS (Waiting times for second appointment is not a data field in the CAMHS Dataset);
- There is a specific waiting time target of 13 weeks for access to psychological therapies, which applies to children and young people and adults (HSCB, 2018:2). Young people referred to CAMHS may be provided with the option of psychological therapy interventions as part of their treatment.[49] (There are no plans to monitor the 13 week waiting time target for psychological therapies within the CAMHS dataset);
- The types of psychological therapies used as part of young people's treatment is not monitored by HSCT or HSCB, and could not be gathered without a trawl of individual patient files. (The type of 'interventions' young people are accessing is not a data field in the CAMHS Dataset); and
- There is currently no monitoring of waiting time targets for urgent or emergency appointments to Step 3 CAMHS. This is despite the Government target for urgent appointment of 5 days and emergency appointments within 24 hours of referral (Number of contacts seen within the target time frame for routine, urgent and emergency referrals is not a data field in the CAMHS dataset).

48 Commissioning plan direction target 4.13.

49 Letter received from HSCB to NICCY- 2 March 2017.

Regional Waiting Time Figures for Assessment to Step 3 CAMHS

As of March 2014, 12% or 114 young people who had a referral accepted to Step 3 CAMHS had to wait more than the Government target of 9 weeks to receive their first appointment. In March 2016, this had decreased to 3% or 19 young people waiting more than 9 weeks to access a first appointment to Step 3 CAMHS across the region.

Table 7.2: Regional waiting time figures for assessment to Step 3 CAMHS

Region	Total waiters	> 9 wk waiters	% > 9 wk waiters
28-Mar-14	934	114	12%
27-Mar-15	1022	99	10%
25-Mar-16	742	19	3%

Source: HSCB Report, Oct 2017 – adapted version
Data based on HSC Weekly Trust Returns as at date stated.

HSCT Breakdown of Waiting Time Figures for Assessment to Step 3 CAMHS

Statutory guidance states that no patient should wait longer than 9 weeks to access CAMHS.[50] Waiting times are calculated from the date of acceptance of the referral, to the time the patient is seen and assessed at their first appointment. The figures in the table above show the numbers of young people that are waiting for a first appointment to Step 3 CAMHS each year, and the number and percentage of those waiting longer than the 9 week target. It shows a substantial number of young people are waiting for an appointment at any point in time. In March 2014, 934 young people had been accepted for referral to Step 3 CAMHS and were waiting for an appointment, this was 1,022 at the same time point in 2015, and had fallen to 742 at March 2016.

50 Set out in Commissioning plan direction target 4.13

Table 7.3: Waiting times for first appointment at Step 3 CAMHS, March 2014 and 2016

Trust	28 March 2014			Trust	28 March 2016		
	Total waiters	> 9 wk waiters	% > 9 wk waiters		Total waiters	> 9 wk waiters	% > 9 wk waiters
Belfast	282	2	1%	**Belfast**	330	18	5%
Northern	391	112	29%	**Northern**	150	0	0%
Southern	95	0	0%	**Southern**	80	0	0%
Western	166	0	0%	**Western**	182	1	1%
Region	**934**	**114**	**12%**	**Region**	**742**	**19**	**3%**
Source: HSC Weekly Trust Returns 28/03/2014				*Source: HSC Weekly Trust Returns 25/03/2016*			

Note: BHSCT and SEHSCT are combined figures.
Source: HSCB Report, Oct 2017

The waiting time data in the tables above shows the number and percentage of young people waiting for an appointment to Step 3 CAMHS, across the different HSCTs at March 2014 and March 2016. It is important to note that waiting time figures are based on one time point in the year, the total number of young people waiting for a referral to Step 3 CAMHS, and the number waiting beyond the 9 week Government waiting time target will fluctuate across the year.

The tables also show the number of young people who are waiting longer than the 9 week waiting time target across each HSCT. In 2014, the NHSCT accounted for most of the regional waiting time figure, with 112 of the 114 young people waiting longer than 9 weeks across the region living in the NHSCT. In March 2016, there were no young people waiting for a first appointment to Step 3 CAMHS in the NHSCT. Regionally, the number of young people waiting longer than the 9 week waiting time target for a first appointment had fallen to 19 young people (or 3% of the overall number of young people waiting to access CAMHS).

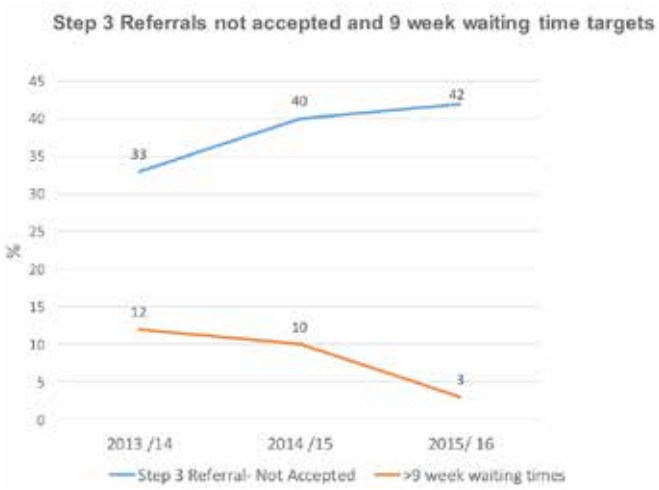
NICCY contacted the NHSCT about the significant reduction in waiting times and was informed that the introduction of Choice and Partnership Approach (CAPA)[51] had been a significant change implemented in the HSCT. One of the aims of CAPA is to improve the flow of young people through the system, to ensure they reach the most appropriate service more quickly.

51 The Choice and Partnership Approach (CAPA), is a model of engagement and clinical assessment principally used in Child and Adolescent psychiatry services. It aims to use collaborative ways of working with service users, to enhance the effectiveness of services and user satisfaction with services. The HSCTs have been working to attempt to apply the principles of this approach to how CAMHS are delivered.

Step 3 Referrals and 9 Week Waiting Time Targets

Regionally, across the reporting period, waiting time figures have dropped, and the percentage of referrals to Step 3 CAMHS not accepted has increased.

Figure 7.5: Step 3 Referrals not accepted and 9 week waiting time targets (regional data)



Source: Based on data provided in HSCB report, Oct 2017

7.3 Attendance at Step 3 CAMHS Appointments

When a child is accepted for referral to Step 3 CAMHS, they are given an appointment time to meet with a CAMHS professional. A young person's attendance will be recorded at each appointment. DNA is when a young person 'Did Not Attend' and did not give advanced notice to the hospital/clinic/professional. CNA is when a young person 'Can Not Attend' and provided advanced notice to the hospital/clinic/professional.

As outlined in Section 1, the Integrated Elective Access Protocol Addendum (IEAP)sets out the systemic principles and processes for the management of patients/clients, from the point of referral, to the point of discharge. It includes the management of DNA or CNA appointments. Under 7.6 of the IEAP it is stated that:

"If a patient / client DNA / CNA their appointment, a review of the risk factors should be undertaken in partnership with the patient / clients General Practitioner (GP) and a second appointment offered, if required. Any decision to discharge should be fully documented and the patient / client and their GP informed in writing. This letter should also include details on how the patient / client can re-engage in services should circumstances change." (HSCB, 2010; HSCB, 2018:2)

The HSCB provided both a Regional and Trust breakdown of the number, and percentage, of DNA and CNA for first appointment and review appointment to Step 3 CAMHS. This was not something that was asked for in the original request for data, but has been very useful information.

(The CAMHS Dataset Framework includes data fields for number of CNA and DNA at first appointment and review appointment.)

Why is this Information Important?
DNA and CNA figures provide useful information that helps to explain how efficiently the system is running, but it also raises questions about the reasons why young people are not attending appointments, when they have been assessed as requiring the support of these services.

The following information was not available as part of our request:

- The reasons DNA and CNA for first appointments and review appointments at Step 3 CAMHS are not monitored by the HSCB. There are no plans for the reasons for DNAs or CNAs to be monitored as part of the new CAMHS dataset. (The CAMHS dataset includes a data field that will monitor the number of young people discharged from services, but this does not include a code for recording when the discharge is due to DNA or CNA) (HSCB, 2018:1).

Step 3 CAMHS - Rates of Did Not Attend (DNA) and Cannot Attend (CNA)

For the 3 year reporting period provided, regional rates of DNA and CNA have remained at 15–16% for first appointments, and 24% for review appointments.

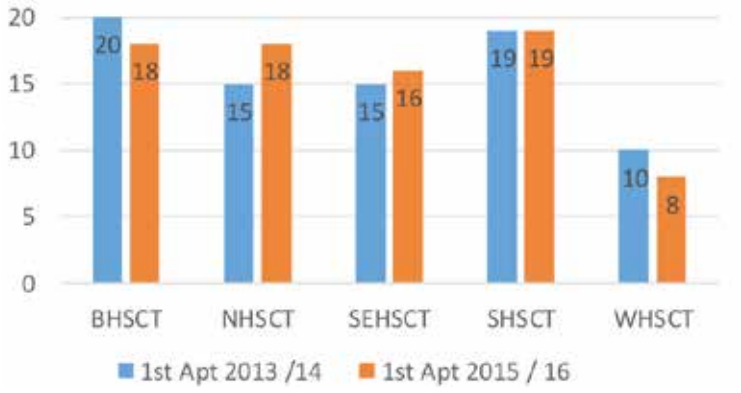
Sections 4 and 5 of the report, which includes the survey and interview findings, outline some of the reasons given by young people about why they are unable to attend mental health appointments.

Figure 7.6: Step 3 CAMHS – % DNA / CNA (Regional data)

Source: Based on data provided in HSCB report - Oct 2017

Between 2013/14 and 2015/16, all of the HSCTs apart from the WHSCT had non-attendance rates ranging between 15–20% for first appointments to Step 3 CAMHS. The WHSCT had much lower rates at 10% in 2013/14 and 8% in 2015/16.

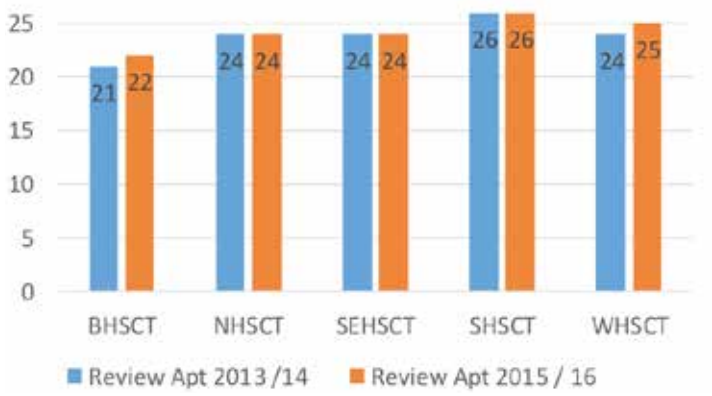
Figure 7.7: Step 3 CAMHS 1st Appointment – % DNA / CNA by HSCT



Source: Based on data provided in HSCB report, Oct 2017

Between 2013/14 and 2015/16 there is very little difference in the percentages of non-attendance for review appointments recorded by individual HSCTs, with non-attendance rates ranging between 21–26%. It is also notable that none of the HSCTs has seen any decrease in the rates of non-attendance, with the BHSCT and the WHSCT showing a slight increase over the reporting period.

Figure 7.8: Step 3 CAMHS Review Apt – % DNA / CNA by HSCT



Source: based on data provided in HSCB report, Oct 2017

Overall, this data shows that a considerable proportion of young people referred to Step 3 CAMHS are not attending, or cancelling attendance for their first or review appointment. Although the number of DNAs and CNAs is monitored, the reasons for non-attendance is not.

7.4 Inpatient (Beechcroft) Referrals

Beechcroft is the regional inpatient unit for under 18 year olds in Northern Ireland. It is based in Belfast and managed by the BHSCT. It provides assessment and treatment for complex mental illness, acute risk, and diagnostic complexity that cannot be assessed or safely treated in the community.[52]

Under certain circumstances, a young person can be detained in hospital on a compulsory basis, if a designated medical expert assesses that they are a risk to themselves or others, if compulsory intervention is not undertaken.

The Mental Health (Northern Ireland) Order 1986 provides the legal framework which gives a doctor permission to detain a young person in hospital for an assessment, care or treatment for their mental health.

Young people entering Beechcroft are admitted either as a voluntary patient i.e. agree to their admission voluntarily, or are formally detained under the Mental Health (NI) Order 1986. Young people who are formally detained cannot leave Beechcroft until health professionals deem their condition has improved. The legislation sets out parameters regarding the length of time a young person can be detained for assessment, and the length of time they can be detained without review. If a health professional wishes a young person who is a voluntary patient, to remain in Beechcroft, a process of formal detention can be undertaken if legal criteria for detention are met. In such circumstances, the status of the young person changes from voluntary to detained.

52 http://www.familysupportni.gov.uk/listing/camhs-tier-4-beechcroft-belfast-trust

Why is this Information Important?
Young people who require inpatient admission are the most vulnerable group of young people, due to the nature and extent of their mental health problems. It is therefore important there is transparency in terms of the accessibility of this service to children and young people.

It was very important that the status of a children's admission to Beechcroft is requested as part of the data collection, including 'occurrences of detention'.

Deprivation of liberty also directly engages Articles 5 and 8 of the ECHR, as incorporated by the Human Rights Act 1998 – the right to liberty and security of persons and the right to private, family and home life. These rights are domestically justiciable and apply to everyone regardless of their age.

What Information was Provided from our Request?

The HSCB provided a regional and Trust Breakdown of the number of inpatient admissions and discharges to Beechcroft.

The BHSCT provided further information on the status of young people admitted to Beechcroft i.e. voluntary, detained, voluntary and subsequently detained as this was not collected by the HSCB.

The RQIA provided information on the detention of children and young people under the Mental Health (Northern Ireland) Order 1986.

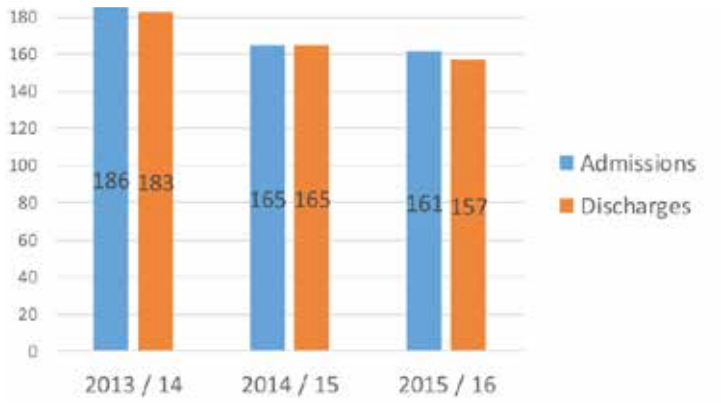
The following information was not available as part of our request:

- The overall number of referrals to Beechcroft that were accepted and not accepted.

Regional Admissions and Discharges to Beechcroft

Across the reporting period the number of admissions to Beechcroft ranged between 186 and 161, and the number of discharges ranged between 183 and 157. The graph also shows that across the reporting period the number of admissions to Beechcroft has decreased.

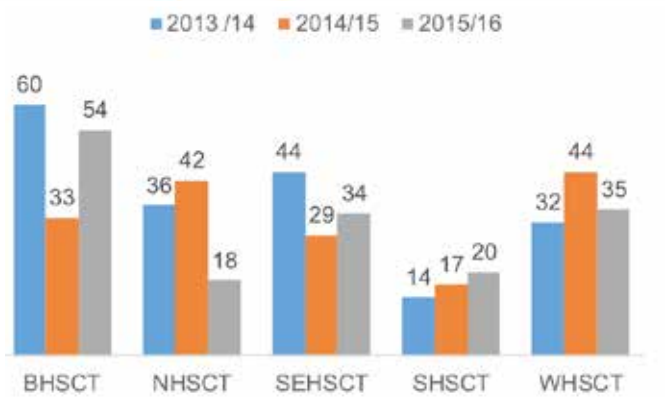
Figure 7.9: Regional Admissions and Discharges to Beechcroft



Source: based on data provided in HSCB report, Oct 2017.

The following Figure provides a breakdown of admissions to Beechcroft by 'Trust of residence' of patients between 2013/14 and 2015/16. Over that period, the highest number of admissions to Beechcroft were young people resident in the BHSCT, this was followed by young people resident in the SEHSCT and the WHSCT. The smallest number of admissions to Beechcroft were young people resident in the NHSCT or SHSCT, however, the percentage of emergency and urgent referrals to Step 3 CAMHS within these HSCTs, are highest (see Figure 7.4).

Figure 7.10: Number of Admissions to Beechcroft by Trust of Residence of Patient

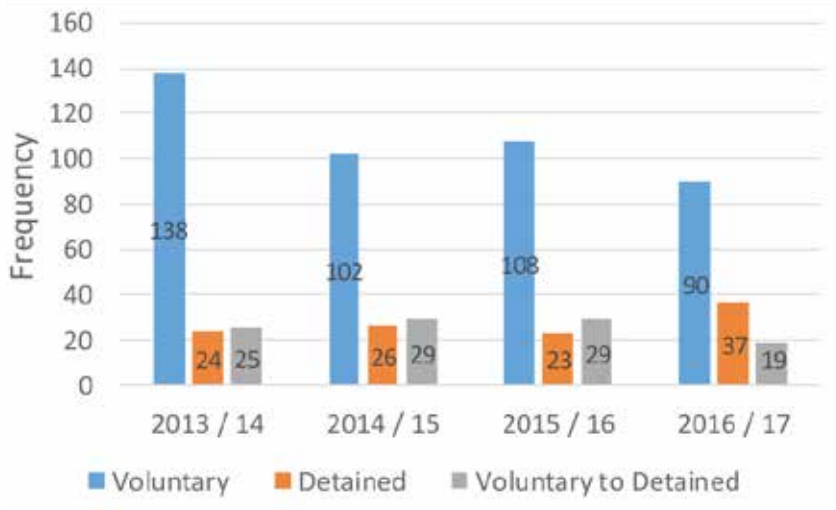


Source: based on data provided in HSCB report -Oct 2017

Status of Admissions to Beechcroft

The following figures provide a breakdown of admissions to Beechcroft by admission status i.e. voluntary and detained. The graph also provides a breakdown of young people admitted on a voluntary basis who were subsequently detained. The data shows that it is much more common for young people to be admitted as voluntary, rather detained patients. It also shows that there has been a 54% increase in the number of young people detained across the reporting period from 24 in 2013 /14 to 37 in 2016 / 17. As the overall number of young people admitted to Beechcroft has decreased over the reporting period, this also means that a greater proportion of admissions are detentions. The number of young people admitted as a voluntary patient but subsequently detained has decreased over the reporting period from 25 in 2013 / 14 to 19 in 2016 /17.

Figure 7.11: The number and status of children and young people accessing CAMHS



Source: Data provided by the BHSCT- 2017.

7.5 Admissions of Under 18s to Adult Mental Health Wards

There are circumstances when a young person may be admitted to an adult mental health ward. These include circumstances where there is no bed available in Beechcroft, in some cases families may request their child be cared for closer to home, or were there is a specific medical need which cannot be treated elsewhere. The HSCB state that the time young people spend in an adult psychiatric ward should be for the shortest time possible, and with specific child safeguarding arrangements in place.[53]

Children and young people should never be detained in a mental health setting with adults. NICCY believes that the practice of admitting children onto adult psychiatric wards should urgently cease. The admission of children and young people to adult wards is an issue of serious concern which NICCY and other agencies have repeatedly highlighted over a considerable period (RQIA, 2012; NICCY, 2013). The risks to children in terms of their protection and safety, and the potentially detrimental impact on their social and emotional well-being are significant. Consequently, NICCY believes it is wholly unacceptable that children are ever placed on adult psychiatric wards. All children and young people should receive treatment in age and developmentally appropriate settings. NICCY believes this is the only way to ensure compliance with international children's rights standards.

53 Letter from HSCB to NICCY dated March 2016.

Article 37 (c) of the UNCRC states children should never be detained with adults in adult mental health wards:

"Every child deprived of liberty shall be treated with humanity and respect for the inherent dignity of the human person, and in a manner, which takes into account the needs of persons of his or her age. In particular, every child deprived of liberty shall be separated from adults unless it is considered in the child's best interest not to do so and shall have the right to maintain contact with his or her family through correspondence and visits, save in exceptional circumstances."

The Committee has also been very clear on this matter, following its examinations of the UK and Northern Ireland as a devolved administration. The treatment of children on adult psychiatric wards was also raised by the Committee in its Concluding Observations, following its examination of the UK Government's compliance with its obligations under the UNCRC in 2008 (UN, 2008), and again in 2016 in the most recent examination of the UK and Northern Ireland's compliance with its obligations. The Committee recommended the State party:

"Expedite the prohibition of placement of children with mental health needs in adult psychiatric wards or police stations, while ensuring provision of age-appropriate mental health services and facilities." (UN, 2016:2)

The Regulation and Improvement Authority (RQIA) have a statutory obligation to monitor all incidents of young people accommodated in adult mental wards.[54] The HSCTs must notify RQIA when an under 18 is admitted to an adult ward, and are required to complete a report detailing the measures they have put in place for these children. RQIA also collects the following details of under 18's in adult wards: Name, Date of Birth, Originating HSCT, Total no of days in hospital, Number of admissions, Admission date, Hospital/ Ward, Reason for Admission, Discharge Date, Discharge Destination, Age, and Status of young person.

Why is this Information Important?
Young people should only ever be treated and cared for in age appropriate settings. Up to date figures on admissions to adult mental health wards provides an indication of whether inpatient provision is compliant with international children's rights standards, and the adequacy of inpatient provisions for children and young people in Northern Ireland.

What Information was Provided from our Request?

The HSCB provided statistics on admissions of under 18 year olds to mental health wards by length of stay (over and under 10 days). The HSCB did not monitor information relating to the demographic profile of young people, number of repeat admissions, average length of stay or discharge destination.

RQIA provided information on the detention of children under the Mental Health (Northern Ireland) Order 1986 i.e. reasons, length and place of detention, length and reasons for delayed discharge.

The following information was not available as part of our request:

- Discharge destination of young people admitted to adult mental health wards is not available.

54 Circulars from the DoH have been issued in relation to 'Under 18 Year Olds in Adult Mental Health Facilities' (2016) and 'Under 18 Year Olds in Adult Learning Disability Facilities'' (2008).

Admissions to Adult Mental Health Wards

The following table shows there has been a significant decrease in the number of young people admitted to adult mental health wards over the reporting period, from 21 in 2014/15 to six in 2017/18. The HSCB has indicated this may reflect the impact of the establishment of crisis teams in the HSCTs, and better service responses to young people who present in crisis. It was expected that the establishment of such teams would have resulted in fewer admissions to hospital.[55]

It is also noteworthy that in 2015/16 there were 18 admissions to adult wards by under 18s in the WHSCT, this is highest figure for use of adult beds of under 18s, across the region. The WHSCT has least coverage of CAIT[56] and is the HSCT furthest away from the regional child and adolescent mental health inpatient facility (Beechcroft). These are both factors that may be impacting on the rates of admission to adult mental health wards for this HSCT.

Table 7.4: Number of Under 18 Admissions to Adult Mental Health Wards between 2014–18 (Regional Figures)[57]

Year	Regional Frequency
2014-15	21
2015-16	27
2016-17	*
2017-18	6

Source: Table produced using data provided by HSCB and RQIA in 2017
*Figure is under 5

The average length of stay for a young person in an adult mental health ward fluctuated over the reporting period, between 7 and 17 days. The maximum length of stay was as high as 100 days in 2014/15, but has fallen to a maximum of 25 days in 2017/18.

55 Information provided by HSCB to NICCY via email, 11 October 2017.

56 Crisis Assessment Intervention Team or CRHT provide support to young people that are at immediate risk and require urgent intensive intervention to meet their needs.

57 One young person can account for more than one admission.

Table 7.5: Under 18s in Adult Mental Health Wards: Length of Stay and Repeat Admissions (Regional Figures)

Year	Average length of Stay (Days)	Minimum/ Maximum Stay	No. of Repeat Admissions
2014–15	17	1–100 days	*
2015–16	7	2–26 days	6

Source: RQIA & HSCB in 2017 & 2018

Table 7.6 below shows where young people are discharged to upon leaving adult mental health wards. The data provided reports four different discharge destinations for young people during the period 2015/16 to 2017/18. These were 'Beechcroft', 'Home', 'Turned 18 years old' and 'Supported Accommodation'. The figures show the most common discharge destination after spending time on an adult mental health ward was, 'home' (n=35; 63%), followed by transfer to Beechcroft (n=11; 20%). The table also highlights that a significant number of young people (n=6; 11%) are discharged back into the community after spending time as an inpatient within an adult mental health facility, rather than being transferred to Beechcroft.

Table 7.6: Discharge destination on leaving adult mental health wards for the period 2014–18 (Regional Figures)

2014–18	Regional Freq.
Beechcroft	11
Home	35
Turned 18 yrs old	*
Supported Accommodation	6

Source: table produced using data provided by RQIA in 2017
*Figure under review

7.6 Extra-Contractual Referrals

An Extra Contractual Referral (ECR) on mental health grounds, occurs when the HSCB approves a consultant's request to transfer a patient to an inpatient mental health facility outside Northern Ireland, for assessment and/or treatment.[58] This transfer occurs when treatment or care is not available through the Health and Social Care system in Northern Ireland, due to insufficient numbers to allow for a specialist service to be developed. Under an ECR, young people are usually provided with healthcare as an inpatient in Britain or the Republic of Ireland.

Why is this Information Important?
It was important for us to gather this information as part of the Review because it provides an understanding of the types of treatment and support that are not available for young people in Northern Ireland, and the extent to which ECR's occur.

It is challenging for a small jurisdiction such as Northern Ireland to provide very specialist services for relatively small numbers of young people. Children and young people's fundamental rights, including their right to family life, as accorded to them through Article 8 of the ECHR, and the requirement that their best interests be a primary consideration under Article 3 of the UNCRC, are engaged by ECRs. Thus decisions must take into account clinical need, and access to the most appropriate and highest standard of healthcare, as well as the right to family life and other UNCRC rights.

What Information was Provided from our Request?

As the numbers of young people receiving services through ECRs are very small, the relevant information that can be shared or published is limited, to prevent young people, or data relating to their treatment, being identified.

The BHSCT provided statistics on ECR's on mental health grounds, although these are regional figures. These indicate that between 2013/14 and 2015/16, eight young people had to be referred outside of Northern Ireland, in order to get treatment for their mental health. During this time period the longest admission of a young person, subject to an ECR for mental health care and treatment, was over 5 years, and the shortest was for 1 year and 4 months. The age of the young people ranged between 16–18 years old. The type of mental health care required by these young people, not available in Northern Ireland, was forensic mental health care and eating disorder care.

The following table shows the number of young people subject to an ECR over the 3 year reporting period. In 2013/14, three young people were subject to an ECR at the cost of £748,901, in 2014/15, three young people were subject to an ECR at the cost of £509,996 and in 2015/16, two young people were subject to an ECR at the cost of £306,715.

Table 7.7: Number of young people subject to an ECR and associated costs

2014- 18	Number of young people	£
2015 / 16	2	306,715
2014 / 15	3	509,996
2013 / 14	3	748,901

Source: BHSCT 2017

58 http://www.hscboard.hscni.net/travelfortreatment/transfer-for-treatment-by-the-health-and-social-care-board-2

7.7 Information on Demographic Profile

Demographic information refers to the key socio-economic characteristics of young people expressed statistically, such as age and gender.

Why is this Information Important?
Establishing the demographic profile of those using child and adolescent mental health services is important as it provides an indication of need across different groups of children and young people. This is required to determine if services are available in sufficient numbers, if some groups of young people find it more difficult to access services, and it is to identify any gaps in provision.

What Information was Provided from our Request?

No standardised or reliable information was available from the HSCB or the HSCTs in relation to the demographic profile of young people using mental health services.

The following information was not available as part of our request:

- A standardised regional breakdown of the demographic profile of users of CAMH services was not provided i.e. by age, sex, mental health diagnosis or presenting need. It is also important that data be available for vulnerable groups of children, including: care experienced children, children with a physical or learning disability, LGBT, newcomer and separated children.

NICCY was informed that, in general, demographic information is not collected by the HSCB. This was described as 'patient level data' that, while held by HSCTs, was not generally available collated into statistical reports. Where it was, there was a great deal of inconsistency and as a result was not useful for the purposes of this report.

(Key demographic data fields are included in the CAMHS dataset i.e. age, gender, ethnicity, presenting need or complaint, postcode relating to patients current place of residence, GP with whom the client is registered and their health and social care number).

The Health and Social Care Board did not provide a breakdown of 'specific groups' of young people that may be accessing mental health services i.e. 'looked after children' or 'young people with a learning disability'. As above, NICCY was informed this was held as 'patient level data' by Health and Social Care Trusts. There are no plans to include 'disability' within the demographic data fields in the CAMHS dataset. The HSCB have stated that a suitable definition of disability is not available.[59]

Furthermore, there were a number of significant challenges when trying to access mental health data on specific groups of young people, with multiple or complex needs, because the data is not centrally collected or easily accessible. In some instances it was unclear which Agency or Department is responsible for collecting information such as:

- Data on young people with a learning disability using mental services was not available through either the CAMHS or Learning Disability Commissioning Directorates at the HSCB;
- Data on Looked After Children (LAC) young people on the waiting list for CAMHS is included in the Delegated Statutory Functions Report, which is published yearly. However, they are not always easy to locate online; and

59 Information provided by email to NICCY on the 1 November 2017.

- Services for young people with alcohol and drug problems are funded and administered through the Public Health Agency. This agency therefore holds information relating to mental health support or services for this group. It was difficult to get up to date data for this group.

7.8 Mental Health Diagnosis or Presenting Need

Mental health clinicians diagnose mental disorders using criteria listed in a Diagnostic and Statistical Manual of Mental Disorders. Many clinicians are reluctant to give a diagnosis to children and young people, particularly those at a younger age, and instead categorise and treat according to the 'presenting need'.

Why is this Information Important?
The mental health diagnosis or presenting need of a young person helps to inform the system about the types of services, intervention and supports that should be in place.

What Information was Provided from our Request?

No standardised or reliable information was available from the HSCB or the HSCTs.

The following information was not available as part of our request:

- Information on the 'mental health diagnosis' or 'presenting need' of children and young people coming through CAMHS, was not collected in a central database by HSCTs, and therefore was not available to HSCB. NICCY was informed that access to this information would require a trawl of patient files ('Presenting need or complaint' is a data field in the CAMHS dataset).

7.9 Conclusions

In summary, there is a limited amount of publicly available, standardised regional Government data on mental health services, available to, and being used by children and young people. Currently, there is no central database providing a reliable regional breakdown of the demographic profile of children and young people accessing Step 1 to Step 5 CAMHS by age, ethnicity, disability, or by presenting need/mental health diagnosis, the reasons referrals are declined, detail on the therapeutic interventions being used, or the outcomes achieved by those accessing services. This dearth of information raises serious questions about the ability of CAMHS to plan, commission and provide services.

Overall, the information returned from the HSCB and HSCTs did not provide the level of detail required to fully understand basic operational aspects of CAMHS, and to adequately plan, deliver and monitor CAMHS. The HSCB has a key responsibility to monitor and ensure services delivered by HSCTs are adequate to meet the needs of children and young people, to support their emotional and mental health. However, this is not possible without key supply and demand data from the HSCTs. Very little operational data on CAMHS is available in the public domain. This lack of available basic CAMHS data, illustrated through this exercise, has highlighted a deficit in transparency and accountability in the planning and reporting of statutory emotional and mental health services. These issues need to be fully addressed as a matter of urgency.

SECTION 8

BUDGET DATA ANALYSIS

8.1 Overview

In total, HSCTs, the PHA and the EA provided NICCY data on a total expenditure in 2015–16 of £31,218,940, on 93 services to support the emotional and mental health of children and young people across Northern Ireland.

Table 8.1: Total expenditure by Steps and HSCT areas, 2015–16

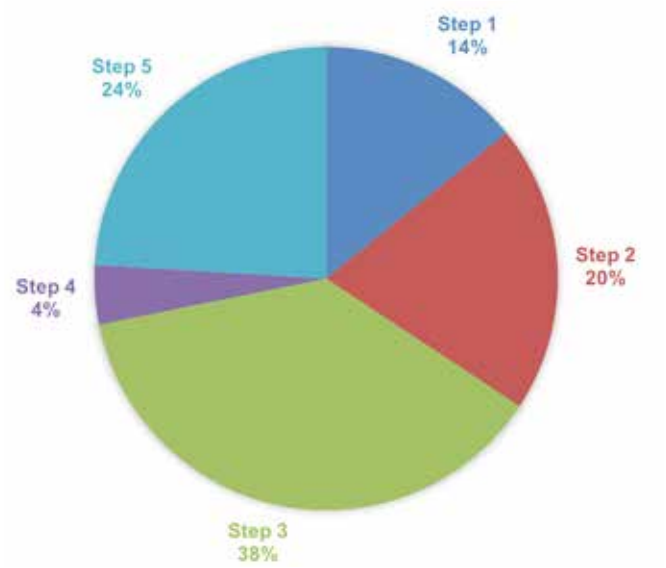
	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Total for five Trust areas
Step 1	£974,927	£810,195	£901,396	£770,310	£966,356	£4,423,184
Step 2	£1,264,395	£1,296,291	£1,115,819	£1,382,436	£1,276,200	£6,335,141
Step 3	£1,870,005	£2,578,047	£1,759,670	£2,813,923	£2,662,822	£11,684,467
Step 4	£472,471	£340,256	£472,471	*	*	£1,285,198
Step 5						£7,490,950
Total						**£31,218,940**

* Figures for Steps 3 and 4 services were provided combined for SHSCT, and for WHSCT

As outlined in Section 3, the analysis of the data provided has, at times through necessity, required some 'crude' calculations. One example is where, in attempting to provide some indication of where young people who avail of services are located, we have in some cases had to use quite crude divisions of budgets across two or more areas. It has not been possible to divide budgets across HSCT areas by the numbers of service users, or alternatively by comparing the numbers of children and young people in each area. We have, in the cases where a service was delivered to young people over more than one Trust area, simply divided the budget equally between areas. This also includes services, such as the EA Nurturing Approaches in Schools Service (NASS), which are not funded in respect of HSCT boundaries.

The following Figure outlines how the reported budget spend on emotional and mental health services for children and young people is broken down by Step, with the largest investment being in Steps 3 and 5.

Figure 8.1: Breakdown of budget reported by Step, 2015–16



8.2 Expenditure on Step 1 Services: Universal health and Well-being/Targeted Prevention

> This involves the adoption of a wide range of services designed to ensure the best developmental and emotional start for all children, and ongoing support and advice to support the psychological well-being and mental health of children and young people. (HSCB, 2015:1)

While it is important to recognise the key role these services play in supporting the emotional and mental health of children and young people, a more limited number of services have that goal as their sole purpose. Investing in maternal care services, school nursing, health visiting and GPs can help to prevent children and young people developing emotional or mental health problems. However, following discussions with the commissioners of these services, it became clear that it would be very difficult to include the investment in these services in this Review, as there was no way of making reasonably robust calculations as to the proportion of these services which impact on the emotional and mental health of children and young people.

We were, however, able to gather data on three types of Step 1 services, as these focused primarily on promoting the emotional and mental health of children and young people:[60]

- Public health education: including mental health promotion, relationship and sexuality education, training to prevent risk-taking behaviour, resiliency and parenting courses, drug and alcohol harm reduction, 'one stop shop' information and advice services focusing on personal health and well-being and signposting to services where required;
- Youth services: including mentoring to vulnerable young men with complex needs, floating support services targeted to address the needs of those who are vulnerable, isolated, 'at risk' as a result of homelessness, or socially excluded, services to support the well-being of transgender individuals and their families, supporting looked after children in recreational activities to improve their health and well-being, and 'Mood Matters' programmes to promote good mental health; and
- Education: data on one service was included in this category, the EA 'Nurturing Approaches in Schools Service (NASS)'. This is a regional service supporting the development of Whole School Nurturing Approaches (WSNA) model of support across the primary sector, building the capacity of 31 funded Nurture Groups.

60 It should be noted that these categories are not exclusive – some services may fall under more than one category. However, we have assigned each service to the category with the closest fit.

With the exception of the last programme, all of these services are funded by the PHA, and the majority are delivered by more than a dozen voluntary and community sector organisations. The remaining two services were commissioned by the PHA, but delivered through HSCTs.

Table 8.2: Public expenditure on Step 1 emotional and mental health services by Trust area 2015–16

	Funder	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Total
Public Health Education	PHA	£349,610	£192,614	£306,300	£210,427	£398,009	£1,456,960
Youth Services	PHA	£99,517	£91,781	£69,296	£34,083	£42,547	£337,224
Education	EA	£525,800	£525,800	£525,800	£525,800	£525,800	£2,629,000
Total		**£974,927**	**£810,195**	**£901,396**	**£770,310**	**£966,356**	**£4,423,184**

In total we received data relating to expenditure amounting to £4,423,184 on 33 Step 1 'targeted prevention' services, primarily focusing on supporting the emotional and mental health of children and young people.

8.3 Expenditure on Step 2 Services: Targeted Intervention

This involves early detection and provision of preventative support to children and families in need. Intervention at this Step is provided to children and young people who are experiencing early developmental/behavioural difficulties and/or mental health/emotional difficulties; or engaging in risk behaviours which are progressively impacting on the child's, young person's and/or families psychological/social/educational functioning. At this Step structured self-help approaches, behavioural, and/or family support are provided to reduce the impact of mental health and emotional problems and prevent their escalation to greater/more significant difficulties. (HSCB, 2015)

These services are targeted at children and young people in need, and include a range of services and interventions. As with Step 1, only a proportion of these focus primarily on emotional and mental health. Again for services with a broader purpose, it proved difficult to provide reasonably robust calculations as to the proportion of these services aiming to impact on the emotional and mental health of children and young people.

We received data relating to expenditure on 37 Step 2 services, across four categories:

- Primary mental health services: these assess and treat children with mild/moderate mental health and emotional well-being issues, with a focus on early intervention and prevention provided through family support group work. These services are funded by the HSCB and delivered by the HSCTs;

- Specialist infant mental health services: data was provided for a service in one HSCT area. We understand that, while there may not be dedicated budgets in other HSCTs, similar services may be provided;
- Family support and social care: these services are provided to children and their families to enable them to overcome difficulties, for example after being bereaved through suicide, or early intervention support when difficulties arise before the involvement of statutory services is required. These may include 1-2-1 counselling for individual children or young people, as well as family support; and
- Youth counselling services: community based services including psychotherapeutic interventions (talking therapies) to young people experiencing mental health difficulties. Some target young people who have been bereaved, or with drug problems, or children and young people with parents who have drug problems. This category also includes the EA's Independent Counselling Service for Schools (ICSS), and which is available to all post-primary pupils in mainstream and special schools across Northern Ireland.

While primary mental health services and specialist infant mental health services are funded by the HSCB and delivered by the HSCTs, Family Support and Youth Counselling services were delivered by around 14 community and voluntary sector organisations and funded by the PHA, with the exception of two EA services.

Table 8.3: Public expenditure on Step 2 emotional and mental health services by Trust area 2015–16

	Funder	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Total
Primary mental health services	HSCB	£292,573	£312,259	£292,743	£517,640	*	£1,415,215
Infant mental health services	HSCB	£0	£0	£0	£98,496	£0	£98,496
Family support and social care	PHA	£421,492	£115,404	£272,746	£115,404	£125,404	£1,050,450
Youth counselling services	PHA/EA	£550,330	£868,628	£550,330	£650,896	£1,150,796	£3,770,980
Total		**£1,264,395**	**£1,296,291**	**£1,115,819**	**£1,382,436**	**£1,276,200**	**£6,335,141**

* The funding for Primary mental health services was not disaggregated from the wider CAMHS budget in WHSCT, and is included in the totals for Step 3.

A total expenditure of £6,335,141 was reported to NICCY on Step 2 services.

8.4 Expenditure on Step 3 Services: Specialist Intervention

This involves specialist diagnostic therapy. Intervention at this Step is provided to children and young people who are experiencing moderate mental health and emotional difficulties which are having a significant impact of daily psychological/social/educational functioning. Intervention at this Step is normally provided through specialist/specific multi-disciplinary teams. (HSCB, 2015)

From Step 3 onwards the funding and delivery of emotional and mental health services is almost entirely through the HSCB, and delivered by the HSCTs. Most are delivered by CAMHS teams, although some, particularly for young people with disabilities, are delivered through other statutory teams.

As most of the services included in Step 3 focus entirely on mental health interventions, collating data on these proved less problematic. The exception to this was the specialist autism service, safeguarding services and behaviour support for learning disability services/ID CAMHS.
The services NICCY received data for were:

- Elective CAMHS teams: these operate on a multi-disciplinary basis providing comprehensive care to children and young people up to 18 years who have emotional behavioural and mental health difficulties;
- CAMHS Eating Disorders: a specialist service which meets the needs of young people suffering from a range of eating disorders up to the age of 18. They also provide consultation and supervision to staff in Steps 2, 3 and 4 who are working with children with mild to moderate eating difficulties;
- CAMHS Addiction: this service is provided to children and young people up to 18 who have drug and alcohol difficulties and have co-morbid mental health concerns;
- Family trauma service: a regional service that provides individual and family treatment to families who have suffered trauma across the five HSCTs;
- ID CAMHS: specialist (Step 2 and 3) mental health provision for children, young people and their families with an intellectual disability and mental health needs. Data was received only from one HSCT relating to this service; and
- KOI ('Knowing Our Identity') regional service: provides specialist intervention to young people and their families to help with gender related difficulties, and ensure young people are understood and supported by those around them – for example families, schools, clubs and activities. Liaises with other services such as local mental health services and community services, which can provide additional support for young people and their families.

Table 8.4: Public expenditure on Step 3 emotional and mental health services by HSCT area 2015–16

	Funder	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Total
Elective CAMHS teams	HSCB	£1,622,553	£2,308,921	£1,512,218	£1,936,423	£2,405,039	£9,785,154
CAMHS Eating disorders	HSCB	£76,050	£131,127	£76,050	£253,259	£82,748	£619,234
DAMHS (CAMHS Addiction Service)	PHA	£63,042	£29,639	£63,042	£53,647	£66,675	£276,045
Family Trauma Service	HSCB	£86,126	£86,126	£86,126	£86,126	£86,126	£430,630
ID CAMHS	HSCB				£462,234		£462,234
KOI Service	HSCB	£22,234	£22,234	£22,234	£22,234	£22,234	£111,170
Total		**£1,870,005**	**£2,578,047**	**£1,759,670**	**£2,813,923**	**£2,662,822**	**£11,684,467**

A total expenditure of £11,684,467 on Step 3 services was reported to NICCY.

8.5 Expenditure on Step 4 Services: Intermediate Care

This involves the provision of crisis intervention and intensive home/residential/or day care services designed to reduce and/or manage those children and young people who are at immediate risk or who need intensive therapeutic care. The primary objective of this intervention is to prevent admissions to acute hospital care. (HSCB, 2015)

While the Stepped Care model contains three services at Step 4, this is a reflection of the direction of travel, rather than the current situation. Two services included in the model are not currently in place: Crisis Residential and Intensive Day Care Support services. Only one service is currently being delivered at Step 4:

CAMHS Resolution and Home Treatment service: these aim to provide rapid assessment and intervention to children and young people whom without intervention could require inpatient mental health care or present serious harm to self or others.

Table 8.5: Public expenditure on Step 4 emotional and mental health services by Trust area 2015–16

	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Total
CAMHS Resolution and Home Treatment Teams (CAIT)	£472,471	£340,256	£472,471	*	*	£1,285,198

* The Western and Southern Trusts were not able to provide disaggregated figures for the spending on this service.

A total expenditure of £1,285,198 on Step 4 services was reported to NICCY.

8.6 Expenditure on Step 5 Services: Highly Specialist Inpatient/Secure Care

Care at this Step is provided for those children and young people who are experiencing highly complex, enduring mental health and emotional difficulties which severely restrict daily psychological/social functioning. At this level the young person will require the input of several specialist agencies and/or acute inpatient or secure care services. (HSCB, 2015) The Stepped Care model contains four services at Step 5, of which three are in place, delivered on a regional basis:

- CAMHS Acute in-patient care: this is a regional service based at Beechcroft, delivered by the Belfast HSCT. It admits young people presenting with a range of severe and/or complex mental health disorders which cannot be managed in the community, delivering assessment and treatment;
- Forensic CAMHS: this is a regional service delivered by the SE HSCT. It includes Step 3 CAMHS services at the Woodland Juvenile Justice Centre, and Step 5 Community Forensic CAMHS; and
- Iveagh Inpatient Unit: a regional inpatient assessment and treatment service for young people with intellectual disabilities. In 2015-16 this was used by all Trusts except for the WHSCT which provided this service at Lakeview hospital, however this has since changes and now all HSCTs use Iveagh.

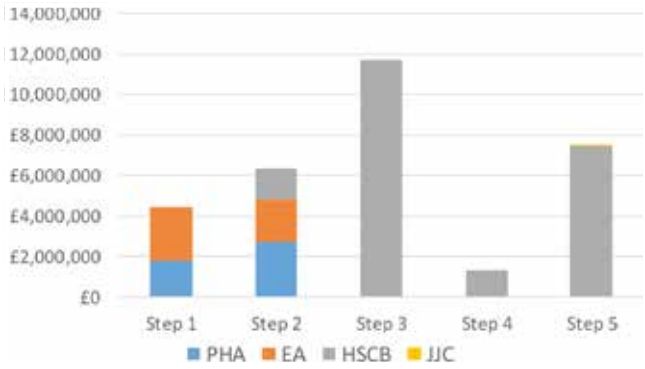
Table 8.6: Public expenditure on Step 5 emotional and mental health services 2015_16

	Delivery	Funder	Expenditure
CAMHS acute in-patient care	BHSCT	HSCB	£5,224,361
Forensic CAMHS	SEHSCT	HSCB/JJC	£168,327
Iveagh Inpatient Unit	SEHSCT	HSCB	£2,079,948
Total			£7,490,950

A total expenditure of £7,490,950 on Step 5 services was reported to NICCY.

8.7 Funding Sources for Emotional and Mental Health Services for Children and Young People

Figure 8.2: Public expenditure on emotional and mental health services by Step, and funding source (2015–16)



In relation to the data received relating to Steps 1 and 2 emotional and mental health services, the PHA and EA provide the majority of the funding to services supporting the emotional and mental health of children and young people. However, it is important to remember the other key Step 1 and 2 services provided to children and young people for which this is not the primary purpose, but which are critical in preventing the mental ill-health of children and young people, for example GP services. In Step 1 many of these broader services are also funded by the PHA, while the HSCB is responsible for funding many of the additional services in Step 2. The funding situation changes significantly from Step 3 onwards, as these specialist mental health services are largely funded by the HSCB.

It is important to recognise this data only includes statutory funding, and does not include the support provided to children and young people from Voluntary and Community Services, who are funded through charitable sources.

8.8 Numbers of Children and Young People Accessing Services and Costs per Head

While most data sheets returned contained financial information, fewer contained information on the number of children and young people accessing services. It should be noted that some administrative data collection systems were not able to easily identify where a child may have accessed a service more than once. For these services, notably those within CAMHS, the figures that were provided reflect the number of accepted referrals, rather than the number of children accessing the service.

Step 1: Out of the 33 services for which NICCY received financial data, 23 also provided data for number of children availing of the services. In total, 14,701 children accessed these services, at an average cost of £241 per child. The cost per child ranged from £6 to £720 for these services.

Step 2: Out of the 37 services for which NICCY received financial data, 22 also provided data for number of children availing of services. In total, 8,743 children accessed these services, at an average cost of £1,120 per child. The cost per child ranged from £98 to £5,734 for these services. It should be noted that the EA's ICSS provided a service for a majority of these children, with around 5,000 accessing it.

Step 3: Of the 16 services for which NICCY received financial data, 9 also provided data for the number of children availing of services. In total 2,529 children accessed these services, at an average cost of £3,728 per child. The cost per child ranged from £1,495 to £9,880.

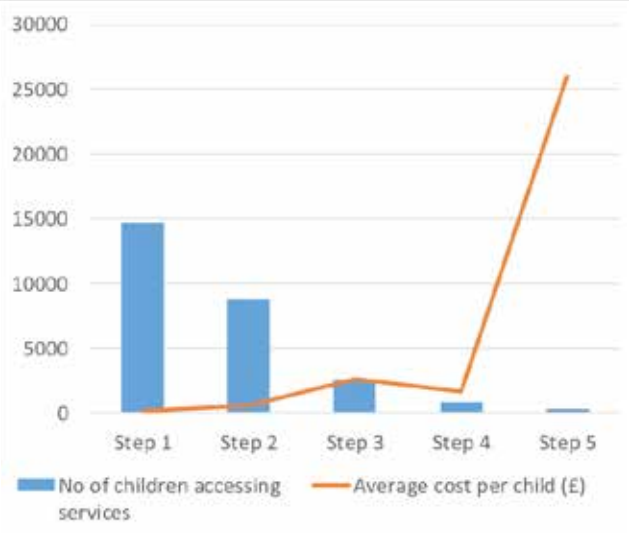
Step 4: We received financial data for CAMHS Resolution and Home Treatment Teams (CAIT) for three of the five HSCT areas.

These HSCTs also provided data on the number of children availing of these services. In total, 805 children accessed these services, at an average cost of £1,602 per child. There was very little variation in cost per child between these services.

Step 5: We received financial data for three regional services, the Acute Inpatient Care, the Iveagh Inpatient Unit and Forensic CAMHS service. Data on the number of young people availing of these services was provided for all three services. A total of 288 young people accessed these services, at an average cost of £26,010 per child. The cost per child ranged significantly between the three services: with acute inpatient care costing £159,996 per child in contrast to the £1,637 per child for Forensic CAMHS.

While figures across the five Steps do not provide a complete picture, due to their partial nature, they do suggest a trend from Step 1 to Step 5, both in the number of children and young people accessing the services and the cost per child. As illustrated by the Figure below, most children and young people are receiving support for their emotional and mental health from universal preventative services, and targeted early intervention, at the lowest cost. Fewer children and young people require more specialist Steps 3, 4 and 5 services. However these become progressively more expensive as one progresses up the Steps of the Stepped Care Model, and more specialist and/or intensive care is required.

Figure 8.3: Number of children accessing services and average cost of services, by Step (2015–16)



8.9 Staffing Mental Health Services

The data provided in relation to staffing emotional and mental health services was very limited, particularly Steps 1 and 2. For these Steps, therefore, the figures were not complete. In contrast, the data on staffing in Steps 3 and 5 was complete.

Table 8.7: Staff working in services

	Proportion of services reporting numbers of WTEs	Total WTE staff reported
Step 1	9 out of 33	13.12
Step 2	14 out of 37	65.39
Step 3	16 out of 16	186.72
Step 4	2 out of 4[61]	26.85
Step 5	3 out of 3	201.15

61 In relation to the two services where WTE data was not reported, the number of staff for one is included in the Step 3 figures, and for the other there isn't strictly a specific Step 4 service.

8.10 Evaluation of Mental Health Services

As discussed earlier, gathering figures on funding for emotional and mental health services for children and young people is of limited value, without any indication of whether the services are both efficient and effective in improving children's outcomes. Where budget analyses are combined with meaningful evaluation, this allows for assessments of where additional resources could be usefully deployed, or indeed, whether resources currently being allocated to some services, with limited impact, should be redeployed to other, more effective, services.

The level of evaluation, of course, must be proportionate to the level of investment in the service. Programmes with significant investment should be more rigorously and robustly evaluated than services with smaller budgets.

Step 1 and 2 services commissioned by PHA were largely monitored on a quarterly basis using regionally approved key performance indicators, alongside a self-evaluation/ review at the end of each year. Some of the smaller programmes only reported having been monitored through noting the number of children attending the programme, while some more significant programmes had been independently evaluated. For example the regional Relationships and Sexuality Education contract and the Early Intervention Support Service (EISS). The EA Nurture programme had also been independently evaluated by Queens University Belfast.

Information on Steps 3 to 5 services generally included more information on a wider range of evaluation methods. For example, from the WHSCT, in relation to their Step 3 Elective CAMHS teams:

"Specialist CAMHS services use a range of methods of evaluation to measure outcomes. These include SDQ, Parent/Carer Group and feedback questionnaires. The CAMHS Service are engaged in the NHS Benchmarking Framework and QNCC which provides comparative measurement on overall performance standard against other CAMHS teams. On a qualitative level a range of initiatives are considered on a regular basis to achieve improvements through service user engagement initiatives. The service has commissioned (a VCS organisation) to act as independent advocate in representing the views of young people on how service improvements can be achieved. The WHSCT CAMHS and ASD Service contributed fully to the regional Sensemaker Audit which has informed the services on a range of valuable developments and improvements."

8.11 Education Authority Services

The EA provided information on eight services funded through DE. However, only two of these could be defined primarily as services to support the emotional and mental health of children and young people, and were therefore included in the above calculations. These were:

The EA 'Nurturing Approaches in Schools Service (NASS)': a regional service supporting the development of Whole School Nurturing Approaches (WSNA) model of support across the primary sector, building the capacity of 31 funded Nurture Groups; and The ICSS, a professional counselling service underpinned by clear professional standards and operating guidelines which are contained in the ICSS Handbook. This service is available in all post-primary schools.

The EA provided information on other services which support the emotional health and well-being of children to which, in 2015-16, it provided in excess of £30 million funding. While these are clearly vital services, they were

not included in the figures earlier in this section due to being primarily education services, as opposed to emotional or mental health support. These include:

- Educational Psychology Service: this service undertakes assessments of educational needs and delivers tailored interventions to children and young people as well as providing advice and training to parents and teachers;
- Behaviour Support Services (primary and post-primary): these services support children and young people with a range of social, emotional and behavioural issues, including bullying;
- Exceptional Teaching Arrangements: this service provides tuition outside of school, usually based on a CAMHS referral. While some children access tuition due to illness, others are identified who have anxiety based issues or emergent mental health issues which impact on their attendance in a mainstream school; and
- Intercultural education service: this helps schools to meet the additional educational needs of pupils from a number of 'target' communities: Traveller, Newcomer, Asylum-seekers, Refugees and Roma.

One service could be considered to have a primary focus on providing emotional and mental health support, but was not included in the above figures, as it does not have a specific budget:

- Critical incident support: The role of the Critical Incident Response Team is to enhance the school's pastoral care system by providing advice, support, guidance and resources to assist school staff to successfully respond to the death of a child or a staff member in the school.

The EA's Youth Service also delivered a PHA funded support service for young people experiencing mental health issues and spending on this was included in Step 2 figures.

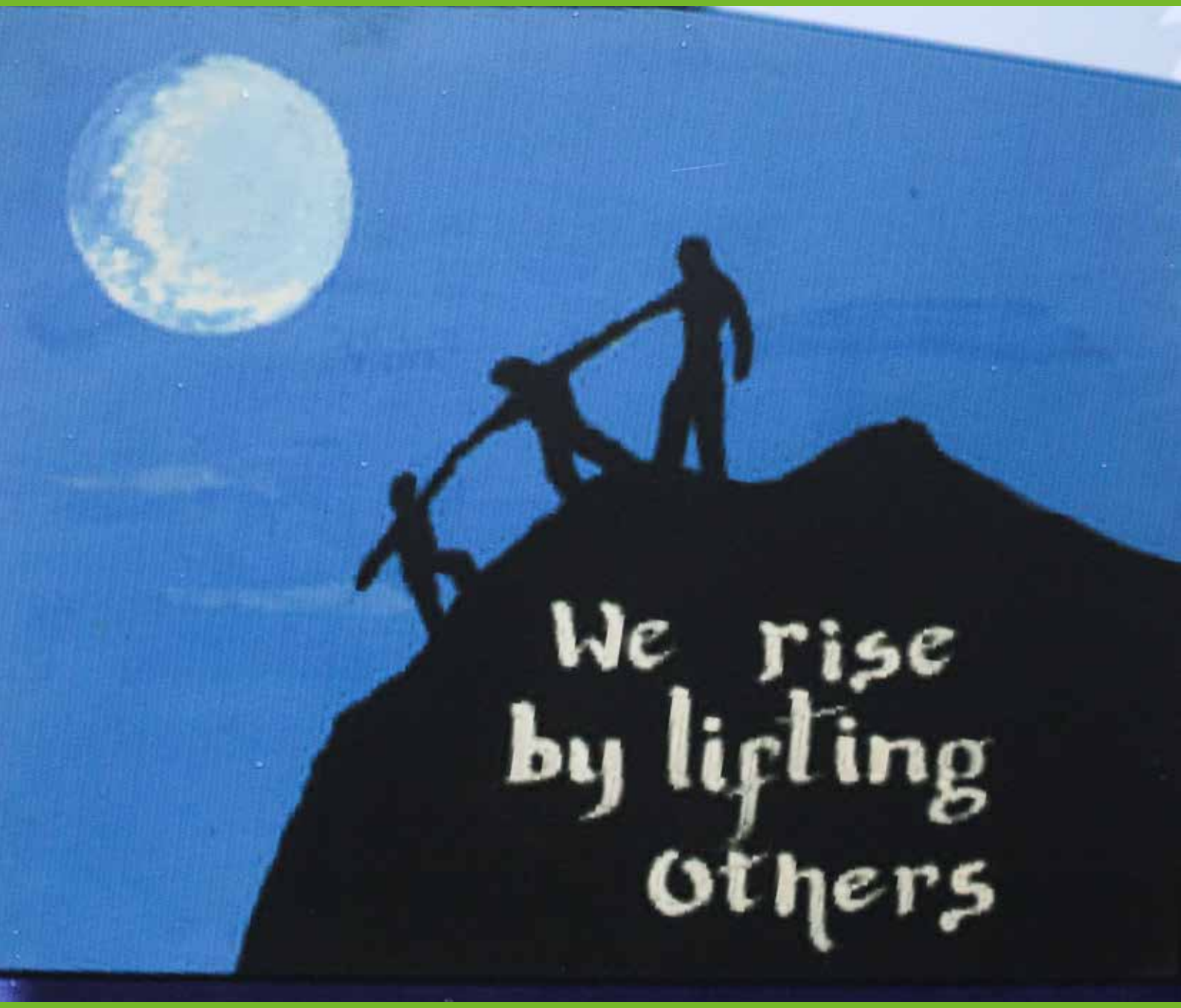
8.12 Conclusion

This section has provided an analysis of the data received from the EA, HSCB and PHA on emotional and mental health services for children and young people in Northern Ireland in 2015–16. It does not include data on important universal health services such as GP care and A&E, or the critical early intervention and prevention services that have a broader focus than mental health such as safeguarding services and family support due to challenges providing a robust estimate of the proportion of funding allocated specifically to mental health support within these.

Despite this, this analysis provides the most comprehensive picture to date of how government funds emotional and mental health services for children and young people in Northern Ireland, and the range of organisations supporting children and young people's emotional and mental health at each Step in the Regional Stepped Care Model. In total, data was provided on 93 services receiving funding of £31,218,940 to support the emotional and mental health of children and young people, across all five Steps.

We received data indicating that over 27,000 young people accessed these services in 2015–16 – although this figure may include some young people accessing a service or course of treatment more than once, or several different services over the year. The cost of services varied considerably, from £6 per child for some Step 1 prevention services, to £159,996 per child for Step 5 acute inpatient care.

This analysis provides an important snapshot of the services funded in 2015–16. Given the widespread recognition of the need for more funding for these services, this should be used as a baseline to map increasing investment in the future.



SECTION 9

THEMES AND RECOMMENDATIONS

9.1 Introduction

NICCY'S VISION
A children and young people's mental healthcare system that ensures that all children in Northern Ireland can enjoy the highest attainable standard of mental health, and have equal and unimpeded access to services and facilities, for the prevention, early intervention and treatment of mental illness.

This section outlines the key themes identified across the Review, and the recommendations emanating from the evidence gathered. The general thematic areas are relevant to all children and young people, and in addition to this, specific reference is made to children and young people with a learning disability, and young people with alcohol and drug problems.

9.2 Key Thematic Areas

1. **The Regional Model for the Delivery of CAMHS**
2. **Mental Health Pathways and Thresholds for Accessing Services**
   - Referral Processes
   - Waiting Times to Access Services
3. **Access to Crisis Mental Health Support**
   - A&E in Mental Health Service Pathway
4. **Support for Young People at Different Stages of Accessing Services**
   - Support while waiting for Step 3 CAMHS appointment
   - Support between Step 3 CAMHS appointments
   - Making and Attending Appointments
   - Discharge from Step 3 CAMHS due to DNA/CNA
   - Support on Discharge from Step 3 CAMHS
   - Co-ordination and Communication between Services
5. **Choice and Effectiveness of Treatment/ Support**
   - Medication as a Treatment Option
   - Psychological Therapies
   - Alternative Therapies and Holistic Approach to Treatment
6. **The Role of a Significant Adult**
7. **Participation and Feedback from Young People**
8. **Outcomes**
9. **Key Aspects of a Good Mental Health Service**
10. **Transition from CAMHS to AMHS**
11. **Mental Health Awareness and Literacy**
12. **Young People with a Learning Disability**
13. **Young People with Alcohol and Drug Problems**
14. **Operational Data on Child and Adolescent Mental Health Services**
15. **Investment in Services within the Stepped Care Model**

9.3 The Regional Model for the Delivery of CAMHS – An Overview

The Stepped Care Service Model for CAMHS is the preferred regional model for the organisation and delivery of a comprehensive array of mental health services and support for children and young people in Northern Ireland (DHSSPS, 2012). The purpose of the regional model was to provide service commissioners and providers with a framework against which to remodel CAMHS provision, to achieve greater consistency in the services being offered across HSCTs, and to create the conditions so that all young people receive an appropriate level of care at the earliest point, whilst also allowing them to move up and down the steps as their needs change.

The Stepped Care Model is underpinned by a whole system understanding of mental health services and a life course approach, both of which are essential to a rights based mental

healthcare system. An emphasis is placed on: *'enabling effective connections between primary care, child health, social care services and specialist CAMHS'*. It establishes that prevention, early intervention and proactive recovery are core elements in the provision of high quality and effective care for children, young people and their families and carers. The model states that the: *'provision of services to enhance mental and emotional well-being is wider than statutory health and social care and involves community and voluntary sector groups, education and youth justice organisations.'* (DHSSPS, 2012)

When the Model was published and agreed in 2012, the goal was for it to be fully established within 5–10 years. There have been positive changes to the provision of services since this model was agreed, particularly in the last 10 years, which reflects the vision set out by the Model, however, there continues to be fragmentation in the availability and accessibility of services (DoH, 2016:2). When the Model was published, figures were not provided on how much funding it would take to fully implement the core services across the region, but it was acknowledged that aspects of it would require additional investment. Unfortunately the core budget for children and young people's mental health services has not changed significantly enough to meet its ambitions for system reform. Innovation is important, as is ongoing system review. However, in the case of children's mental health, substantial additional, sustainable funding is required to ensure that the needs of children and young people are being met at the earliest opportunity, and in the most effective way.

Although the Stepped Care Model is to some extent a 'conceptual model' and not necessarily a plan of specific services, it is incredibly useful for establishing the broad range of services and support the system agrees should be in place to: *'address the physical, emotional, social and educational needs of CYP in order to promote positive mental health.'* (DHSSPS, 2012). This Review and consequent recommendations are framed with a view to ensuring that it is effective in improving services and outcomes for children and young people.

In view of the comprehensive nature of the Stepped Care Model, it is the framework upon which this Review has been based:

- **Strand 1** – focused on children and young people's experiences of services across all 5 steps, in particular Steps 3 – 5; and
- **Strands 2 and 3** – focused on mapping and analysing available operational and investment data.

During the course of the Review, NICCY has found a lack of recognition of the Stepped Care Model as an overarching system wide policy framework. This was most evident within services or agencies that are not mental health specific. The Education Authority (ea) has been very clear that it does not align itself to the Stepped Care Model, perceiving it to be relevant to statutory mental health services, and not the education system. The EA have stated that the Independent Counselling Service for Schools (ICSS) and Education Welfare Service are not part of the Stepped Care Model.[62] There is clearly a lack of agreement and shared understanding between the health and education system on this point, as the education system generally, and ICSS more specifically, are integral to the system wide approach envisaged by the Stepped Care Model (DHSSPS, 2012). Furthermore, the Education Welfare Service and ICSS are listed as one of a number of specific referral access points into Step 3 CAMHS (HSCB, 2018:2). Unfortunately,

62 Meeting between EA and NICCY- 29 November 2017 and written feedback 4 September 2018.

regional data on the referral sources to Step 3 CAMHS was not available for this Review, which would have clarified the extent to which these education services are making referrals into statutory mental health services. The lack of connection with the Stepped Care Model was also evident in conversations with those involved in Children's Disability services, who described its services as very separate to statutory mental health services.

The mental health care system must be part of the broader transformation plans for the health and social care system (Bengoa, 2016). It makes sense to see mental health alongside physical health and social care, as in young people's day to day lives they are inextricably linked. There is broad recognition of the need for parity of esteem between physical health and mental health (RCP, 2013).

In the context of realising the vision set out in the Stepped Care Model for CAMHS, there is also a need to ensure that equal value is placed on services and professionals working across different steps of the Model. This includes equal value and parity of esteem between prevention and early intervention services (Steps 1 and 2), and more specialist mental health services (Steps 3 – 5).

The development of a Managed Care Network was one of the key overarching recommendations in the 2014 Review of Beechcroft and Acute CAMHS Pathways, and the implementation of such a Network was agreed by the DoH within a 2015/16 Action Plan for implementing these recommendations (Rees et al., 2014). The Network is not currently operational,[63] but its purpose will be to ensure better integration and co-ordination of 'acute' or 'high intensity' services across the region i.e. Step 4 and 5 of the Stepped Care Model. The Managed Care Network's will be responsible for developing the acute care pathway and agreeing protocols and arrangements to achieve a more integrated and effective response to young people with high intensity/acute needs, regardless of where the young person presents. Young people in the Lakewood Secure Care Centre and Woodlands Juvenile Justice Centre are included in the Network.

As already highlighted, effective care of children and young people with mental health problems spans beyond specialist mental health services, to include services within the broader health and social care system i.e. primary care, social services, and justice. The involvement of the education system and the Voluntary and Community Sector (VCS) is also essential to the development of an integrated, holistic approach. There is considerable opportunity for this to be driven forward through the operational out-working of the Managed Care Network.

9.4 Mental Health Pathways and Thresholds for Accessing Services

The mental health pathways described by young people during the Review often included contact with a number of services and professionals from across the Stepped Care Model.[64] Typically, this included a combination of contacts with School, GP, and VCS organisations and Step 3 CAMHS. Unfortunately, there were many examples provided in the course of this Review of young people having difficulties with accessing appropriate mental health services, and having to speak to multiple professionals before getting support. Some young people's

63 The establishment of the Managed Care Network and the day to day operation will be overseen by a Clinical Director and Network Manager. The commissioning arrangements are being undertaken by the BHSCT and it is anticipated that the posts will be filled in the Autumn – email correspondence from HSCB to NICCY, 9 August 2018.

64 See Sections 4–6 – young people's experience data for more detail.

experiences had led them to believe that unless they were presenting with 'severe mental health problems you would not be taken seriously or given help'. There were also examples of young people who were suicidal and who had attempted suicide, not being able to access mental health support. This was a particularly concerning problem raised by young people who had co-occurring alcohol or drug problems, and who had experience of presenting to A&E during a mental health crisis.

The complicated mental health pathways that young people and practitioners have described in the Review, appear to be completely contrary to one of the main aims of the Stepped Care Model, which is to 'simplify patient pathways' (DHSSPS, 2012).

This Review has identified significant pressures for services within Step 1, 2 and 3 of the Stepped Care Model, and in particular, GPs, VCS Services and Statutory Community CAMHS Services. It also found that A&E has a critical role in responding to young people in mental health crisis. Practitioners from across these services referred to capacity issues resulting in young people being referred back and forth between different services. The young people surveyed as part of this Review also had very mixed views regarding the ease of access to support across a range of services.[65]

During the Review, we heard from a range of professionals that increasing demand for services with no extra funding, and in some cases reduced funding, was leading to decisions about whether to accept a child for a service, being made solely or mainly on the basis of service capacity and existing resource, rather than on meeting the needs of the child. Decision making processes that are based on capacity and resources, rather than the needs of the child is not in their best interests, as is required by the UNCRC.

The following cyclical process was described by young people and practitioners:

- Long waiting times and difficulty with a young person being accepted at Step 3 CAMHS leading to health professionals, normally a GP, suggesting that young people try a Step 2 Service first, even though they may assess a young person as more suitable for Step 3; and
- VCS (Step 2) services cannot offer support to a young person due to a lack of capacity or due to the level of risk presented by the young person, so they automatically refer them on to another service, this is often the GP.

The impact of insufficient investment in services to meet needs has been raised in the relatively recent 'Review of Beechcroft and Child and Adolescent Acute Care Pathways' (Rees Report) which found a, 'culture of referring on' by services because they are working in an environment where demand is out-stripping its ability to respond (Rees et al., 2014). It went on to say that this practice of 'referring on' prevents the joint working that is needed to ensure children and young people receive a seamless service. During the practitioner workshops conducted as part of the Review, there was a strong view that this issue will not go away unless there is a long term, sustainable 'funding and practice partnership model' developed across services and sectors included in the Stepped Care Model.

In the absence of sufficient investment in the full range of services across the Stepped Care Model, specialist services can become crisis services, with children and young people being seen only when their condition has deteriorated. The Rees Report commented on

65 See Sections 4–6 – young people's experience data for more detail.

the demand that is placed on services at the more acute end of the Stepped Care Model due to a lack of services in the community, when it stated that: *'Step 5 in-patient services appear to have become the lightning conductor for all the services provided in the community and is predominately responding to crisis admissions'* (Rees et. al, 2014).

HSCTs are developing a 'single point of entry system' which is designed to receive all first referrals for a mental health assessment. The aim of a single point of entry system is that all referrals are triaged as quickly as possible, and directed to the most appropriate destination without delay. Having one point of referral is designed to be a gateway for all requests for mental health assessment for Step 3 CAMHS.[66] There are also currently plans to develop a children and young people's neurodevelopmental and emotional well-being services framework (CYPNEW). The intention of the framework is to place a greater focus on integration across emotional health, well-being and developmental services, including the establishment of a single system of care and single point of entry for emotional, developmental and mental health problems e.g. ASD, ADHD and CAMHS.[67]

Changes to the system to ensure that mental health pathways for young people are as direct as possible and ensure that support is provided in the shortest timeframe possible, are essential. Single point of entry and triage systems are processes that can ensure the most appropriate support is identified as quickly as possible, however they also rely on sufficient capacity across the system, so that services that are assessed as being best suited to support young people are able to take referrals. The evidence NICCY has gathered shows that services across the Mental Healthcare System are finding it difficult to meet demand.

Referral Processes

The HSCB has developed regional referral guidelines for Step 2 and 3 CAMHS, that outline the range of health professionals who can make a referral to services that fall with these steps. The list of referral agents include GP, Child and Family Social Services, Paediatric Services, Child Health Services, Education Welfare Services including the Independent Counselling Service for Schools (ICSS), voluntary agencies within the Stepped Care Model and Family Support Hubs (HSCB, 2018:2). It was apparent from our engagement with practitioners supporting young people to access Step 3 CAMHS, that there is a lack of clarity about who can refer young people to it.[68]

In the course of the Review, NICCY was unable to access regional monitoring data on the main referral sources to Step 3 CAMHS.[69] However, all the evidence gathered as part of this Review indicates the vast number of referrals to Step 3 CAMHS[70] come from a GP, and potentially a significant proportion of the urgent and emergency referrals. This demand places considerable pressure on one part of the primary health care system.

The challenges for GPs is compounded further when one considers they have variable levels of training on mental health before coming into practice. Some may have undertaken

66 Triage is a pre-assessment process that doesn't require a face to face appointment between the young person and the appropriate mental health practitioner. The referral will be reviewed against regionally agreed referral criteria.

67 Briefings from DoH to NICCY, November 2017 and July 2018.

68 The issue was highlighted during the practitioner workshops held in May 2018 and also during engagement with the Education Authority – 29 Nov 17 and 4 September 18.

69 Referral Source is a data field in the CAMHS Dataset currently being implemented. See Section 7 for more information.

70 Referrals that require an appointment within 9 weeks of the referral being accepted.

mental health training, but this is not compulsory, and the appointment system GPs operate within in Northern Ireland only allows 10 minutes to carry out a consultation with a patient.

'Time is the commodity we do not have. Mainly no training in this field. I am happy to treat adults but feel child mental health often requires specialised assessment and much more time than we have.' (Quote from a GP)

During the Review, NICCY engaged with representatives from the Royal College of General Practitioners in Northern Ireland (RCGPNI), and carried out a short survey with members.[71] It is clear that GPs would like to see developments that would allow them to better meet the mental health needs of children and young people, the following were suggested:[72]

- Better training in mental health for GPs, and a greater range of options to offer young people;
- Better communication between primary care and specialist mental health services;
- More clarity on the referral criteria and pathways from GP to other services. This included a better knowledge of the VCS organisations available in the community to refer young people on to. The lack of local knowledge of services was identified as being particularly problematic for locum GPs working across HSCTs;
- Introduce a Mental Health practitioner role that is attached to or hosted at GP surgeries;
- Open up referral pathways to ensure that health professionals, other than a GP, are aware of their role and the process for making routine referrals to Step 3 CAMHS; and
- Quicker feedback to GPs following a referral to Step 3 CAMHS, particularly if it is not accepted.

Practice Examples

GP Mental Health Forum
GPs are generally working very separately from other services included in the Stepped Care Model, however in the WHSCT there is a GP Mental Health Forum which brings GPs and VCS organisations together, to develop local relationships and exchange local knowledge. It provides GPs with up to date information on VCS services, that GPs can refer young people on to, and where VCS organisations are already working with young people that require GP services, the VCS organisation can provide supporting information to GPs concerning an individual young person's needs.

CAMHS Telephone advice line
A telephone advice line for statutory CAMHS that parents/carers, or young people could use was mentioned during the practitioner workshops, as a way of improving the communication and support offered by services whilst young people wait for an appointment or between appointments. There are examples of this type of support being offered elsewhere e.g. Leicester statutory CAMHS.

GPs have a very significant and challenging role in the mental health service pathway. Of the young people surveyed as part of this Review, referrals to Step 3 CAMHS was the most common form of action taken by a GP, when young people went to them about their mental health (66%, n=157).[73]

71 Nine responses returned from a short survey promoted through RCGPNI member newsletter and twitter – January 2018.

72 A 2016 survey of 302 GPs reported that 78% are seeing more children and young people with mental illness and 61% are seeing more young people self-harming than five years ago (British Journal of General Practice, 2016)

73 See Section 4 for more detail.

As GP services are the gateway to specialist mental health support, young people and their parents and carers have expectations that the GP will have a sufficient level of expertise and knowledge. Young people expected GPs to provide more help for them than prescribing medication or signposting on to other services. Unfortunately, many young people who engaged with this Review did not have a good experience when they went to their GP about their mental health. In the online survey, young people reported a very mixed view of their GP service across the three main areas that we asked them about i.e. information and access, facilities and services and quality of care. Only 35% of young people stated that their GP was able to give them useful information to help them understand their mental health needs, and 44% reported the support they received was helpful.[74] Other studies, have also found that young people do not regard their GP as a source of help for emotional support (Corry and Leavey, 2017; Divin et al., 2018).

In both the young people's survey and interviews, conducted as part of this Review, young people expressed confusion about why they needed to go through their GP to be referred to Step 3 CAMHS, particularly as they did not associate GPs as being mental health experts. The need to go to a GP to get access to mental health support was particularly frustrating for young people who had already been accessing support from Step 2 services e.g. Community and Voluntary Sector organisation, Self-Harm Intervention Programme (SHIP), or the Independent Counselling Service for Schools (ICSS). For some young people, this resulted in a reluctance to visit their GP to talk about their mental health problems.

The regional referral guidelines state that referrals can be made by 'voluntary agencies within the Stepped Care Model' (HSCB, 2018:2). This refers to VCS organisations that are funded by statutory agencies to provide emotional or mental health support. However, there are a wide range of additional VCS organisations who provide mental health services for children, which are not funded by government, that are unable to refer directly into Step 3 CAMHS. Under current referral pathways, these additional VCS organisations must refer a young person to a GP, who then makes a referral to Step 3 CAMHS. In many cases, the VCS organisation may have built up a relationship with the young person, in contrast to the GP who may not know the young person or their circumstances.

Practice Example – SHIP Programme

The Self-Harm Intervention Programme (SHIP) is a regional early intervention service for all age groups who self-harm, and their families and carers, to prevent progression to more serious problems.

Children and young people aged 11 years and over can be referred to SHIP. Referrals are made to SHIP from statutory CAMHS. The Step 3 CAMHS referral route can create a lengthy process for a young person to get access to SHIP. A number of schools NICCY has been in contact with, have expressed frustration at the length of the referral process to get access to SHIP.
The PHA are considering the possibility of other referral pathways into SHIP.

During 2017–18, 1,328 (13%) of clients to SHIP were under 18s, which is a relatively small proportion of the overall clients supported. Self-harm is one of the main presenting issues coming through school counselling services in all areas and types of schools (DE, 2017) and under 18s represents an increasing proportion of those

74 Please note the average rating across the seven services contained in the survey for both these statement was 49%.

presenting to A&E due to deliberate self-harm, as reported through the DoH Self Harm Registry. These trends indicates a significant need for easily accessible and responsive support for under 18s who self-harm.

Annual data is not yet published on SHIP, as the service has been operational since 2015, it is vital that this reporting begins.

Practice Example

During the Review we have heard that, where there is a good working relationship between a GP and a VCS organisation, young people can be 'fast tracked' to Step 3 CAMHS, where the GP processes the case based on the assessment of the VCS organisation, who knows the young person well.

Services already working with a young person are in a much better position to identify a need for other services, such as Step 3 CAMHS, and to provide the information required as part of the referral process. Having to go through GP services can mean further delays in young people accessing services, and young people having to explain their situation to another adult, often an adult that they have never met, may be uncomfortable talking to or do not know very well. During the practitioner workshops that formed part of this Review, VCS organisations that work with young people with mental health problems agreed that it would be better for young people if a greater range of VCS organisations were able to refer to Step 3 CAMHS directly.

This Review has identified significant challenges with the role of GPs in the mental health pathway that needs attention, and which can only be addressed by considering the Stepped Care Model, and the role and resourcing of all key stakeholders within it. A 'whole system approach' to children mental health is vital.

A significant theme raised by young people throughout the Review, were problems with the initial process of a GP making a referral to Step 3 CAMHS. Young people tended to articulate this as having to have multiple appointments with their GP, before being referred on to Step 3 CAMHS, having to wait a long time to hear about the referral, or not being sure what was happening with it.

The referral process was also discussed with representatives from the RCGPNI and during the practitioner workshops. Some of the key issues raised about the referral process by GPs and practitioners were:

- Increasing numbers of referral forms being returned to the GP for more information, because the forms do not have enough information to allow an initial assessment to be made. During the course of the Review we have also heard that referrals are more likely to be accepted by Step 3 CAMHS if specific 'key words' are used on the form;
- Referral forms are much more likely to be returned to the GP by Step 3 CAMHS if a young person has not been to a Step 2 service first;
- No written or verbal response from Step 3 CAMHS to GP or young person once a referral is made to CAMHS; and[75]
- Referrals not being accepted by Step 3 CAMHS on the basis of the referral form only, without communication being made with the GP, to discuss the basis upon which the decision not to accept the referral was made.

75 The HSCB have stated that the HSCT follow IEAP guidelines which requires all referrals to be processed within 3 days of the date of referral and if a referral is not accepted they are redirected. Written correspondence to NICCY, September 2018.

"Biggest problem is difficulty accessing urgent and timely support, lengthy waiting lists due to lack of services means that as a GP I can get an adult seen faster than a child with mental health problem."
(Quote from a GP)

"The health and well-being of children and young people is an absolute priority for GPs and we need the right tools and information to be able to do our jobs to the best of our ability, in the best interests of our patients."
(Dr Grainne Doran, Chair of the Royal College of GPs in NI)

One very concerning issue which came to light in the course of the Review is the extremely high number of referrals to Step 3 CAMHS, not being accepted.[76] The regional average 'not accepted' referral rates to Step 3 CAMHS in 2015 /16 is much higher in Northern Ireland (42%) compared to England (28%) (OCCE, 2017). It is also deeply concerning that no information was available from the HSCTs or HSCB on the specific reasons why young people were not accepted, and no specific monitoring appears to be undertaken on whether young people are being successfully referred on to other services, deemed more appropriate.

It is unacceptable that such a large number of young people are waiting for a service, to be told after weeks or months, that they do not met the threshold for referral.

Regional threshold criteria[77] for accessing statutory CAMHS has not changed over the period that referral figures provided relate to. However, the perception of the young people and professionals that support young people to access services is that in practice, if not in policy, accessing statutory mental health services has become more difficult. The consequence of 'unaccepted referrals' are delays in young people getting access to the most appropriate services or support, placing further pressures on an already overstretched part of the mental health system and having a negative impact on young people's confidence in mental health services.

Waiting Times to Access Services

During the Review, when young people referred to problems accessing help for their mental health, one of the main issues raised was the often-protracted length of time it took to get help once they asked for it. On average, approximately only half (49%) of the young people surveyed agreed they were able to access services and support when they needed it. There was also significant variation across key services with respect to this statement.[78]

A key part of this Review has been gathering a detailed understanding from young people themselves about the stages or events between the first symptoms of their mental health problems developing and accessing professional support.

Young people described a number of common stages that they had gone through before accessing support. These are:

1. Initial lack of awareness that symptoms were mental health problems;
2. Working through denial and fear of asking for help;
3. A period of coping with problems alone;
4. Speaking with significant adults at home, school or community;

76 Referral Data is discussed in detail in Section 7.

77 Regional threshold criteria refers to conditions or symptoms that must be present in order for a referral to be accepted by a statutory service i.e. Step 3 – 5 services.

78 Survey responses are available in Section 4.

5. For young people requiring more support, this often led on to looking for other professional help, often starting with a GP;
6. Young people described a varied range of support offered to them once they spoke to their GP, which may have included referral to Step 3 CAMHS;
7. Problems attempting to access Step 3 CAMHS; and
8. Challenges with engaging with services that are not always designed or delivered in an age appropriate or enabling way.

It was apparent during the Review that young people themselves are often delaying asking for help, until they get to a point where they can no longer cope. Once young people do recognise they need help, the pathway to access the right help is not always as straightforward or as responsive as young people need it to be. The role of GPs in the mental health pathway is set out in detail in earlier sections of this discussion, but it is clear that many young people experienced considerable waiting times between speaking to their GP and getting access to support.

As detailed in Section 7, official waiting time figures for Step 3 CAMHS show that few young people are waiting beyond the 9 week waiting time target, to be referred for a first appointment to Step 3 CAMHS. However, official waiting time figures for Step 3 CAMHS services provides a very small part of the overall length of time young people are waiting before receiving help. It does not include the often protracted time period before a referral is made on their behalf to Step 3 CAMHS, or the length of time young people wait before asking for help or attempting to access support. Research on children and young people's mental health has estimated an average 10 year delay between symptoms of poor mental health emerging and receiving help (Khan, 2016).

The length of time young people are waiting between mental health symptoms emerging, and accessing support, casts significant doubts about how well we are addressing stigma, and developing mental health awareness and literacy in children and young people. It also raises the question of whether waiting times for access to a routine Step 3 CAMHS referral should be reduced from 9 weeks. A 4 week waiting time target from 'accepted referral to first appointment', is currently being trialled with eating disorder services and specialist services for young people with psychosis in England, and consideration is being given to reducing waiting times to 4 weeks for all routine referrals (DoH and DE, 2017).

The time young people are waiting between a referral being made to Step 3 CAMHS, and the decision about whether the referral is accepted or not accepted, is not being monitored. The system does not monitor the length of time young people wait between first appointment and review appointment either. These are critical points in a young person's engagement with a clinician, and in the progression of their treatment and recovery. Until waiting times at key points are monitored and regulated across Northern Ireland, a significant part of a young person's journey through statutory CAMHS and access to treatment, is being overlooked, to the detriment of the young people in the system.

There is a statutory waiting time target of 13 weeks for access to psychological therapies that applies to both children and young people and adults (HSCB 2018:2). However, the length of time young people are waiting to receive psychological therapies is not monitored against this target and there are no plans to.

Waiting times are one of a number of measures necessary to fully understand the adequacy of service provision. However, waiting time targets are at risk of becoming an arbitrary measure, if the basis for target setting is focused on best use of capacity and resource, rather than the best interests of the child or young person. The 2011 Review of CAMHS by RQIA also highlighted this issue, when it reported that there is a danger in waiting lists being the only benchmark for service quality, and that the 9 week waiting time target is not necessarily a true indicator of quality of care. It also stated that achieving this target in some HSCT's had resulted in a reduction of the range of services available (RQIA, 2011).

A lack of timely support from mental health services can have a profound and long-term impact on young people, the most obvious being a deterioration in young people's mental health. This was also evident from the experiences of young people who took part in this Review. For some, the delay in access to support had escalated to life threatening crisis situations. The lack of timely interventions by mental health services had also affected future help-seeking behaviour and the ability to engage with therapies or treatments offered. This was particularly the case for those young people who were referred between multiple services over a long period, without getting access to effective support.

It is important the right support is available when young people are ready to receive it. A speedy response will also reinforce young people's belief that how they feel is being taken seriously, and provides the reassurance they need that help is available. The long term consequences for young people, of our mental healthcare system failing to do this, cannot be over-emphasised.

9.5 Access to Crisis Mental Health Support

Community based Crisis Assessment and Intervention Teams (CAIT)[79] are a very welcome addition to the support and services available to young people who require urgent intensive intervention, to meet their needs. The primary objective of this intervention is 'to prevent admission to acute hospital care, but where admission is required, the service aims to provide earlier step down from in-patient care'. 'CAIT also has a role in providing support to other services such as Emergency Department presentations or Gateway'. (HSCB, 2018:2)

CAIT can respond to young people presenting with an immediate mental health need, and provide an important function in directing young people away from A&E or Out of Hours GP, when medical intervention is not required. It also reduces the need for young people to be admitted to inpatient care. Previous reviews of the statutory CAMHS system in Northern Ireland have reported that variations in the availability of suitable on-call support can contribute to increasing levels of need being managed by GPs, Community Based and Acute Services (Rees et al, 2014).

CAIT services for children and young people are at different stages of development across the HSCTs, which means they may not always be available in an area or at a time when young people are in crisis. The HSCB informed us that all HSCTs have protocols and arrangements in place to provide a 24/7 response to young people presenting in crisis.[80] However, the evidence gathered through this Review, shows that there is currently quite a substantial difference in the coverage of dedicated crisis intervention services for under 18s across the HSCTs. (See Appendix 1 for an overview of crisis mental health provision in each HSCT).

79 CAIT is also known as Crisis Response Home Treatment Teams (CRHT).

80 Written correspondence to NICCY, September 2018.

The operational data gathered as part of this Review has shown a substantial reduction in the number of young people being admitted to adult mental health wards.[81] Although it is difficult to accredit any one change to the overall fall in admissions, the HSCB has indicated that this reduction may be reflecting the impact of the establishment of CAIT teams. A&E remains the only regional medical emergency service available 24 hours a day, 7 days a week. When a dedicated CAIT service is not available or when medical intervention is required A&E or the Out of Hours GP service are likely places for young people and their families to seek help. During the Review, a small number of survey respondents had experience of using the Out of Hours GP service (n=27) and generally they had a mixed view of the support they received.[82] It is clear from the findings of this Review that the Out of Hours GP service is not the most appropriate service for a young person during a mental health emergency.

A&E in the Mental Health Service Pathway

A quarter (23%) of the young people surveyed had attended A&E due to their mental health. A&E is not specifically included in the Stepped Care Model under Step 4 crisis intervention, nor is it mentioned in the recently published CAMHS pathway document (DHSSPS, 2012, HSCB, 2018:2). The introduction of specialist CAIT teams are welcome in diverting young people away from A&E, unless there is a medical need. However, as outlined above, A&E continues to be a service that some young people will need to access and this should be more clearly reflected in the model. This Review has found that A&E is part of the journey for many young people in accessing mental health services. A&E should be fully included as part of the whole system response to children's mental health needs, thereby enabling more effective connections between primary care and mental health services and support.

As stated above, a quarter of the young people surveyed had been to A&E during a mental health crisis but an even higher proportion (75%) of the young people with drug and alcohol problems, that were interviewed, had attended A&E during a mental health crisis, and some had attended A&E on many occasions.

Young people who present to A&E during a mental health crisis often have a wide range of complex needs that have precipitated the crisis. In treating young people, A&E medical staff prioritise their immediate medical needs. This Review has found some extremely concerning issues about the standard of support available to young people attending A&E, particularly those under the influence of alcohol and/ or drugs, have suicidal thoughts, or have attempted suicide.

The experiences shared by young people has highlighted significant problems with the support that is available for young people that are suicidal, and also with the aftercare support for young people who have attempted suicide. The lack of support was particularly apparent with A&E services, but is also evident in the response to young people from other statutory services including GP services, Community CAMHS and In-Patient Care.

A worrying number of young people stated they had left A&E whilst suicidal. This may be partly due to the fact this part of the system is not equipped to deal with the volume and complexity of the needs of young people with mental health problems and because pathways to other services need to be quicker, clearer and more robust. A&E is set up to deal with

81 Admissions fell from 21 in 2014 / 15 to 2 in 2016 / 17, however, we note that this rose to 6 during 2017 /18 – See Section 7 for further details.

82 See Section 4 for further details.

physical health needs, such as a substance overdose or cuts and not the mental health problem underlying it. Joint working and co-ordination between A&E and mental health services needs to improve significantly, if we are to respond appropriately to very vulnerable and unwell children and young people. There are plans to develop service specific integrated care pathways between A&E and CAIT to improve the interface with other high intensity children's services, it is critical that this work is taken forward.[83]

As previously stated, A&E is not visible in the Stepped Care Model of CAMHS even though it is a key service which comes into contact with young people with mental health problems. Not having a clear strategic position within the Regional Model for CAMHS, undoubtedly creates weaknesses for policy development, workforce planning, service planning and commissioning.

A&E did not score highly across any of the rights based indicators young people were asked to rate them on. For example, with respect to their mental health, 60% of the young people disagreed that the support they received was helpful. Furthermore, young people did not think that the medical staff in A&E had sufficient training to support them during a mental health crisis, or to ensure that they were able to access the specialist support they needed. CAMHS pathway guidance stipulates that a referral to Statutory CAMHS by A&E should be seen within 24 hours (HSCB, 2018:2). Engagement NICCY had with staff members in two A&E departments raised concerns about the lack of robustness of the care pathways between A&E and Community CAMHS services, including CAIT.

Young people described having very long waits at A&E for someone to become available to help them during a mental health crisis. They explained that this was often because appropriately trained staff were not on site.

A&E, by its very nature, is not a calm environment. The heightened emotion and distress in A&E can often exacerbate a young person's already precarious mental health condition, particularly if they have to wait a long time to be seen. In A&E, there is a statutory waiting time target of 4 hours for patients to be seen. This is much too long for young people in mental health distress and some young people indicated that they had left A&E without being seen by a staff member because they could not wait any longer. Northern Ireland has the highest percentage of patients breaching four hour waits (28%) (RCPCH, 2018).

During the practitioner workshops we heard about police being called to deal with young people during a mental health crisis, because the A&E staff did not know how to respond to a young person who was agitated or aggressive. The involvement of police can heighten a young person's agitation and we were told of cases where young people were taken into custody and some charged with assault.

There were also problems reported by young people concerning the discharge process from A&E. Some young people talked about being discharged without having seen a mental health practitioner, or without being discharged into the care of a trusted adult. The 'Card Before You Leave' (CBYL) scheme has been in place since 2010. The intention of the scheme is to provide a next day mental health follow-up service for patients who attend an A&E with self-harm or thoughts of suicide, and who have been identified as low risk to themselves or others. The scheme aims to ensure that any patient being discharged

83 Review of Acute CAMHS Action Plan 15/16.

from A&E receives a card prior to discharge, giving details of contact numbers for support and details of their follow-up care (HSCB and PHA, 2013). We understand that every A&E department should be applying the CBYL scheme, but unfortunately there are significant gaps in the data available regarding the number of young people that receive CBYL, and how effective it is for under 18s. None of the young people we engaged with through the Review talked about the CBYL.

Practice Example

The WHSCT has introduced a Clinical Decision Unit as part of the A&E department at Altnagelvin Hospital. The unit is for patients who may require a short period of observation, further investigations, or other interventions that cannot be completed within the four hour timeframe within the Emergency Department. It can accommodate patients for up to 24 hours. Young people that present to A&E, who have taken alcohol and drugs, are being fast tracked to this Unit as soon as they are identified by staff. Young people are therefore not having to sit for long periods of time in the A&E reception.

The WHSCT also have emergency accommodation, referred to as the 'crash pad', which provides a supervised safe place for young people to de-escalate. There is also access to on-call social work teams.

During the practitioner workshops, a number of voluntary and community organisations (VCS) talked about accompanying young people to A&E to support them during a mental health crisis and to ensure that they did not leave until they were seen by a medical practitioner. Youth workers reported that they can face difficulties with A&E staff when giving them information, because they are not a parent or guardian, and when the young person is over 18 years. Workshop participants felt that arrangements should be put in place so that VCS organisations can advocate for young people in these situations, particularly for very vulnerable young people without family support, and who may be regularly presenting to A&E.

The lack of follow-on professional support in the hours or days following presentation to A&E was a criticism raised by the young people. This was a very common experience highlighted repeatedly during the interviews with young people with drug or alcohol problems.

Just over half of the young people (54%) disagreed, or strongly disagreed, that they felt comfortable and safe when they attended A&E about their mental health. Young people reflected on the fact that facilities were often not appropriate or safe for an actively suicidal or self-harming young person. One young person talked about being placed alone for long periods of time in a patient cubicle, that contained medical equipment and instruments that they could have used to harm themselves.

Young people also remarked on the fact that the professional approach was not always age appropriate or empathetic. Of the young people surveyed, 31% disagreed or strongly disagreed that they were spoken to in a way they could understand, by staff they met in A&E.

The 4 hour standard waiting time for A&E is one benchmark of the standard of care for patients, however, equally important service standard measures for this population are quality and safety of care (RCPCH, 2018). There is no central monitoring system for young people that attend A&E with mental health needs, nor is there a systematic regular review of A&E facilities for how they respond to people, where mental health problems are a factor. The Northern Ireland Human Rights Commission Inquiry into emergency health care, reported on the lack of monitoring and review of emergency

department's response to patients in mental health crisis, dementia or disabilities, and highlighted the need for minimum care standards (NIHRC, 2015:2).

Practice Example

NHSCT uses a model where Crisis Response Home Treatment (CRHT) has a joint protocol with Rapid Assessment Interface Discharge (RAID) professionals based in the A&E, to ensure there is 24/7 cover and that children are seen within 2 hours. The protocol's intention is that a young person would be seen by a mental health practitioner based in A&E who would link them on to appropriate support e.g. medication, counselling and GP service. The DoH and HSCB are currently considering regional roll-out of the RAID model. (Response by DoH to NICCY request for information - 24 April 2018).

It is vital that crisis/emergency mental health services respond sensitively, appropriately and quickly to children and young people in a crisis situation. This must also include them having a range of support they can offer young people, or other services that they can refer young people on to.

9.6 Support for Young People at Different Stages of Accessing Step 3 Services

A recurrent issue raised by young people was that they would have liked more support at different stages of accessing Step 3 CAMHS. This included, whilst waiting to access the service, between appointments, and on discharge.

Support While Waiting for a Step 3 CAMHS Appointment

A consistent theme through this Review is the significant length of time it can take between young people seeking help and accessing services. The length of time it had taken young people with more complex needs, such as alcohol and drug problems, was particularly protracted.

Young people reported that it would have been helpful if they had been offered some support while waiting for their statutory CAMHS appointment. Young people were interested in alternatives to medication, such as their GP providing them with self-help coping strategies, online resources or help to set up face-to-face support with a voluntary and community sector organisation.

Practitioners talked about the value of having an on-call telephone number that young people, parents and carers or health professionals could phone to speak to a mental health practitioner, to get advice or reassurance between their statutory CAMHS appointments.

Young people indicated that they had not been able to access interim support if they were waiting on a referral or assessment by another service. This included young people not being able to access school counselling if a GP was making a referral to statutory CAMHS. It was also common for young people, waiting for an assessment for ADHD/Autism/ASD, being unable to access support for their emotional well-being or mental health. However, during the practitioner workshops there were a number of examples of organisations that work on multi-agency collaborative basis. This mixed picture indicates an inconsistent approach regarding the support that is accessible to a young person when they are already involved with another service.

Support Between Step 3 CAMHS Appointments

For young people receiving services, the gaps between appointments were often too long for their needs. A common theme raised by young people was the value of having some form of 'wraparound support' available to them between statutory CAMHS appointments. A number of examples of effective wraparound support was shared during the interviews, where the young people talked about the value of accessing statutory services and VCS services at the same time.

Young people talked more positively about their experience of statutory mental health services, when they also had VCS support, they could access between the clinical appointments. Unfortunately, there was inconsistent evidence of this type of support being available or accessible to all young people. During the practitioner workshops, there was a clear consensus from both statutory and VCS practitioners that a multi-sectoral and multi-agency approach was the best way of meeting the needs of children and young people with mental health problems. However, there were concerns that this approach was not always possible, and was a particular problem in areas that did not have good VCS infrastructure.

The Review has found that VCS organisations are supporting young people who have mental health needs of a much more serious nature, than they should be working with, because of waiting times, or other problems young people have with accessing specialist statutory services.

Making and Attending Appointments

Within the survey and during the interviews, young people referred to the challenges they faced with making and keeping mental health appointments. This issue was also reflected in available regional data, which confirms that since 2013 'Did Not Attend' (DNA) and 'Cannot Attend' (CNA) figures for first appointment and review appointment for Step 3 CAMHS were approximately 15% and 24% respectively. The reasons for non-attendance is not monitored by the HSCB, and there are no plans to include this data as part of the new CAMHS dataset. Furthermore, during the Review process data was not available on the number of young people discharged from services due to CNA/DNA. It is important that the system closely monitors this practice and clear guidance should be included in the regional Integrated Elective Access Protocol (IEAP) regarding this (HSCB, 2010).

In the RQIA Review of CAMHS carried out in 2011, high rates of DNA and CNA at first appointment was noted. RQIA stated that non-attendance: *'should be reviewed by the Trusts and the commissioning body to maximise efficiency'* (RQIA, 2011, pg 6). Whilst it is important to review DNA/CNA rates, in order to ensure that appointment slots are filled, it is also important for the system to understand the 'barriers' that contribute to young people's non-attendance at appointments. This is at the core of a system, which realises the rights of children and young people.

Challenges with being able to attend appointments with services, was a general issue raised by young people during the Review, that related to a range of services i.e. GP, School/College/University, CAMHS out-patient appointments, and VCS services. Section 4 of this report shows that 42% of young people surveyed had cancelled or been unable to attend an appointment about their mental health. The most common reasons given was that the appointment time given did not suit (51%), they didn't feel well enough on the day (51%) and they forgot (31%).

Young people whose mental health problems included high levels of anxiety or depression, which made leaving home very difficult, said that having the option of the health

professional coming to their own home, or closer to home, would have made it easier for them to attend an appointment.

Support with making appointments was also highlighted by the young people who completed the survey and those who were interviewed. This was particularly the case for young people with alcohol and drug problems, who said they needed support to remind them about appointments times, and escort them from their home to their appointment. Some of the young people interviewed were already getting this type of support and it often came in the form of a support worker attached to a VCS organisation.

These examples highlight how some young people require a significant amount of support and flexibility in order to attend appointments, and engage with mental health services or support, particularly statutory services. Ensuring this support is available for young people is fundamental to reducing the numbers not attending appointments, and ensuring that young people are accessing the vital mental health support they need.

During the Review, young people identified a range of practical changes that would help with making and attending appointments, these include:

- An online booking system;
- Appointment slots available outside school hours;
- The option of appointments being held in their own home or close to home;
- Reminder texts about appointments; and
- The option of a telephone catch up with counsellor between appointments.

Discharge from Step 3 CAMHS due to DNA / CNA

The Integrated Elective Access Protocol Addendum (IEAP) sets out the systemic principles and processes for the management of mental health patients, from the point of referral to the point of discharge (HSCB, 2010; HSCB, 2018:2). This includes the management of appointments where patients DNA or CNA. The IEAP is general policy that applies to both adults and children and young people. Within the policy it states that some specialist areas of mental health will need to tailor the policy to reflect the specific needs of their patients, however, there does not appear to be any specific regional guidance around this for under 18s.

Case Study: Discharge Procedure for Mental Health Patients due to missed appointments

The Equality Commission Northern Ireland (ECNI) recently took a case on behalf of a 19 year old who had been accessing mental health services over a number of years (ECNI, 2018). The case focused on allegations that the Adult Mental Health Services (AMHS) in the BHSCT had failed to provide her with adequate care and management in accessing mental health care.

The case was upheld and the BHSCT accepted they had not fully complied with the IEAP policy. The policy states that: *'if a patient missed two consecutive appointments they would be discharged'* and this was strictly enforced. ECNI found that the BHSCT had not applied the part of the policy that states that: *"a patient should not be discharged from a service until a review of risk factors has been carried out with their GP, and the joint decision taken to discharge the patient. This decision should be fully documented and the patient and the GP informed in writing."*

The BHSCT also acknowledged its failure to make reasonable adjustments and had accepted it had breached its obligations under the Disability Discrimination Act (NI) 1995.

The case highlights very important issues that are as relevant for children and young people because the Disability Discrimination Act, 1995 and the IEAP policy both apply to child and adult mental health services.

The professionals NICCY engaged with as part of this Review also recognised the issue of young people being discharged from services, without follow-on support being arranged as part of the discharge planning. Seven out the nine GPs surveyed, reported that young people they had referred to Step 3 CAMHS had been discharged due to DNA/CAN, without their involvement in a risk review. Although a small sample, it indicates a potentially significant issue with compliance with the regional IEAP guidelines as outlined above (HSCB, 2010; HSCB, 2018:2).

Support on Discharge from Step 3 CAMHS

Young people talked about the difficulties they faced when a course of treatment ended, but there was no follow-on support provided for them to transition to. Young people raised this issue in the context of their discharge from Step 3 CAMHS and inpatient care.

One young person talked about the value of having follow-on support after completing a short time-limited psychotherapy course. In her experience, once the course finished there was nothing else to move on to that would help maintain her progress or provide a form of aftercare support. In terms of inpatient care, over three quarters of young people with experience as an inpatient thought they would have benefited from more support upon discharge from hospital.

Suitable follow-on support was something that young people reported as being very important, in the context of helping them continue and maintain their recovery. Young people highlighted a range of supports they thought would have helped them, including, more regular outpatient appointments and support to bridge the gap between inpatient and outpatient care, such as a day hospital.

There was also a consensus from young people, parents and carers and practitioners that more intensive community support is required for young people under 18 years old.

Practice Examples

Day Hospitals are available for adults who do not require hospital admission, but need intensive support in the community. A similar type of service model is not currently available for under 18s.

Similarly, Recovery Colleges offer courses for mental health service users, carers, professional and the general public. The courses are co-designed and co-delivered, have a recovery ethos and focus on the needs of those with severe and enduring mental health problems, and are multi-disciplinary. These courses are available to 16+ year olds, however, generally it is 18+ year olds that attend.

https://www.communityni.org/organisation/belfast-recovery-college

Co-ordination and Communication Between Services

Poor co-ordination and communication between professionals was a common issue raised by young people. There were a number of common themes where services had not worked well together. These include:

- Community CAMHS, CAIT and A&E;
- School and CAMHS;
- School, Social Services and CAMHS; and
- CAMHS and AMHS.

Young people described feeling physically and emotionally exhausted, and in some cases re-traumatised by having to repeat their circumstances to different professionals, because of a lack of co-ordination across services. The Review found that young people expect services they engage with to be connected, to share relevant information and agree on the overall support.

Practice Example

A mental health passport was suggested during the practitioner workshops, as a possible solution to the problem of young people having to constantly repeat information to different professionals.

Across NHS England, young people and parent/carers worked together to develop a Mental Health Services Passport template. Each passport is created by a young person or parent/carer (for younger children) with the support of their practitioner. The aim of the passport is to help young people using services, or parents with younger children, to own and communicate their story when moving between different services. It provides a summary of their time in the service, which will be owned by the young people or parent/carer, and be shared with any future services if and when they wish.

https://www.england.nhs.uk/mental-health/cyp/iapt

Many of the young people NICCY engaged with through the Review found signposting, as a form of advice, very unhelpful and ineffective. Young people provided examples of being signposted from one service to another, without sufficient support to make a successful transition. It is vitally important that vulnerable young people and their families are not left to navigate the complexities of the CAMHS system unaided.

There is currently no regional monitoring system established across all HSCTs to track young people moving between services, or from one step of the Stepped Care Model of CAMHS to another. This would help to identify young people who are at risk of 'getting lost in the system', 'falling through the gaps' or 'bouncing around the system'.

The Review identified a significant number of very vulnerable young people 'falling through the gaps', because the system was not in place to ensure that professional responsibility for a child only ended once they have been successfully referred to another service deemed to be more appropriate to meet their needs. Examples included poor or non-existent handover between a GP and the mental health services the GP was referring them on to, and young people falling through the gaps when transitioning from CAMHS to AMHS.

In situations where a young person does not meet the criteria for a service, or where there is a waiting list, professionals should work together to ensure that alternative support is provided. There were examples provided during the Review of organisations that do provide a 'soft handover', although these were rare and mainly related to practices used by VCS organisations, when making referrals to statutory services. It was also clear that this form of good practice was driven from localised relationship building and working practice, and not driven by broader regional policy.

The CAMHS Pathway Guidance sets out the standard that is required by a referral agent when making a referral into Step 3 CAMHS (HSCB, 2018:2). It states that the referral agent should take responsibility for ensuring

that young people are successfully referred. This Review has found that in practice this does not always happen, in some instances, the referral agent is not made aware that the young person has been discharged, or deemed unsuitable for the service.

9.7 Choice and Effectiveness of Treatment and Support

Medication as a Treatment Option

In the information provided through the Review survey and interviews, a theme arising was young people being offered medication when they did not want it, and young people disagreeing that they had been given a choice of alternatives.[84] This feedback raises concerns about a reliance on medication for treating mental ill-health in young people and the extent to which alternative choices are available to young people.

Medication was a very common form of treatment offered to young people with mental health and alcohol and drug problems. Many of young people interviewed were reluctant to take medication because of the problems they had with substances, including misuse of prescription drugs. The interviews also raises concerns about the adequacy of the support and supervision available to young people that are prescribed medication, who have a history of alcohol and drug misuse.

Information on the types of drug based treatment options provided to young people are not regularly published or monitored. However, we know from government statistics that large numbers of prescriptions of anti-depressants are being made to young people in Northern Ireland. In 2017, 12,765 were given to 2,706 under 18 year olds, a proportion of whom were under 12 years of age.

Table 9.1: Anti-depressant prescription rates to children and young people in 2015 and 2017

	Number of prescriptions to C&YP under 18	Number of C&YP under 18 in receipt of medication	Number of prescriptions to children under 12	Number of children under 12 in receipt of medication
2015	12,250	2,686	425	169
2017	12,765	2,706	459	133

Source: Information gathered by NICCY from BSO 23rd August 2018.

NICE (2017) guidelines on the identification and management of children and young people with depression aged 5–18 years old[85], state that Fluoxetine should be the first line treatment for children and young people aged 12+, with moderate to severe depression. This is followed by Citalopram and Sertraline as second line treatments, in circumstances where a child or young

84 See Sections 4–6 for further details.

85 The NICE guidelines were developed in 2005 and last updated in Sept 2017.

person is unresponsive to Fluoxetine.[86] The evidence for Fluoxetine's effectiveness in children aged 5–11 is not established. The NICE guidelines state that Fluoxetine should be 'cautiously considered' for 5–11 year olds with moderate to severe depression, and where they have been unresponsive to a specific psychological therapy after 4 to 6 sessions, and following a multidisciplinary review.[87]

In Northern Ireland, young people aged under 18 years old are being prescribed additional anti-depressant drugs that have not been clinically trialed with that age group. In total during 2017 at least 11 different anti-depressants were prescribed to young people. This is despite NICE guidance which has advised that Fluoxetine, Citalopram and Sertraline are the only drugs suitable for young people, only after a range of other options have been tried, and only as a combined treatment with psychological therapies.[88] It is also the case that Fluoxetine is the only antidepressant for which clinical trial evidence shows that the benefits outweigh the risks for 12+ year olds.[89]

NICE guidance recommends that Paroxetine and Venlafaxine should not be used for the treatment of depression in children and young people,[90] however official data shows that for the consecutive years 2014 to 2017, Venlafaxine has been prescribed to under 18 year olds.[91] Separate information provided to NICCY by the BBC shows that Paroxetine has been prescribed to under 18s during 2017/18.[92]

Psychological Therapies

The anti-depressant prescribing figures for under 18 year olds raises questions about the extent to which psychological therapies are being offered to children and young people, rather than, or in addition to medication. There are no publically available statistics on the therapies provided to children and young people as part of their treatment.

The CAMHS pathway document lists the range of psychological therapies 'suitable' for children and young people. However this is not the same as the range of therapies 'available' or 'being used as part of the treatment provided to children and young people' (HSCB 2018:2). At the time of writing, there was a lack of information on the specific psychological therapies available and being used with children and young people. However, it is known that the specific therapies offered by each Heath and Social Care Trust vary.[93]

NICCY notes that the lack of clarity about the range of available treatments, and the lack of evidence of NICE Guidelines being applied to their use, was also reported in 2014 Review of Acute CAMHS in Northern Ireland (Rees et al. 2014). A Guide to Mental Health Psychological Therapies for 18+ year olds was published in 2015 by the HSCB (HSCB, 2015:2). The aim of the guide was to strengthen and embed psychological therapies into professional practice across all mental health services. Regrettably a similar comprehensive guide has not been developed for young people.

86 Section 1.6.4.9 of the NICE guidelines on the identification and management of children and young people with depression aged 5–18 years old.

87 Section 1.6.2.5 of the NICE guidelines.

88 Section 1.6.4 of the NICE guidelines.

89 Section 1.6.4.3 of the NICE guidelines.

90 Section 1.6.4.13 of the NICE guidelines.

91 Information gathered by NICCY from BSO, 23rd August 2018.

92 FOI Information provided to NICCY by BBC, June 2018

93 Response to request for information from NICCY to HSCB, dated 2 March 2017.

We understand from figures provided by the HSCB that regional recurrent funding of £50,000 was invested in training in psychological therapies for children and young people in 2015/16.[94] This is compared to millions of pounds spent on prescription medication. It represents a grossly higher and disproportionate spend on medication, compared to non-drug based treatment. There would also appear to be much less focus on under 18 year olds, than 18+ year olds, with regards to initiatives such as the primary talking therapy hubs.

The new CAMHS dataset that is in the process of being implemented and is expected to record some information on the types of treatments used with children and young people (HSCB, 2018:1) This regional data will be useful in understanding the range and frequency of use of different treatment options and whether the choices available to young people meet relevant NICE Guidance. The dataset will not provide information on the length of time young people wait to access psychological therapies specifically. This is despite the fact that there is an existing 13 week target for access to psychological therapies for both adults and children (HSCB, 2018:2).

Alternative Therapies and Holistic Approach to Treatment

During the Review, young people articulated very clearly that they want greater access to alternative forms of support and treatment than the traditional types currently being offered. For example, young people talked about the fact that the traditional face-to-face counselling sessions can be very difficult, and that they do not always find it helpful to talk directly about their problems in this way. While NICCY is aware that there are alternative approaches being used with young people, this Review has been unable to get clear information on the availability and frequency of use of alternative types of therapy or interventions.

Young people suggested a range of alternative approaches that they would like to have incorporated into treatment sessions. These included animal therapy, art based therapy, my life story/scrap books and peer support. There was a lot of support from young people for more activity based counselling sessions, where young people were doing things while talking, rather than talking alone.

Young people were unanimous in their feedback that it is essential that the root causes of mental ill-health are addressed, as part of the overall mental health support received. Young people articulated very strongly that they needed both practical and emotional support to address the issues causing them distress, anxiety or depression.

Young people identified a wide range of factors which had caused or contributed to their poor mental health, and some issues seemed to be group specific.[95] This highlights the multiplicity and complexity of the issues which are often at the root of young people's mental ill-health. Dealing with multiple adversities and toxic stress were very common issues for the young people interviewed as part of this Review who had drug and/or alcohol problems. Issues faced by this group of participants included child sexual exploitation, neglect, physical abuse, domestic violence, substance and alcohol misuse in the family and bereavement. It became evident during the interviews that for some young people the impact of extremely difficult childhood experiences had not always been

94 Ibid.

95 See Sections 4-6 for further detail.

identified or responded to effectively. This lack of a timely intervention was despite many young people talking about how they, or their family members, had been in contact with a range of health professionals. It was also clear from the interviews that drugs and/or alcohol were being used as a way of coping with the symptoms of their mental ill-health, even where this had not initially been the case.

Young people with a learning disability face many of the same issues as their peers without a learning disability, with regard to the pressures of growing up and moving into young adulthood e.g. sexuality, sexual health, relationships etc. The young people we engaged with through the Review also talked about experiencing bullying because of their disability or disabilities. The young people with a learning disability interviewed as part of this Review were in their late teenage years and for them discrimination in the workplace, concerns about their financial security and financial independence weighed heavily. Although many of these issues tend to appear slightly later for young people with a learning disability, than a typically developing child, the support for young people to deal with these issues is not available as readily, and comprehensively, as it should be.

9.8 The Role of a Significant Adult

The critical role of a 'significant adult' was an emergent theme from both the survey responses and the interviews carried out with the young people. Young people described the vital role that a trusted adult had in supporting them at all points, from first seeking help, managing appointments to supporting them between appointments. The importance of a significant adult, including a non-kin mentor, is a common feature in much research regarding children and young people. It is recognised that significant adults have a key role in helping young people to access their rights, including their rights to services and support for their mental health, welfare, housing, education training or employment (Martynowicz, 2012).

The young people NICCY engaged with in the course of this Review were clear that they choose who to talk to about their mental health, based on who they trust and can confide in, and not on the basis of the competency of the person regarding their knowledge or expertise of mental health issues. The young people who took part in this Review spoke to family and friends first about needing help for their mental health. This was followed by a range of professionals including GP/CAMHS, A&E, Hospital, School Counsellor/Teacher, Support from a Charity, Social Services, and Faith/Youth Leader.

Many of the professionals who young people reported that they first approached to talk about their mental health, did not necessarily have a specific role as a mental health practitioner/professional, or have mental health training. However, the initial response from professionals to a young person's mental health problem is critical. This Review found many examples where a young person did not have a good experience or did not feel understood which made it much more difficult for them to engage with services going forward or to benefit from interventions offered to them.

Adults within school are often one of the main significant adult groups who young people approach for support. The survey results found that young people are seeking out support from a range of adults within their school. Of the young people who had sought support from within their school, the most commonly accessed form of support was a school counselling service (71%). Over half reported they had accessed support from members of school teaching staff (56%). These are staff members who do not necessarily

have a specific role in responding to mental health, and who may not be trained or skilled in addressing mental health problems. Other staff who young people reported that they had spoken to, but less commonly than might be expected, were pastoral care staff (32%) and the school nurse (10%).

Practice Example

The Department for Education and NHS England have through the Mental Health Services and School Links Pilot, worked together to test a joint training approach to strengthen relationships between schools and NHS mental health services. The pilot has shown that common successful elements were the identification of specific leads in schools and mental health services and joint management by both parties. The independent evaluation showed that the pilot strengthened communication and joint working arrangements between school and mental health services. It also found specific improvements in the understanding of referral routes, improved knowledge and awareness of mental health issues among school leads and improved timeliness and appropriateness of referrals.

The proposals recognised that additional resources and training are required to support teachers and schools to develop mental health leads in schools and NHS mental health support teams. Specific funding, including a Teaching and Leadership Fund is being proposed to take this initiative forward (DoH and DE, 2017).

The findings from this Review highlight the importance of a whole population approach to mental health, which includes ensuring that we all have adequate knowledge about mental health, how to look after our mental health and where to go for help if we need it. Communities, with key community representatives taking a lead, can play a hugely significant role in creating the conditions in which family, friends and neighbours have the knowledge and confidence to support each other to look after their mental health.

9.9 Participation and Feedback from Young People

Children and young people should be facilitated to actively participate in the services they receive. Young people's views and experiences should be embedded in the policies and practices developed for services. This feedback should be distinct from the participation and feedback from parents/carers. Meaningful participation is a fundamental children's right as articulated by the UNCRC, in particular Articles 12, 17 and 3, which establish young people's rights as active participants at every level of decision making impacting on their lives, in accordance with their age and evolving capacity. Research also shows that a child or young person's assessment of their own mental health often varies from their parents' and for this reason it is vital that both perspectives are heard (Patalay and Fitzsimons, 2017).

In the Review, there were four indicators included under the quality of care section and three of them specifically focused on how well young people's participation rights were being upheld. The indicators were 'I felt listened to and respected', 'I was spoken to in a way that I could understand' and 'I felt involved in the decisions that were being made about my care or treatment'. Across all of the rights based indicators young people were asked about, these were the areas that young people rated services most highly. On average, agreement ratings were highest for the statements, 'I was spoken to in a way I could understand' (73%) and 'I felt listened to and respected' (57%).

Overall average agreement rating were much lower for the statement, 'I felt involved in the decisions that were being made about my care' (42%). This was also the statement which had most variation in how young people rated services (agreement ratings ranged between 16% and 75%).[96] Against the statement, 'I was given a choice of treatment and support'; on average, 40% of those surveyed agreed that this was the case. However, inpatient service was given a 19% agreement level and A&E 23%. In fact all of the services generally had a low agreement rating against this statement apart from the VCS (67%).

The generally lower score for statutory services, including the Step 4 and 5 services, may be explained by the fact that these services are likely to be working with young people with the most serious mental health problems, including those requiring crisis support. However, this does not explain the generally low average rating against this statement for other services such as GP and School/College and University. Nor does it explain the reason why the VCS scored much higher across all of the quality of care indicators.

It is very important that consideration is given to young people's experiences of services, and to understand what changes could be made to make them more acceptable to young people. Involving a young person in the decision making process about their choice of treatment and support, is important, as it can help them to understand why health professionals are choosing a particular course of treatment, can engender self-empowerment, and can be part of the therapeutic process itself. The young people engaged with through this Review reported that whilst they felt listened to and treated with respect, they did not feel like that they were involved with decision making regarding their treatment.

9.10 Outcomes

On average, approximately half (49%) of those surveyed did not find mental health services and support they had accessed, helpful. A number of services rated lower than average on this statement, these were GP (44%), Community CAMHS (45%), Inpatient Care (39%) and A&E (34%). The parents/carers survey, although a much smaller sample size, closely reflected the young people's perception of services (see Section 3 for further information).

The fact that such a high proportion of young people surveyed disagreed that the service or support they received was helpful, is concerning. This is particularly alarming for statutory services which received the lowest ratings against 'helpfulness of services'.

Interestingly, the 'outcome' or 'helpfulness' results for Community CAMHS are consistent with those of a recent study published in the British Journal of Psychology, which looked at the self-reported outcomes of 4,464 adolescents receiving support across 75 CAMHS in England. It found that only 53% of those with anxiety, 44% with depression and 35% with depression and anxiety showed reliable improvements after a course of treatment. The study concluded that although improvements were higher than previously reported, there may be a need to set more realistic expectations on what impact treatment can have, including with the young people who seek help (Edbrooke-Childs et al., 2018).

The limited impact of statutory services, and in particular inpatient services is worrying, considering the fact that the most unwell young people will be referred to them. Inpatient services are also the most

96 See Section 4 – Table 4.3.

expensive services to deliver and include the most intrusive forms of treatment, where young people can be detained in hospital on a compulsory basis, if a designated medical expert assesses that they are a risk to themselves or others, if compulsory intervention is not undertaken. It is expected that the CAMHS dataset will gather basic self-reported outcome information, prior to discharge, from children and young people and their families regarding the services they received (HSCB, 2018:1).

Young people and their parents/carers were asked if they had ever made a complaint about mental health services. In the vast majority of cases, neither the young people (62%) nor the parents/carers (80%) surveyed, had made a complaint.

The information from this Review highlights the absolute necessity of embedding a range of feedback mechanisms into the delivery of services, which includes feedback on services/support more generally, and the measurement of clinical outcomes and outcomes that are defined by and important to young people.

Practice Example – Children and Young People's Improving Access to Psychological Therapies Programme (CYP IAPT)

CYP IAPT is a change programme delivered by NHS England in partnership with Health Education England.

It aims to:

- Work with existing services that deliver mental health care for children and young people (provided by NHS, Local Authority, Voluntary Sector, Youth Justice);
- Create, across staff and services, a culture of full collaboration between the child, young person and/or their parents or carers by:
    - Using regular feedback and outcome monitoring to guide therapy in the room, using a mixture of goals and symptom measures suitable for the child, young person and/or family/carer – [Child Outcomes Research Consortium (CORC); CHIMAT; PHE Fingertip tools; Mental Health Services Data Set];
    - Improving young people's participation in treatment, service design and delivery – Young Minds Amplified– improving access through self-referral;
    - Improving the efficiency of services by training managers and service leads in change, demand and capacity management; and
    - Improving access to evidence-based therapies by training staff in in an agreed, standardised curriculum of NICE approved and best evidence-based therapies.

This programme does not create standalone services, but works to embed these principles into existing services. The programme began in 2011 and by March 2017 it was working across services covering 90% of the 0-19 population.

https://www.england.nhs.uk/mental-health/cyp/iapt/

9.11 Key Aspects of a Good Mental Health Service

It is vital that mental health services and support are accessible and respond appropriately to young people. During this Review, young people were asked to describe what a good mental health service should look like. They were asked to think about the physical space and the approach of staff who work there. The recurrent key aspects that young people associated with 'good mental health service or support' include:

Professional approach: young people commonly referred to preferring a professional approach that was relaxed, non-clinical, age appropriate and non-judgmental. Young people also valued services which instil hope, and were able to offer both emotional and practical support. They talked about the need for accessible information about the boundaries of confidentiality between young people and mental health professionals, and assurances that these boundaries would be stringently adhered to.

Flexible working: many of the young people found the 9am-5pm service model, commonly used by statutory services such as CAMHS, GP and school based counselling, difficult. Young people consistently highlighted the need to be able to access support at a range of times, including weekends and evenings, without the need for an appointment. This was particularly the case for young people who have chaotic lifestyles, and require flexible support that can be accessed when and where they need it. Currently the only statutory community based 'out of hours' service for mental health is crisis response.

Physical environment: young people consistently emphasised the importance of the physical environment, and how they find they are much more comfortable when their appointments are held in an environment that is non-clinical and informal. Young people also talked about the value of having appointments in familiar places, such as those in the community, and not attached to a hospital.

Joint working: young people highlighted the effectiveness of support received from both statutory and voluntary and community sector organisations, working collaboratively. A partnership approach by statutory mental health services and VCS organisations, could ensure that young people could access the clinical and practical support they required. This approach was favoured, as it gave young people more choice and flexibility around when they can access support the support they required.

Many of the characteristics of a good mental health service provided by young people reflects the approach that is already taken by VCS and Youth work organisations, however, these are not the preserve of this sector. Any organisation, including the statutory sector, should ensure that they provide a developmentally appropriate, youth friendly, accessible service that is designed to meet the needs of young people and which can provide continuity of care during times of transition (McGorry et.al., 2013).

Adoption of a non-clinical or non-medicalised approach to the delivery of all forms of mental health services, including services delivered by statutory services, was discussed at the practitioner workshops carried out as part the Review. It was recognised that statutory/ clinical based professionals and VCS and youth sector practitioners have different roles, and that clinicians cannot, and should not, build relationships with young people in the same way as youth workers. It was also agreed that it would be useful to have a set of universal core values for all professionals working with young people. Central to these core values is the ability to connect with a child or young person in a way that is age appropriate, person centred and non-judgemental. The professionals also recognised the complementary role of statutory and VCS, and how collaborative working can be very productive, and lead to more effective support systems for children and young people.

Both groups of young people interviewed as part of this Review talked about the value of having easily accessible mental health support available in colleges or universities. Young people described these places as familiar to them, with staff that they know, feel safe around and trust.

Practice Example

The THRIVE Model has been developed in England as an alternative to the commonly used tiered based system, like the Stepped Care Model, which is based on the provision of services to meet the increasing severity and complexity need. THRIVE attempts to create a clearer distinction than in the current tiered system between treatment and support, self-management and intervention (Wolpert et al., 2015)

The purpose of THRIVE is to place a greater focus on enabling care to be delivered according to the needs and preferences of children, young people and their families. It also aims to build on multi-agency working that includes health, education, social care and broader community support, and to ensure that children, young people and families are active decision makers in choosing the most appropriate approach. The Model is subject to ongoing evaluation and an i-THRIVE community of practice has been developed to test the models effectiveness, share best practice and collect outcomes data.

The HSCB in Northern Ireland has joined as an associate member of this network. However, it is unclear how the model is being tested in Northern Ireland, including the Children and Young People Improving Access to Psychological Therapies (CYP IAPT) which is complementary to it.

9.12 Transition from CAMHS to AMHS

In the context of mental health, transitions refers to the process whereby young people move from child to adult services. The transition boundary from statutory Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS) is 18 years in all 5 Trusts, but referral to adult services can occur 6 months before the transfer date (Leavey et al., 2017).

The National Institute for Health and Care Excellence (NICE) have produced guidelines on transition from children to adult services for young people using health or social care services that sets out good practice in transitions (NICE, 2016:2). There have also been many reports written that have highlighted issues with the transition process for young people that are moving from CAMHS to AMHS. These reports include the Bamford Review, which provides a strategic vision for the development of a service for children and young people with mental health problems, at the time it was published it highlighted concerns about the lack of liaison between CAMHS and AMHS (Bamford, 2006). Significant failings in the transitions process have been identified in more recent reports, including the PHA commissioned IMPACT study in 2017 (Leavey, 2017). These significant reports have identified areas requiring critical policy and practice change.

The poor transitional practice that is often highlighted in reports on young people's experience of moving between child and adult services, was also the general experience of the young people surveyed as part of this Review. 15% reported they had experience of moving from child to adult mental health services. Of these 37 young people, over half (54%) disagreed that they felt supported whilst moving to adult mental health services, or they felt involved in the decisions being made about

their move to adult mental health services (55%). Young people also reflected on the fact that moving to adult services without a smooth transition that took account of their readiness for change, had negatively affected their longer term treatment and recovery.

The young people NICCY engaged with highlighted a number of specific issues that are important in the context of service development:

- Young people would like more preparation for moving between CAMHS and AMHS, and there was a strong consensus that there should be a bridging service for young people aged between 16-25 years old, that allows for a smoother transition between services; and
- Young people wanted there to be better communication between CAMHS and AMHS during the transition period.

The HSCB has received non-recurrent investment through the Transformation Fund for a pilot project to improve transitional arrangements for young people moving from CAMHS to AMHS. The initiative will involve the appointment of a Band 7 staff member in each HSCT for a period of 16 months to develop a regionally agreed protocol to ensure a more consistent response for all young people transitioning to adult services.[97]

Moving between child and adult services can be a particularly destabilising time in a young person's life because relationships have to be re-built with different professionals. There is a significant risk that without proper support young people may not engage with adult services. We know that for young people with particularly complex needs, including a learning disability, the delays in decisions about provisions within adult services can be unacceptably long.

There will be some young people who do not meet the criteria for AMHS services who had been receiving CAMHS, a vital part of the transition process for these young people is being provided with information about alternative support and help to access this.

9.13 Mental Health Awareness and Literacy

There were varying levels of mental health awareness and literacy amongst the young people engaged with in this Review. Young people who had been accessing services for some time had a good understanding of mental health issues and how services work, but they talked about this being something they had picked up themselves, over time, as they attempted to navigate the system.

The lack of mental health awareness and literacy was particularly apparent for young people with a learning disability interviewed as part of this Review. There was also limited awareness of, or involvement with, mental health services. This presented considerable challenges with identifying relevant participants for the Review. Although prevalence of poor mental health is higher in this group of young people, there appears to be limited targeted interventions. The Review found a considerable lack of support for young people and their parents/carers to develop mental health awareness and literacy, and to address the stigma and fear of talking about mental health problems.

If young people are unable to recognise what emotional well-being and mental health is, or have not been supported to develop their understanding or vocabulary around this, it is less likely that intervention will happen early enough or be effective. The need to educate children and young people, and normalise

97 Email correspondence from HSCB to NICCY, 12 October 2017 and 9 August 2018.

conversations about mental health and emotional well-being, is extremely important in the context of early intervention. A lack of mental health awareness and literacy can prevent young people from recognising poor mental health in themselves, and can impede full engagement in certain therapies, requiring a certain level of vocabulary in order to talk about feelings, emotions and mental health.

Young people and adults that NICCY engaged with through this Review recognised this gap and agreed that the education system has an important role to play in developing this knowledge and awareness.

There are many examples of programmes being taken forward by individual schools, but there is no consistent regional direction which can ensure that every school provides high quality information and education on mental health. This fragmented approach was undoubtedly part of the reason for the highly mixed response from young people in terms of provisions in school.

9.14 Young People with a Learning Disability

During the Review, many young people with a learning disability (and their parents/carers) indicated that mental health problems and services were not relevant to them. This was very surprising and disconcerting, when set within a context where it is known that there is a much higher prevalence of poor mental health within the population of children and young people with a learning disability, compared to their peers without a learning disability. Mental health services for children and young people with a learning disability, need to be available, accessible, visible and of a quality which is able to meet their needs.

The ongoing implementation of a regional model for the delivery of CAMHS includes a commitment to the development of specialist services for young people with a learning disability (DoH, 2016:2). However, current models of mental health services available for children and young people with a learning disability vary across Health and Social Care Trusts.

The Southern Health and Social Care Trust have developed a specific mental health service for those aged under 18 years called ID-CAMHS, this service is fully integrated into generic CAMHS. For the remaining HSCTs, young people with a learning disability are signposted to generic CAMHS or to learning disability services, and the decision regarding which service young people are directed to tends to be determined by their IQ level. There is no regional policy on this practice, and therefore each HSCT sets its own IQ cut off point, although it tends to sit around 50-60.

The segregation between mental health and learning disability services means there is a lack of professionals who are trained and experienced in working with children and young people who have a learning disability and a mental health problem (Burke, 2014). The range of professionals that a young person may come into contact with about their mental health, and the variation in the level of specialist support they can offer, is also affecting the choice of treatment and/or therapies that are available.

The provision of specialist mental health services, only to young people who have an IQ score assessed above a certain level, must be urgently reviewed. NICCY is extremely concerned that access to CAMHS on this basis, without the provision of an equivalent service, could be construed as discrimination.

This Review has identified that across HSCTs, Children's Learning Disability Services and Children's Disability Services have a major role in supporting children and young people's emotional and mental well-being, where they

do not meet the IQ based referral threshold for generic CAMHS. However, there appears to be very little integration or visibility of these services as part of the Stepped Care Model. In general across all strands of the Review, mental health services for children with a learning disability are not visible in many HSCTs. The exception to this seems to be in the SHSCT in which the ID-CAMHS service is part of generic CAMHS. Young people with a learning disability have been largely invisible in CAMHS operational data obtained as part of the Review, because the data on demographic profile of those using mental health services is not disaggregated by disability.

In the course of collating and analysing data to inform this Review, the issue of high rates of detention of children and young people admitted to the Iveagh Centre, was raised in discussions with professionals working with children with mental ill health and a learning disability. It is worth noting that two professionals who NICCY engaged with on this issue, stated that there appears to be a practice of parents being informed that their children have to be detained under the Mental Health (Northern Ireland) Order 1986 in order be admitted to Iveagh. Detention then allows staff to use restrictive practices that they would not otherwise be permitted, if the young people were admitted to Iveagh on a voluntary basis. If this is the case, it is NICCY's firm view that decision making of this kind is not in the best interests of the child as required by Article 3 of the UNCRC. NICCY also believes that the inappropriate detention of children and young people under the Mental Health (Northern Ireland) Order 1986 engages Articles 5 and 8 of the ECHR, the right to liberty and the right to privacy and family life respectively.

Under Article 10 of the Mental Health (Northern Ireland) Order 1986 there is an obligation to declare a period of detention for treatment of a mental illness for insurance and driving purposes, travel, to employers and for jury service. This obligation to declare periods of detention for treatment for a mental illness has a significant adverse impact on children and young people in terms of their life chances, and ability to access opportunities in the same way as children and young people who have never been detained for treatment of a mental illness. In the development of the Mental Capacity Act (Northern Ireland) 2016, the (then) DHSSPS and DoJ stated its intention to amend Article 10 of the Mental Health Order to include an extension to the disregard provision, so that children under 16 would not have to declare detention for treatment of a mental illness, in recognition of the extremely detrimental impact of the obligation contained under Article 10 on the child's life and future (DHSSPS and DOJ, 2014). It is extremely unfortunate that the proposed extension of the disregard provision was not included in the Act.

9.15 Young People with Alcohol and Drug Problems

This Review found significant and concerning gaps in provision for young people who are experiencing co-occurring mental health and alcohol or drug problems. These gaps were apparent across all of the Steps in the Steps Care Model, and in particular within Steps 4 and 5.

The interviews with young people found a very poor response from services once help was sought. Young people were told to stop using alcohol and/or drugs before they would be eligible for support from statutory mental health services. Generally, young people under the influence of substances are not medically fit for assessment. The current practice would be to ask relatives to take them to A&E as a place of safety and they can be assessed when medically fit. However, young people repeatedly stated that they needed support to stop using alcohol and/or drugs, and reiterated the need for a therapeutic response to their mental health problems to be carried out in tandem.

Children and young people are using alcohol and drugs as a way of managing or coping with the symptoms of their mental health problems. It is therefore critical they are able to get access to a holistic range of support. The consequences for young people of a lack of services to support all of their needs was stark, and evident in the experiences young people shared with NICCY as part of this Review. The negative impact was particularly apparent for young people with the most serious problems, who described being 'passed between' or 'bounced around' different parts of the mental healthcare system, with a high proportion of these young people having regular crisis incidents, requiring them to attend A&E.

The lack of follow-on professional support in the hours or days following presentation to A&E was also a serious concern raised by the young people. This was a very common experience highlighted repeatedly during the interviews with young people, with drug or alcohol problems. This lack of a robust mental health pathway between A&E and specialist mental health services clearly reflects the broader challenges that professionals face when responding to young people with mental health and drug and alcohol problems. The existing mental health legislation (Article 3 (2) of the Mental Health (NI) Order 1986) states that a young person cannot be detained whilst they are under the influence of substances, and as a consequence these young people cannot be hospitalised for inpatient care. Furthermore, there is no rehabilitation centre or safe place for young people with co-occurring mental health and drug and alcohol problems, and this creates a vicious cycle for the small group of young people in this situation.

During the practitioner workshops, a statutory professional remarked that there was 'very little they could do' for this group of young people. Other participants talked about there being a limited number of health professionals in the community that have the specialist skills to work with young people with co-occurring mental health and alcohol and drug problems.

The findings from the Review also highlighted the need for much closer supervision and monitoring of young people with a background of alcohol and drug problems, who are prescribed medication for their mental health by a health professional. Young people talked about sourcing a range of street drugs and prescribed medication from drug dealers. Some young people also talked about misusing the medication they were prescribed by their doctor.

A small number of young people mentioned they had bought prescription drugs online. Although this Review is not in a position to determine how common this practice is, the potential health implications are very concerning. There have been recent media reports of anti-anxiety medication, usually only available on prescription, being sold to young people as young as 13 years old (BBC Online, Feb 2018).

9.16 Operational Data on Child and Adolescent Mental Health Services

For the purposes of this Review, there was a limited amount of standardised regional Government data available on child and adolescent mental health services. This includes a lack of a reliable regional breakdown of the demographic profile of children and young people accessing emotional and mental health services across Step 1 to Step 5 of the Stepped Care Model by age, ethnicity, disability, or by presenting need/mental health diagnosis. There is also a lack of aggregated information on key issues important to service delivery, such as the specific reasons referrals are declined, detail on the therapeutic interventions being used,

or the outcomes achieved by those accessing services. This dearth of information raises serious questions about the ability of the mental health system to plan, commission, evaluate and provide services.

This lack of available data has highlighted a deficit in transparency and accountability in the planning and reporting of statutory mental health services. These issues need to be fully addressed as a matter of urgency. The absence of robust systems to collate disaggregated data on the lives of children and young people who are accessing or attempting to access mental health services and support, makes it impossible to comply with children's rights and equality obligations.

NICCY welcomes the developments currently underway to fill the gaps in the operational data on mental health services for children and young people (CAMHS dataset) and population need data (prevalence survey). They will provide a range and depth of information that Northern Ireland has never had before. It is imperative that these data systems are established as a matter of urgency, kept up to date, and used as the evidence base for the planning and delivery of mental health services. It is also important that this data is part of a central, publically available database.

9.17 Investment in Services within the Stepped Care Model

It is widely accepted that the resources allocated to funding emotional and mental health services for children and young people in Northern Ireland is inadequate. As stated earlier, in 2017 only 7.8% of the overall mental health budget was allocated to child and adolescent mental health services, although these figures do not take account of many of the emotional and mental health services provided by the EA and PHA which fall within Steps 1 and 2.

The fund mapping work carried out as part of this Review clearly demonstrates the range of funders and agencies providing services to support children and young people's emotional and mental health. In Steps 1 and 2, three key bodies fund the critical universal preventative and targeted early intervention services: the PHA, the EA and the HSCB. Moreover, most of these services are provided by voluntary sector organisations, some of which are able to draw in additional resources through charitable funding. It is important that all these agencies work together in planning, commissioning, delivering and evaluating these services.

While most of the services coming within Steps 3 to 5 are funded by the HSCB, it became clear through the process of gathering the fund mapping data, that there are different funding streams within the HSCB, and that the funding of mental health services, particularly for children and young people with disabilities, is considerably complex. Activity and financial resources are organised within 'Programmes of Care', and through these health services are planned and monitored.

The majority of the existing investment in CAMHS is within Trust baseline funding and reflects an accumulation of historical investment rolled forward year on year. Baseline resources are already committed with staff employed in the services established within Trusts, and are periodically reviewed to reflect changing local priorities, population data and any requirement for efficiencies.

Planning for new CAMHS investment is taken forward through the HSCB regional commissioning group and the HSBC Finance Directorate subsequently allocates funding to Trusts on the basis of 'capitation fair shares'. A 'capitation formula' is a statistical formula designed to measure the relative need for resources across localities, and is used to distribute additional resources. The formula is

built up from individual programme of care models, taking account of a range of factors, including differences in population size and age/gender mix, and this is aggregated to provide a 'composite fair share' for each locality. In the absence of prevalence data it is not based on known assessment of mental health needs.

Within HSCTs, the configuration of services reflects historical developments rather than necessarily the most efficient structures. Consequently a number of services are sitting in inappropriate directorates or programmes of care, preventing the flow of funding reaching the intended group, and limiting the impact of services on intended outcomes. One example of this is the 'Children with Severe and Profound Intellectual Disabilities' team in the Northern Trust and the South Eastern Trust. This does not currently sit in the same Directorate as CAMHS, resulting in children and young people with disabilities receiving very different mental health services than other young people.

Commissioning is fragmented, which makes it difficult to identify appropriate funding sources for new innovations or for changes to current services. In some cases staff must approach a number of commissioners across different Directorates to fund important work. During the Review this became apparent when seeking information about funding for mental health services and support for young people with a learning disability.

The Children's Services Cooperation Act 2015 (CSCA) places a statutory duty on all 'Children's Authorities' to cooperate in improving children's well-being, and empowers these organisations to 'pool funds' for this purpose. It has provided a renewed focus on the coordination of services, particularly where there are many organisations and agencies delivering a range of services to children and young people. The Children and Young People Strategic Partnership plays an important role in supporting the co-ordination of funding and service delivery across agencies.

9.18 Conclusion

NICCY welcomes the positive developments in child and adolescent mental health services over the past decade. However this Review has identified the significant variation in the availability, accessibility, acceptability and quality of mental health support available to children and young people in Northern Ireland, and therefore has made recommendations to address this.

This Review has actively sought out local and international examples of good practice, as they offer an important opportunity for service commissioners and providers across the education, the health and social care and the third sectors, to deliver improvements and join up their services. However, this Review has found that good practice in local systems is piecemeal, and embedded within the formal structures and commissioned services. Dedicated professionals, who work tirelessly to support young people, cannot have the impact they desire until the complexities and fragmentation of the mental health system is comprehensively addressed.

The necessary, significant and sustainable improvement in the quality and accessibility of mental health support for children and young people must become a regional health priority. If sustainable progress is to be made, it is imperative that the barriers identified in this review are removed. Positive change can only be achieved if all relevant stakeholders are involved in the Regional Stepped Care Model and that they work together, in a meaningful and genuinely collaborative manner.

It is important that there is clear recognition that there is no hierarchy in terms of those involved in supporting young people's mental health. All services, whether statutory or non- statutory, specialist mental health or focused on children and young people's broader well-being, are vital parts of a whole system approach. It is critical that young people access the most appropriate service as quickly as possible. Children and young people should only ever be referred to the most appropriate service, which is assessed as most likely to achieve the best outcome for them.

Mental health services and support must be available and responsive to children's needs - despite the barriers and challenges that young people faced whilst seeking help or receiving services, the vast majority stated that they would advise others to seek help for their mental health if they needed it, but there is significant room for improvement and the contributors to this Review have identified what needs to be done.

9.19 Recommendations

Children and young people require support and services from a range of groups and bodies to support their emotional and mental well-being. However, one of the key findings of this Review has been that there is insufficient coordination in the planning, commissioning and delivery of these services, across all the groups and agencies in question. This has directly impacted on young people's experiences of these services, and limits the effectiveness of the system as a whole.

A system-wide response is required to the challenges outlined in this Review. All relevant agencies and sectors must engage together, cooperating to improve children and young people's emotional and mental well-being. This is reflected in how the recommendations are articulated; in most cases this report does not specify any one agency or department against individual recommendations.

The Regional Model for the Delivery of CAMHS

NICCY recommends the establishment of a high level multi-agency, multi-sectoral project board that is tasked with the development of a comprehensive, adequately resourced action plan for taking these recommendations forward. This work should be embedded into the existing transformation agenda, and should include:

a) The development of a Children and Young People's Mental Health Transformation Fund to drive the change required. This should be a long term and sustainable 'funding and practice partnership model' which takes account of the investment required across all key services and sectors included in the Stepped Care Model;
b) The use of the fund mapping methodology and analyses of need, to map increases in spending on emotional and mental health services over time, and to demonstrate how additional resources are being effectively and efficiently allocated to meet the needs of children and young people;
c) Formalisation of the relationship between Statutory CAMHS and the Voluntary and Community Sector (VCS), through the development and implementation of clear strategic policy direction;
d) The development of a culture and practice of multi-disciplinary and multi-sectoral team working; and
e) Full implementation of the Managed Care Network (MCN) as a matter of urgency, and review of its potential as a mechanism for co-ordinating and operationalising a whole system approach to the delivery of human rights compliant mental health services for children and young people.

Pathways and Referral Processes

2. The Department of Health (DoH) should review the implementation of the Regional Referral Criteria for Step 2 and 3 CAMHS to:

a) Develop a comprehensive training and awareness raising programme, to ensure that all 'referral agents' are aware of the referral process and their role within it;
b) Develop regional protocols which allow a broader range of VCS organisations working with young people with mental health problems, to make a direct referral to Step 3 CAMHS or with the support of a GP (fast track process via GP); and
c) Introduce multi-disciplinary and multi-agency decision making processes in individual care planning, to ensure that support pathways for young people are direct and effective.

3. Steps must be taken by the HSCTs and the HSCB to address the reasons why young people referred to Step 3 CAMHS are not having their referrals accepted.

4. Progress the development, implementation and monitoring of service specific integrated care pathways, such as those involving A&E, CAIT and SHIP. These must be informed by the staff and professionals working across the agencies involved.

Professional Support

5. Introduce a mandatory programme of mental health training for all professionals likely to come into contact with young people with mental health problems, this must include GPs. The training needs to develop core professional competencies to respond to young people in a sensitive, competent and age appropriate way. This should include refresher training every 3 years.

6. Designated mental health practitioners, trained to work with young people, should be attached to every GP surgery, and statutory mental health professionals should also be available to every primary and post primary school in Northern Ireland.

7. Introduce Community Mental Health Fora across Northern Ireland, which bring GPs and VCS organisations together to develop local relationships and exchange local knowledge.

Support for Young People at Different Stages of Accessing Step 3 Services

8. Review appointment systems and consider the introduction of:

a) An online booking system so young people and carers have more control over the appointment time given;
b) Appointment slots available outside of school hours;
c) The option of appointments being held in their own home or close to home;
d) Reminder texts about appointments; and
e) The option of making remote contact with a trained mental health counsellor between appointments i.e. telephone, text.

9. Introduce a Mental Health Passport Scheme that contains key information on young people, which they want professionals involved in their care to be able to access.

10. Introduce a dedicated telephone advice line for statutory CAMHS, which professionals, parents/carers and young people could use as a way of improving the communication and support offered by services, whilst young people are waiting for an appointment or between appointments.

11. Develop a children and young people specific Regional Integrated Elective Access Protocol (IEAP).

12. A range of community based after care supports must be available to young people discharged from Community CAMHS or inpatient care.

13. Provide resources to GP's to allow them access to a greater range of self-help supports to offer young people.

Care Planning and Treatment

14. The administration of prescription medication for young people must comply with NICE guidelines. Where medication is prescribed to a young person with a history of alcohol and/or drug problems this should be risk assessed and appropriately supervised. HSCB must monitor prescribing data to ensure compliance with NICE guidelines.

15. The complete range of evidence based, effective psychological treatments and alternative therapies should be made available to children and young people. Targets for accessing such treatments should be set in the best interests of children and young people, met, closely monitored and reviewed.

16. Joint care planning processes should be developed and reviewed, to ensure that key services work collaboratively and in a co-ordinated manner to support young people to address the biological, psychological and social factors that are causing or contributing to their poor mental health.

17. The practice of admitting children onto adult mental health wards should end. Children and young people requiring inpatient mental healthcare should receive it separately from adults.

18. Children should receive the most appropriate and effective inpatient care for their mental health. This should be tailored and appropriate to the level of need, and include the provision of inpatient intensive care where necessary.

19. Reasons for the increase in the number of young people being detained in Beechcroft need to be urgently interrogated. Similarly, an examination of the variances in referral rates to Beechcroft by HSCTs should be carried out. A clear policy response and actions should be taken forward as a result, in the best interests of children and young people.

20. The reasons for Extra Contractual Referrals, treatment received and outcomes for children and young people should be closely monitored. Services which are not currently available in Northern Ireland should be provided, so that all young people who require treatment for mental health problems can receive it close to their family and community. This should include secure forensic mental health provision and complex eating disorder treatment.

Access to Crisis Mental Health Support

21. Implement RCPCH 'Minimum Care Standards for Children and Young People in Emergency Care Settings who Present with Mental Health Problems' (RCPCH, 2018).

22. The DoH should enhance the statutory framework, requiring RQIA to routinely inspect A&E Departments against the 'Minimum Care Standards for Children and Young People in Emergency Care Settings who Present with Mental Health Problems' (RCPCH, 2018). This should include appropriate, robust enforcement powers and the provision of sufficient resources to carry out this role.

23. Crisis intervention support for children and young people should be available 24 hours a day, all year round, in all HSCTs.

24. Include a Clinical Decision Unit, or equivalent service model, as part of every A&E Department in Northern Ireland. This would be useful for young people who may require a period of observation, further investigation or other interventions which cannot be completed within the four hour timeframe within A&E Departments.

25. An evaluation of the compliance with and effectiveness of the Card Before You Leave scheme (CBYL) for children and young people in A&E should be carried out.

Participation and Feedback from Young People

26. Development of an action plan to strengthen advocacy, enhance peer support, and develop practice standards to evidence the involvement of young people in service development, and in their own care planning.

27. Revise and establish fora in each HSCT to support the active engagement of children young people and their parents/carers, to inform both acute and community care. Views expressed through this engagement should be considered at the practice based meetings, where day to day issues are raised and discussed.

28. Develop user-friendly guidance for young people and parents/carers which explain their right to complain, and sets out the minimum standards of care they should expect.

Transition from CAMHS to AMHS

29. A Regional Transitions Policy and Procedure which is compliant with NICE Transition Guidelines should be developed and implemented, to ensure that all young people transition smoothly between CAMHS and AMHS.

30. Specific attention should to be given to meeting the support needs of children and young people who do not meet the transition criteria for adult mental health services.

31. Develop a mental health 'bridging service' for young people aged 16 - 25 years old, that allows for a smoother, flexible and young person centred transition between services.

Mental Health Awareness and Literacy

32. Comprehensive mental health and wellbeing education for pupils should be provided as a core part of the education curriculum. This should ensure that all young people have sufficient vocabulary to talk about their emotional well-being and mental health, know how to look after their mental health, have an understanding of the help available and how to access it.

33. Education and mental health service providers should develop formal partnerships in order to holistically meet the needs of children in education at all levels, and for those children and young people receiving their education 'other than at school'.

34. Equal emphasis should be placed on the measurement and improvement of the well-being of children and young people in education, as on academic attainment. Schools should be inspected by ETI on their ability to develop the conditions required to nurture young people's well-being.

35. Information, guidance and training should be provided to parents, carers and children at key stages and transition points across childhood.

36. A programme of public awareness and community capacity building on mental health and emotional well-being should be developed, and regionally implemented with a specific focus on geographical areas, and groups with the highest risk factors for poor mental health.

Young People with a Learning Disability

37. A comprehensive and integrated mental health service model across Northern Ireland for children and young people with a learning disability, should be agreed and implemented. This model must ensure that young people with a learning disability can access comparable services and support as young people without a disability.

38. Assess how widespread the practice of determining eligibility of access to specialist mental health services (CAMHS) solely or mainly on the basis of IQ is, and take all necessary measures to ensure that access to services is always on the basis of need.

39. A comprehensive review of community based emotional, mental and behavioural support services for young people with a learning disability should be carried out without delay.

40. Immediate steps must be taken to ensure that all detentions of children and young people in the Iveagh Centre under the Mental Health (Northern Ireland) Order 1986 is proportionate and appropriate.

Young People with Alcohol and/or Drug Problems

41. Statutory CAMHS should adopt a 'harm reduction approach' to ensure that young people can access mental health support whilst withdrawing from substances. Appropriate levels of supervision and support for young people withdrawing from substances should be provided.

42. Universal and timely access to Drug and Mental Health Services (DAMHS) should be available across Northern Ireland. DAMHS should be closely aligned to CAMHS, and closely linked to Step 2 commissioned drugs and alcohol services.

43. Step 4 specialist intensive community based support and interventions for young people with drug and/or alcohol and mental health problems should be expediently developed, and provided across Northern Ireland. This should include day treatment programmes and age-appropriate interventions.

44. Inpatient care and treatment should be provided for young people with co-occurring drug and/or alcohol and mental health problems, who cannot be safely and effectively supported within the community. This provision should take a holistic approach to need, provide a range of interventions and be fully integrated into the Stepped Care CAMHS service model.

Data and Monitoring

45. The DoH should develop a universal health information system linked to every individual child, to inform every health professional coming into contact with a child and/or their parents/carers. This should link to other information systems, such as UNOCINI. 'Patient level' data should be integrated into statistical reports as part of a transparent and accountable information reporting system, so that the impact of services on outcomes for children and young people can be tracked.

46. Government should ensure that the first Northern Ireland Prevalence Survey of children and young people's mental health is completed by year end 2019/20, and published soon thereafter. Further prevalence surveys should be repeated every 3–5 years.

47. The CAMHS Dataset should be fully implemented across each HSCT. Adequate resources should be provided to establish and maintain the system. Data should be published on a regular basis, in line with other health statistical reporting. The Dataset should be augmented to include additional basic information and data, required to monitor services and effectively plan CAMHS. These include:

Out patient

a) Information on young people who are accessing emotional well-being and mental health services through Learning Disability Teams/Disability Teams;
b) The specific reasons for referrals not being accepted to Step 3 CAMHS; and
c) Track young people moving between services within the Stepped Care Model for CAMHS. This would help to monitor the length of time and the pathways required for young people to access support. This must include young people who are not accepted for referral to Step 3 CAMHS.

Waiting Times

d) Collection and monitoring of additional waiting time statistics:

   i) Waiting times for services beyond Generic Step 3 CAMHS, to include key services across Steps 2 – 5 and waiting times for urgent and emergency appointments to Step 3 CAMHS;
   ii) Waiting times between referral being made and referral being accepted or not accepted;
   iii) Waiting times for second appointment to Step 3 CAMHS;
   iv) Waiting times for access to psychological therapies; and

e) Data on the types of psychological therapies and alternative therapies used as part of young people's treatment plan.

Attendance at Appointments

f) The reasons for DNAs/CNAs should be recorded and monitored. Specific attention must be given urgently to addressing the reasons for non-attendance; and
g) Record the numbers of young people who are discharged from CAMHS due to DNA/CNA and monitor compliance with IEAP guidance.

Inpatient

h) Record and monitor referrals not accepted to Beechcroft inpatient unit.

Adult Wards

i) Discharge destinations of young people admitted to adult mental health wards should be recorded and monitored.

Demographics

j) A greater range of demographic information for specific groups of young people should be collected e.g. those with a physical, learning, sensory disability, looked after children; LGBT children; Newcomer and Separated Children.

Outcomes

48. A greater depth of information regarding patient experiences and outcomes should be collected and monitored, including outcomes defined by, and important to' young people e.g. improvements in relationships with friends and family – in addition to psychometric scores of mental health.

49. Universal health services, such as GP and A&E, should agree on and implement a set of standardised information system codes, to record and monitor the numbers and profiles of young people with mental health problems and/or drug and alcohol problems accessing their services.

50. When a young person is admitted to a general paediatric bed for mental health treatment or care, the DoH should request that RQIA are notified, and provided with information on what care and treatment is being provided.

The Northern Ireland Commissioner for Children and Young People commits to monitoring the implementation of these recommendations, and will engage with all relevant agencies to ensure improved outcomes for children and young people. NICCY will publish monitoring information on an annual basis.

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Glossary

A&E	Accident and Emergency
AMHS	Adult Mental Health Service
BHSCT	Belfast Health and Social Care Trust
CBYL	Card Before You Leave
CAIT	Crisis Assessment Intervention Team
CAMHS	Child and Adolescent Mental Health Services
CRC	Committee on the Rights of the Child
CNA	Can Not Attend
CSCA	Children's Services Co-operation Act
CYPSP	Children and Young People's Strategic Partnership
DAISY	The Drug and Alcohol Intervention Service for Young People
DAMHS	Drug and Mental Health Services
DHSSPS	Department of Health NI
DoH	Department of Health NI
DH	Department of Health England
DNA	Did Not Attend
EA	Education Authority
ECR	Extra Contractual Arrangements
ECHR	European Convention on Human Rights
EDS	Eating Disorder Service
ETI	Education and Training Inspectorate
ENOC	European Network of Ombudsmen
EWO	Education Welfare Officers
HSCB	Health and Social Care Board
HSCT	Health and Social Care Trust
ICSS	Independent Counselling Service for Schools
ID-CAMHS	Intellectual Disability Child and Adolescent Mental Health Services
IEAP	Integrated Elective Access Protocol
JJC	Juvenile Justice Centre
LAC	Looked After Children
MCN	Managed Care Network

MHO	Mental Health (NI) 1986
MSA	Mental State Assessment
NICCY	NI Commissioner for Children
NISRA	NI Social Research Agency
NHSCT	Northern Health and Social Care Trust
NICE	National Institute for Health and Care Excellence
OCCE	Office of the Children's Commissioner in England
PHA	Public Health Agency
RCPCH	Royal College of Paediatrics and Child Health
RQIA	Regulation and Quality Improvement Authority
SHIP	Self-Harm Intervention Programme
SHSCT	Southern Health and Social Care Trust
SEHSCT	South Eastern Health and Social Care Trust
UNCRC	United Nations Convention on Rights of the Child
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
VCS	Voluntary and Community Sector
WHO	World Health Organisation
WHSCT	Western Health and Social Care Trust

Appendix 1: CAMHS Care Pathway

Stage 1: Coming into CAMHS

Stage 1.1. A referral is Made to CAMHS
The CAMHS Pathway document lists the professionals who can make a referral to Step 3 CAMHS i.e. GPs, hospital, other health and social care professionals, Education Authority services, or relevant voluntary organisations who may be involved with the family. The pathway document does not indicate which referral agents are applicable at each step in the pathway, GPs are the only health professional that can make a routine referral to Step 3 CAMHS. Self-referrals are not accepted by Step 3 CAMHS.

Triage is a pre-assessment process based on a written referral form; it does not require a face-to-face appointment between the young person and the appropriate mental health practitioner. The referral will be reviewed against regionally agreed referral criteria and the referral prioritised as one of three types of referral:

- **Emergency:** referrals that require a face-to-face assessment with 24 hours of receipt of the referral. This will include young people who are actively suicidal, acutely psychotic, presentation of anorexia with severe physical signs, those who are severely depressed and/or in need of crisis assessment or intensive home treatment/ acute care admission. This includes young people who present to A&E with self-harm;
- **Urgent:** referrals that require a response within 5 working days of receipt of the referral. This will include young people with severe symptoms of depression, severe deterioration in emotional state and behaviour at home and school, not thought to be due to drugs, alcohol or physical illness; and
- **Routine:** referrals that require an appointment with 9 weeks (Please note: there is an additional statutory waiting time target of 13 weeks for access to psychological therapies that applies to under 18s and over 18s).

Stage 1.2. Family/Carers and Young Person are Provided with Information on the Referral

CAMHS staff will acknowledge receipt of the referral within 7 days and provide a CHOICE appointment in writing, detailing what will happen at the appointment. A CHOICE appointment is part of the Choice and Partnership Approach (CAPA model) that has been agreed across HSCTs. The aim of CAPA is to engage young people and their families whilst managing supply and demand within CAMHS. In doing so, it places the needs of families at the center of CAMHS. As its name suggests, CAPA relies upon the principles of 'Choice' and 'Partnership'. New CAMHS users and their families are invited to an initial 'Choice appointment'. They are offered a choice of day, time, venue, clinician and intervention. Following this, families are invited to book 'Partnership appointments'. Here, the families will aim to work in partnership with the CAMHS professional on mutually agreed goals.

CAMHS staff will personalise the young person's appointment to take account of their particular needs, and will provide information in a suitable format to help the young person understand all that will be involved.

Stage 1.3. What will Happen if a Young Person is not Deemed Suitable for CAMHS

The pathway document states that, if CAMHS believes that another service is more appropriate, this will be explained to the referrer and the referrer will be advised about other services that may be better suited

to meet the young person's needs.
No further detail is provided in the CAMHS pathway document about this stage.

Stage 2: Sharing Information and Agreeing the Way Forward

2.1. First CAMHS Appointment – Referred to as a CHOICE appointment

According to the pathway document, a CHOICE appointment is a joint discussion between CAMHS staff, the young person and their family, and this will be an opportunity for the young person to tell their story and gets their family's views.

During this appointment the young person's wishes and feelings will be discussed, and decisions will be made with their full involvement.

The young person and their family/ carers will be asked questions about their concerns, hopes and expectations. This will also include the young person being asked questions about their safety, including things that make the young person feel unsafe, and how they can keep themselves safe.

The CAMHS professional the young person meets at their first appointment may, or may not, be the best person to provide their treatment, and the young person will asked for their views about who the best person might be.

2.2. Information and Treatment/Support Options Available

At the first appointment the young person will be provided with information about the support available to them, and involve them in decisions being made about treatment options and activities they could do to promote their health and well-being.

2.3 Development of a Care Plan

CAMHS staff will identify services that match the young person's needs, and work with them and their family/carers to identify and develop their care plan, that will focus on solutions. A Care Plan is a document that outlines the young person's care requirements, and includes what services will do to support the young person and their family. Every young person will receive a copy of their Care Plan, which should include information about:

- Strengths, hopes, goals, resources;
- Personal safety;
- Care and treatment options;
- Physical health and well-being; and
- Contacts with other agencies and what their role is in a young person's care and treatment - including names and contact details.

3. What to Expect During my Involvement with CAMHS

3.1 CAMHS Working with other Agencies/ Professionals to Support the Young Person and their Family/Carers

CAMHS will involve other professionals or services where it may help the young person's recovery. CAMHS will ask the young person and their family/carers for permission to do this, and they will work with them as appropriate.

3.2 Review and updates of Care Plans

A young person's progress will be reviewed regularly, and Care Plan's updated as necessary. The young person's family/carers will also be involved.

This will be based on the needs of the children and young people, and in partnership with any staff who are working with them. The care and treatment interventions set out in my Care Plan will be monitored to determine progress.

3.3 Measuring Individual Clinical Impact/ Outcomes

CAMHS will gather information in order to

measure progress over time; this will include asking the young person how they feel at the beginning and end of the care or treatment programme. A young person's family will also be involved in this process.

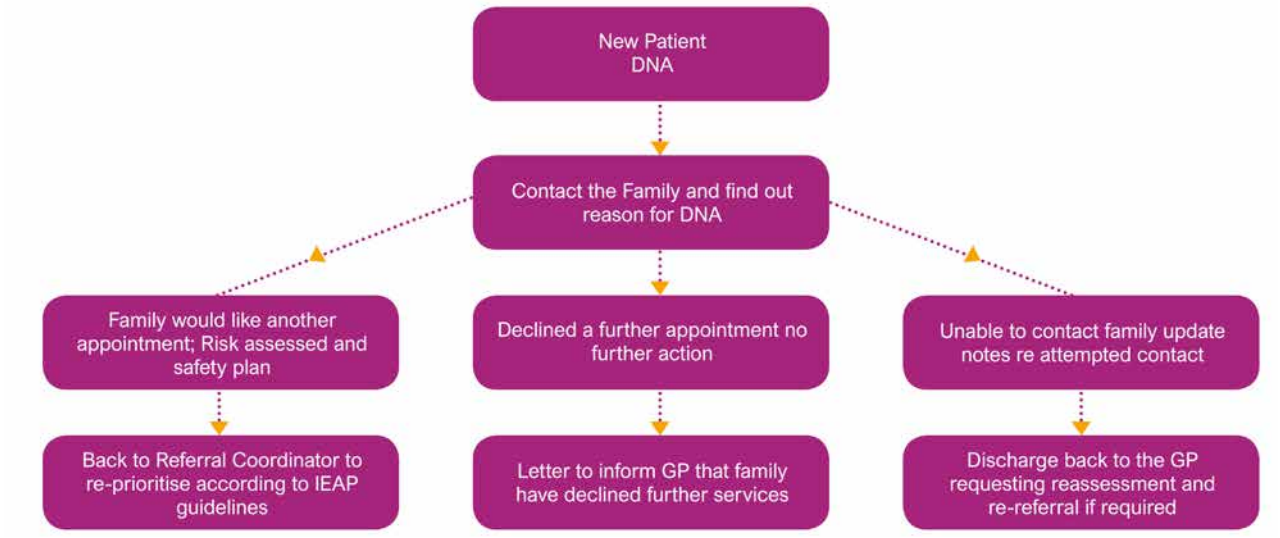
4. Moving on and Recovery

Being Discharged from CAMHS

The young person and their family/carers will be involved in any discussion and decisions about discharging the young person from CAMHS. The decision about whether a young person is discharged from CAMHS will include reviewing their progress against goals set out in their Care Plan. A Discharge Plan will be written, which will include arrangements for discharge from CAMHS.

The Process if a Young Person does not Attend an Appointment

If a young person Does Not attend (DNA) or Can Not Attend (CNA) an appointment, Section 12 of the regional Integrated Elective Access Protocol (IEAP) will be applied. This states that a young person will not be automatically discharged due to non-attendance. A further appointment will be offered, in accordance with their assessed needs and risks that may be identified, and will be followed up. If the young person does not attend or cancels the second appointment, there will be a review of the clinical risks that resulted in the non-attendance. This will be done in partnership with CAMHS and the CAMHS referrer.



Source: CAMHS Pathway - March 2018

4.2 Signposting to other support/services on discharge from CAMHS

CAMHS will work with the child, young people and their family to identify supports upon discharge from CAMHS.

A letter will be sent to the young person's GP to notify them of the young person's discharge from CAMHS, and the plans that have been put in place to support them on an on-going basis, should they need them. The young person and their family/carers will be informed about how to re-enter the service if and when they need to.

For young people who are reaching 18 years old, but still require the support of mental health services, this may involve a referral being made to adult mental health services. CAMHS will make contact with Adult Mental Health Services 6 months before they are due to be discharges from CAMHS. This will be to share information about the care they have been receiving and their future needs.

4.3 Feedback on Services

The young person and their family/carers will be given the opportunity to give feedback about their experience of CAMHS. This information will be used to better understand the benefits of the service, how it can improve, and what if any changes are required.

When young people have additional needs, such as drug and alcohol problems or learning disability, then the pathway can diverge from CAMHS to a range of other services or supports. This will be dependent on a number of factors including the services available within individual Health and Social Care Trusts.

Crisis Assessment Intervention Services

Each of the HSCT have different crisis mental health service coverage for 0–18 year olds:

- **BHSCT/SEHSCT** – a dedicated service is available 24 hours a day, 7 days a week, 365 days of the year;
- **WHSCT** – the Card Before You Leave (CBYL) is used during Saturday and Sunday between 9am – 1pm and at all other times support is provided through normal CAMHS service;
- **SHSCT** – crisis support service is available up until 5pm on a week day, and 5pm on a weekend and bank holiday; and
- **NHSCT** – crisis support service is available up until 9pm on a week day and Saturday and 2pm on a Sunday and bank holiday.

How to get Help

If you are a young person reading this report and need support with your mental health talk to your parents/guardians, GP, teacher or another trusted adult.

You can also contact the following organisations:

Childline
0800 1111
www.childline.org.uk

Childline provides a 24 hour free telephone advice line and online 1-2-1 chat advice for any child or young person who has a concern.

Samaritans
116 123
www.samaritans.org

Samaritans offers a confidential hotline which is free to use by anyone who needs help. They also have branches across Northern Ireland.

Contact NI
0808 808 8000
www.contactni.com

Contact NI runs school based, community based and specialist counselling services free of charge. They also run the lifeline helpline.

For more detailed information on this report or support for Children and Young People please see our website www.niccy.org

For further information:
Email: info@niccy.org
Phone: 028 9031 1616
Please contact the communications team at NICCY if you require an alternative format of this material.

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