



'STILL WAITING'

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

Young Person's Report

September 2018

NICCY
PROMOTING THE RIGHTS OF
CHILDREN & YOUNG PEOPLE

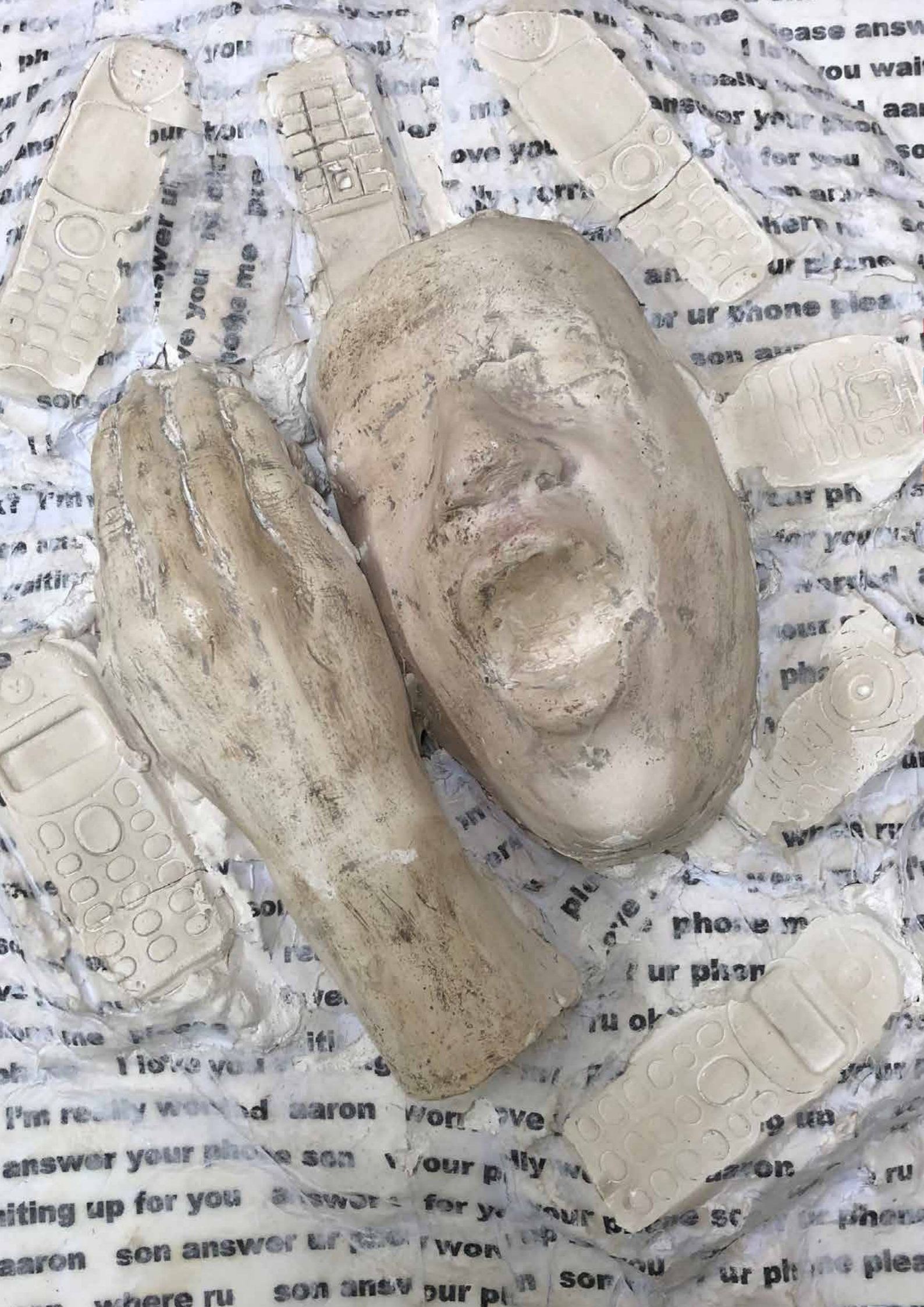






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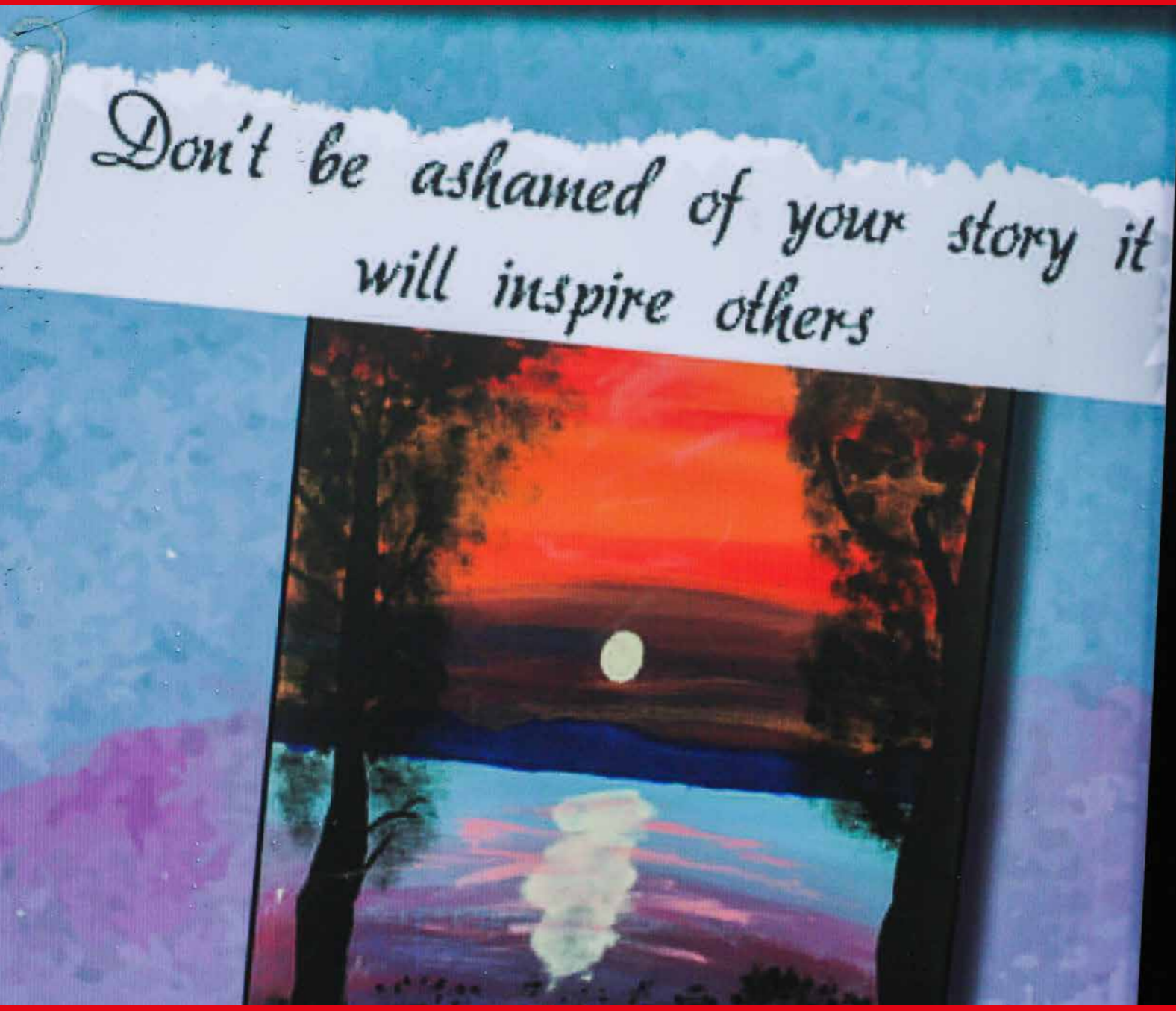
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Artwork Acknowledgments

We thank the children and young people from the Upper Springfield Youth Team in West Belfast who kindly allowed us to use their artwork on the front cover, back inside cover and Executive Summary page. It was created as part of a project in which they explored the issues impacting on local young people's mental health.

We thank the young people from Bloomfield Youth Safety Partnership in East Belfast who kindly allowed us to use their artwork on the back cover. 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.

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



BACKGROUND



About NICCY

"As the Northern Ireland Commissioner for Children and Young People (also known as 'NICCY') my job is to promote and safeguard childrens and young people's rights and best interests and to make sure Government does the same. It is important for me and my team to know when children and young people are being treated differently, and to understand their thoughts and concerns so that we tell Government what they need to do to improve services, to make sure all children and young people can fully enjoy their rights."

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

What is the UNCRC?

NICCY has to take full account of the United Nations Convention on the Rights of the Child (UNCRC) which are your rights, or the promises made to you by Government. This includes your right to be heard and have your views taken seriously, be healthy, get a proper education, be supported in your family or wherever you live, be able to play and take part in leisure activities. Most importantly, the UNCRC says that the best interests of young people should always be considered when adults are making decisions about you.

The UNCRC is clear that children and young people have rights to good quality **mental healthcare**. This includes being given help to get the healthcare you need, when and where you need it.

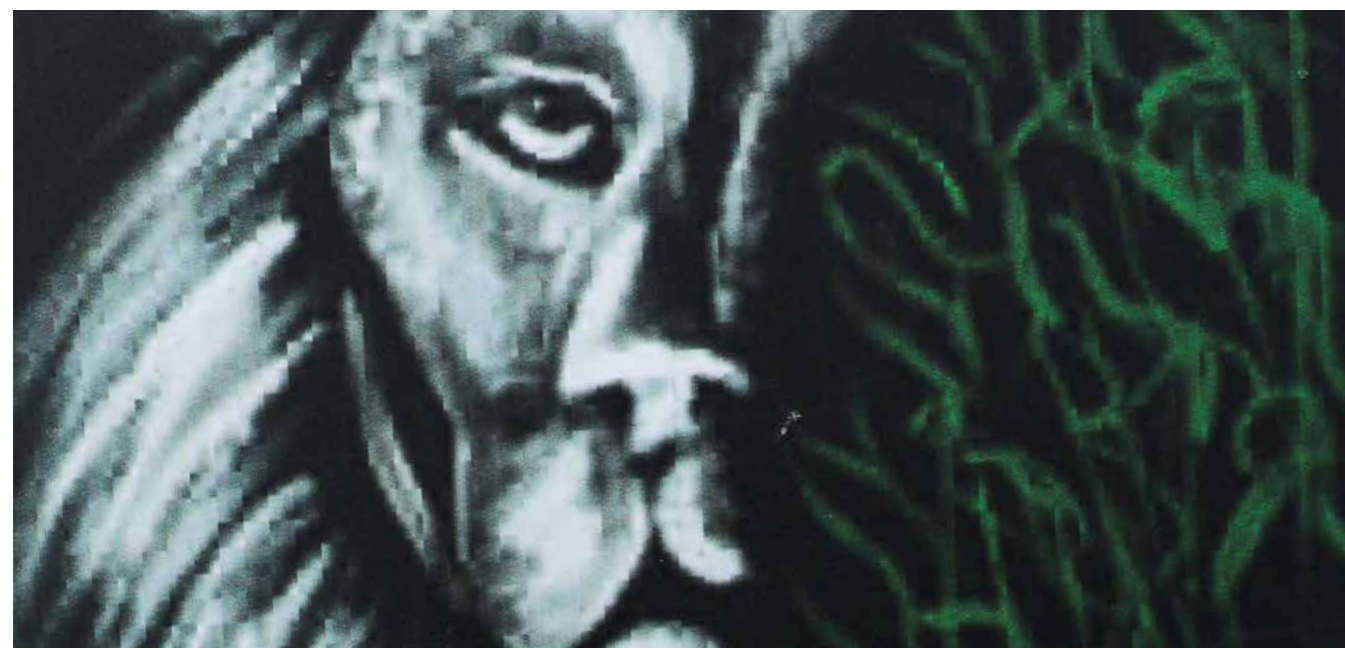
Article 24 says that all children and young people have a right to the best possible health and access to services that promote and maintain good health. This applies to both physical and mental health.

What is Mental Health?

When we use the word 'mental health' for short, we mean a young person's 'emotional well-being and mental health'. A child has to be well enough to be able *'to develop and become aware of their own unique personality, to build their own identity, to fulfil their 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'* (Definition developed by European Network of Ombudspersons for Children, 2018).

Mental health is important; it can affect how a person feels about themselves, how they get on in school and how they relate to their friends and family. Young people can experience a wide range of different emotional or mental health problems. This can include things like depression, anxiety, stress, bipolar disorder and eating disorders.

It is important that young people look for help with their mental health if they need it. Such as talking to a parent, carer, GP or someone you trust or contact one of the organisations listed at the end of this report.



There are many different services that young people may have been, or are, in contact with about their emotional well-being and mental health. In this report we asked young people about services provided by:

- ▶ **GPs (Doctors);**
- ▶ **School or College;**
- ▶ **Youth and Community Organisations;**
- ▶ **Community CAMHS (specialist mental health service delivered by Government);**
- ▶ **Accident and Emergency (A&E); and**
- ▶ **Inpatient Care.**

I and my colleagues in NICCY have spoken to many young people. They told us that looking after their mental health and having support when they need it is really important.

A big focus of this report is to give young people with experience of mental health problems a chance to tell us about their experiences of mental health support and services. This information will help Government to understand what changes need to be made to make services better.

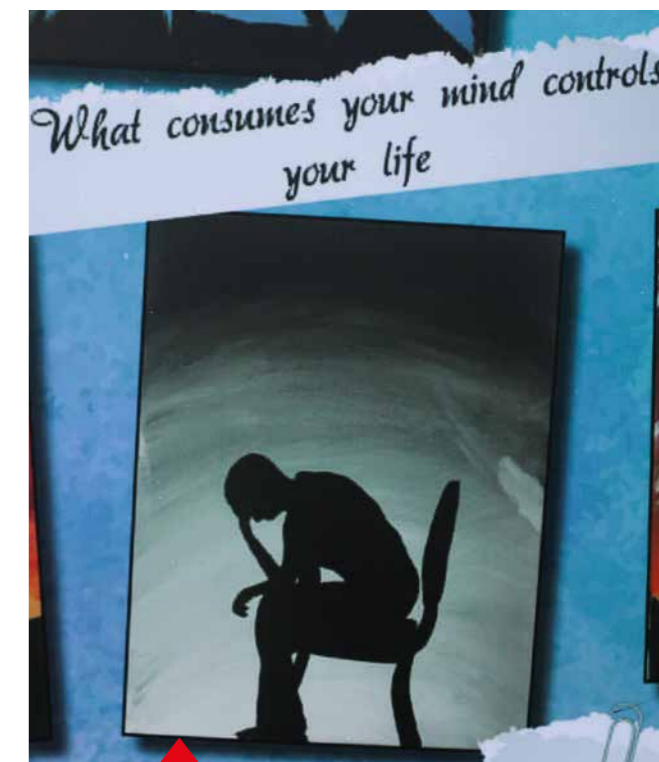
Why we have Written this Report?

There is a lot of research that tells us that 14–18 years old is a common age for mental health problems to start. For this reason, it is very important that Government takes action to promote positive well-being and to make sure that services and support are available to both identify and respond to mental health problems.

We also know from talking to young people that they can face many barriers to asking for help and in getting the right support. In order to better understand a number of things about services and support for young people, and what a good mental health service would look like, we asked some questions:

- ▶ Is the right amount and type of support in place?
- ▶ Are all young people able to access services when and where they need them? If not, what are the barriers that prevent this?
- ▶ Are all young people offered a quality of service which adequately meets their needs, is age appropriate and improves well-being?
- ▶ Are young people's views taken into account when developing policies and services, and when decisions are being made about their individual care?

We looked at the information collected by Government on the types of mental health problems young people have, and the services and support young people are accessing. We also looked at the amount of money that is spent on children and young people's emotional well-being and mental health.



Who took Part in the Review?

- ▶ NICCY carried out a survey with young people aged 11–21 years old and a shorter survey with parents / carers. 600 young people took part but the number of respondents for each service varied depending on young people's experiences;
- ▶ We also carried out face-to-face interviews with 32 young people with a learning disability and young people with drug and/or alcohol problems. We chose two groups of young people who had particular problems getting support for their mental health; and
- ▶ NICCY also talked to adults that work in mental health services or who support young people to access services. 76 parents and carers also responded to a survey.



REPORT FINDINGS

What did we find out? General Findings

Young People's Experiences

- ▶ Young people talked about the positive support they had received, but many also talked about where services could have been better;
- ▶ Overall young people had very mixed views on the availability, accessibility and quality of support provided to them for their mental health;
- ▶ One consistent message from young people was the hope that sharing their experiences would help to improve the system for other young people; and
- ▶ The vast majority of the young people (77%) said they would advise friends or family to look for help from mental health services, if they had emotional or mental health problems.

Staff working in Mental Health Services

- ▶ Mental health workers are very committed to improving the mental health and well-being of children and young people; and
- ▶ There is still work to be done to make sure that a range of services and professionals work together and understand their role in supporting children and young people's emotional well-being and mental health e.g. GPs, Teachers, Counsellors, Psychiatrists, Social workers, Youth workers and other organisations working with children and young people.

Government Planning for Mental Health Services

- ▶ Government is not collecting enough information on children and young people's mental health needs, the services young people are using, and whether they are helping young people;

- ▶ Services are under a lot of pressure to meet the needs of young people with mental health problems; and
- ▶ More work is needed to make sure all children and young people in Northern Ireland can access the right type of help for their mental health when and where they need it.

Funding for Mental Health Services

- ▶ Government bodies told us about more than £30 million they are spending each year supporting children and young people's emotional well-being and mental health, through schools, community groups, and health services. But we know this is not enough.

Looking for Help

Many young people are waiting too long before asking for help. This means it is really important that when they do seek help, they get the right kind of support quickly and easily. It also highlights the importance of promoting positive well-being and supporting young people to seek help earlier:

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

"(..)The one thing I would change is the stigma and stereotype that accompanies getting help for mental health, that you 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 (..)."

Information about Services and Access to Support

The Report found that getting information on services or accessing mental health support is not always quick or easy. Many young people described having to speak to multiple professionals, across a range of services before getting access to support:

“(It would be good) 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.”

“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.”

It is concerning that on average, only half (49%) of the young people surveyed, said they were able to get help when they needed it. Very unwell young people talked about their mental health getting worse, and in some cases, a lot worse because they were not able to get support quickly enough:

“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.”

The GP is one of the main people young people go to see when they are looking for help for their mental health. They are also one of the main people that can refer them to specialist mental health services. Lots of young people didn’t have a good experience of going to their GP because the GP didn’t know enough about mental health:

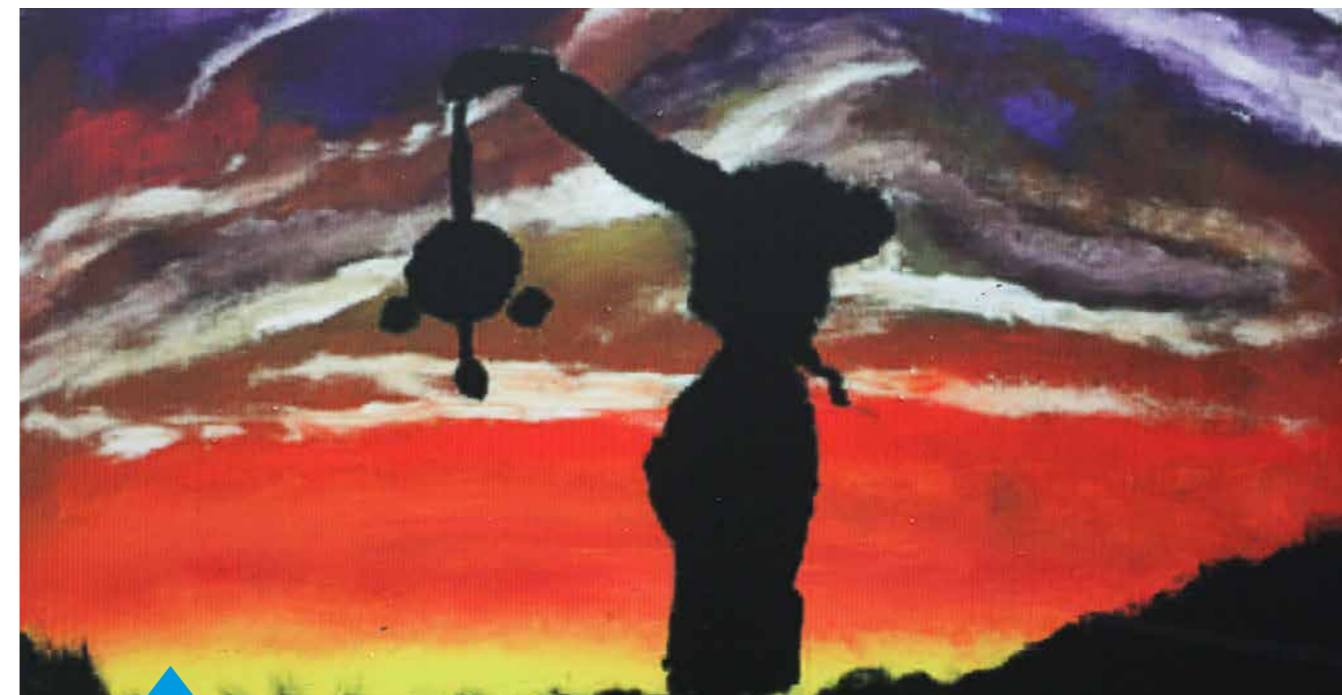
“GPs are not the best trained around mental health and this has a major impact as when I told my doctor about my mental health, they couldn’t help me understand as they aren’t trained very well with mental health, self harm and suicide.”

We spoke to GPs about this and they also want to be able to help young people more when they come to them about their mental health – but they said they need more support to do this. They said they **need more training, more types of self-help support options that they can offer young people and better communication with specialist mental health services.**

During the Review, GPs, Youth and Community organisations, and children and young people said it would be good if more types of professionals helped young people to access specialist mental health services, especially young people that had already been getting help from a Youth or Community organisation, school counselling or Self Harm Intervention Programme:

“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.”

“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 (..).”



Emergency Mental Health Support

The report looked at young people’s experience of getting support when they had a mental health crisis and needed support immediately. There is support available but there are differences in young people’s access to this type of service depending on where they live:

“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.”

Lots of the young people who had gone to Accident & Emergency (A&E) during a mental health crisis said that the support wasn’t helpful. A&E staff need to have better training in mental health, and there needs to be a separate section of A&E that young people can go to for help. It also found that services, such as mental health services and social services need to work more closely with A&E to make sure that the support young people receive is quicker and helps to meet all of their needs, not just what is immediate:

“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.”

“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).”

The Importance of a Supportive Adult

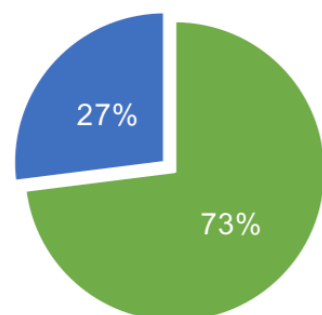
Young people said they talk to adults about their mental health based on who they can trust and not on how much that person knows about mental health. The Review identified a need to make sure all supporting adults are able to identify poor mental health in children and young people and are able to respond in a timely and sensitive way:

“Certain teachers would talk to me and it would help a bit but was not professional help (..)”

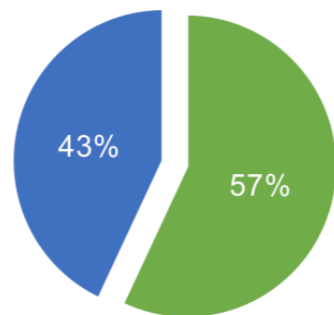
“I felt respected and listened to within this organisation as the counsellor was able to remember my name and remember my situation and all the problems that were going on in my life as she was able to refer back to them most of the time, this made me feel more at ease to open up to an extent most of the time.”

Participation of Young People in their own Mental Health Care

I was spoken to in a way I could understand

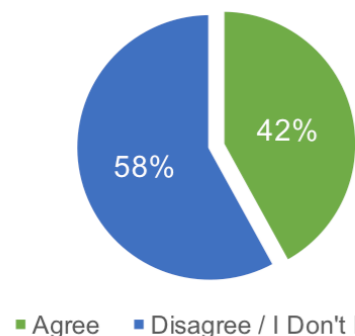


I felt listened to and respected



Overall, across all the services young people were asked about, 73% agreed that they were spoken to in a way they could understand, and 57% said they felt listened to and respected. These were two areas that young people were most positive about in terms of services and support.

I felt involved in decisions being made about my care or treatment



Young people were asked whether they felt involved in the decisions being made about their care or treatment, when they went to different places for support. Overall, 42% agreed that they were involved in decisions, but there were big differences in how well young people believed different services did this. Voluntary and Community Sector Organisations (75%) and Schools/Colleges (52%) generally did much better.

Choice of Treatment and Support

Lots of young people talked about wanting to have greater choice of treatment / care available to them that included different types of psychological or alternative therapies. The Government needs to collect more information on the range of non-drug based therapies available or being used with children and young people and make sure that young people are given the treatment that best meets their needs.

“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.”

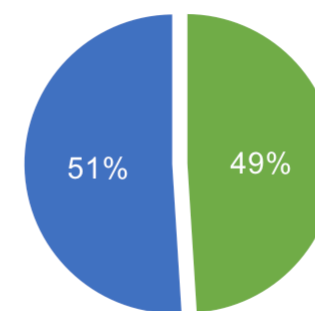
“I was not listened to at all, the psychologist cut me off and made a decision about my treatment based on other young people my age and their experiences and what she thought would suit my AGE not my NEEDS.”

Young people also told us that they needed practical support to help them to cope with the things causing their poor mental health or making it worse.

“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...”

Helpfulness of Services

The support I received was helpful



Overall, half of the young people surveyed did not find the support they received helpful. A number of services rated below average on this statement – GP (44%), Community CAMHS (45%), Inpatient Care (39%) and A&E (34%).

Young people and their parents also expressed a lack of knowledge of how to make a complaint about a mental health service.

The Key Characteristics of a Good Mental Health Service

Young people identified the following things as being part of a good mental health service:

1. A professional, relaxed, non-judgemental, non-clinical, age-appropriate approach;
2. Clear and consistent boundaries of confidentiality;
3. Services should be flexible and operate outside of Monday to Friday, 9am–5pm hours;
4. Easy access to more support, or more regular support, if they needed it;
5. A physical environment that is non-clinical and informal, with appointments in places familiar to the young people;
6. The ability to access clinical and practical support at the same time; and
7. Support while waiting for an appointment, between appointments and when discharged.

“Making the appointments more regular as a 3–4 week or longer wait is a very long time.”

“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.”

“Whilst waiting on the support from the mental health team I had support from a community organisation (..) while I waited on the mental health team it was some form of support (..)”

“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.”

Moving from Children to Adult Mental Health Services

Young people that had experience of moving from children’s mental health services to adult mental health services highlighted the need for more preparation and support before moving services, and more flexibility on when they move:

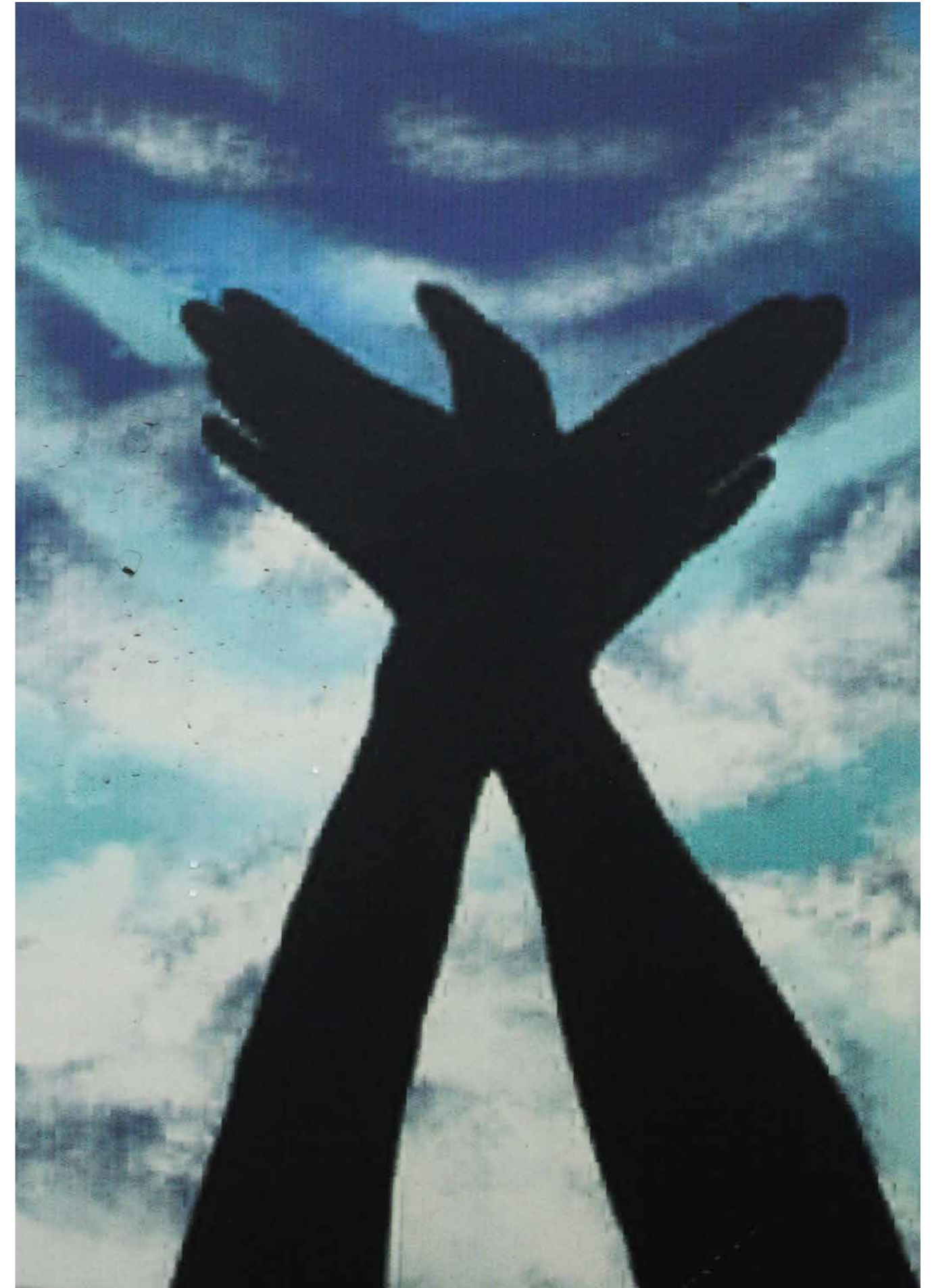
“CAMHS had been so helpful and aware the transition would be stressful and kept me with them as long as they could.”

“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 (..).”

Mental Health Awareness and Understanding

The Review found varying levels of mental health awareness and understanding among young people. There needs to be more support for young people and their parents or carers to develop awareness and have the right language to express feelings and describe mental health. This support must include addressing the stigma and fear around talking about mental health problems:

“(...) a child (should have help) 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...”



Support for Young People with Additional Needs

The type of mental health services available for children and young people with a learning disability varies depending on where they live.

A learning disability affects the way a person learns new things in any area of life. It may affect the way they understand information and how they communicate. This means they can have difficulty:

- ▶ Understanding new or complex information;
- ▶ Learning new skills; and
- ▶ Coping independently

(adapted from People First)

Many young people with a learning disability do not have access to a service that can support them with their mental health needs, and understand their learning disability:

"(...) 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."

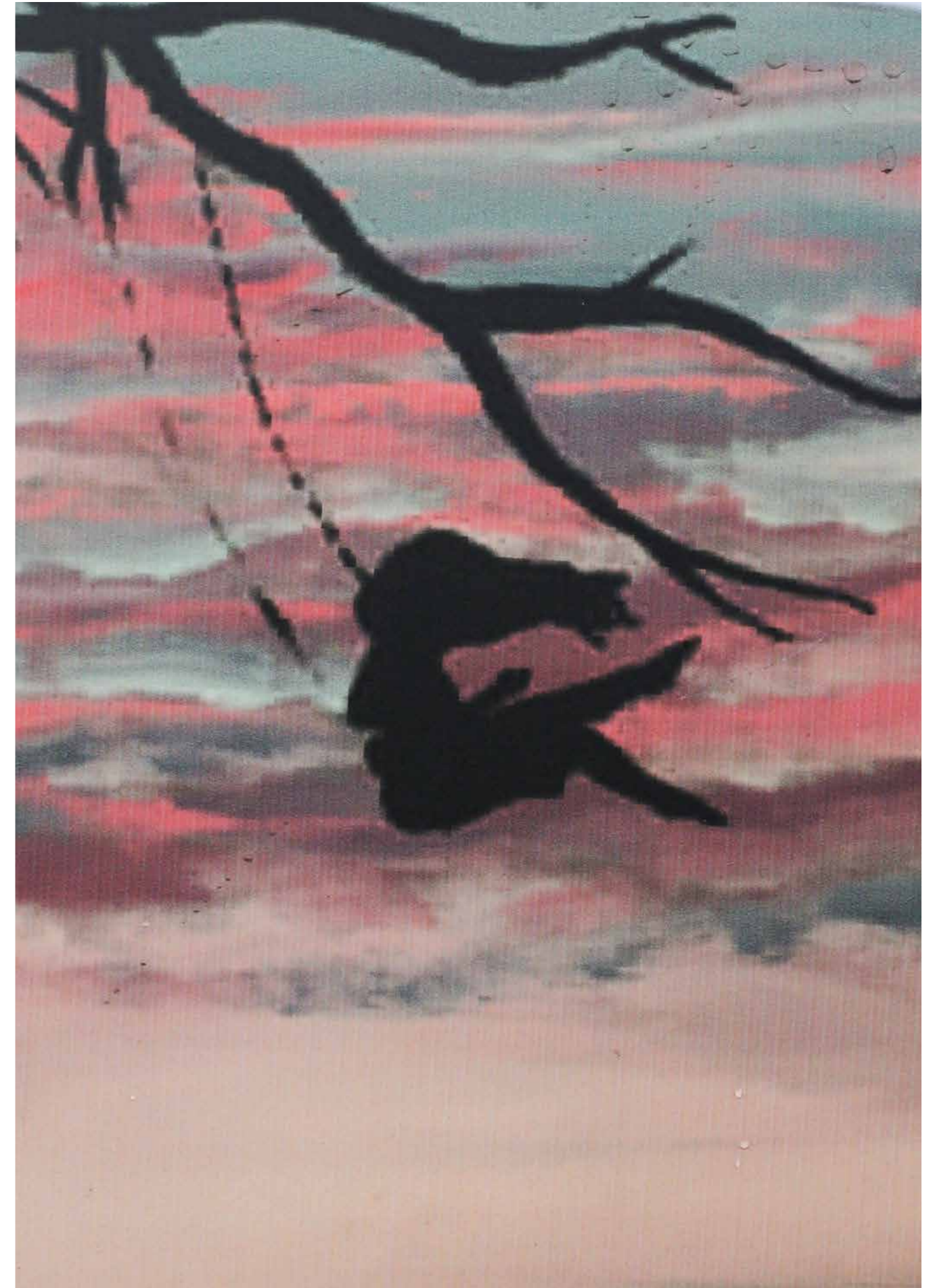
"It's trying to find the right help I can't seem to get it. And me granny has tried and the school and the tech's been helping but the only help is kind of about more severe stuff I think."

"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..."

Young people with alcohol and / or drug problems told us they need support with their mental health and alcohol and drug problems at the same time. The Review found young people are not always getting all of the support they need. Services need to improve for young people who have these sorts of problems and who need intensive support in the community, or need to be in hospital with staff that can understand their mental health needs and their drug and alcohol problems:

"(..)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 at a very young age and I didn't know who to go to."

"(..) 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?"





RECOMMENDATIONS FOR GOVERNMENT

After thinking about all the things young people and adults that support them have told us, NICCY has asked the Northern Ireland Government to take the following actions. Lots of different Government Departments have a role in making these happen:

Working Effectively

Government should:

- ▶ Set up a project board that includes all of the key organisations that work on children and young people's mental health. This board should create an action plan to address all of these recommendations;
- ▶ Allocate additional money to promote children and young people's mental health, and support them when they have poor mental health;
- ▶ Collect better information about levels of need, the services provided and the difference services are making, so that the right services are in place;
- ▶ Make sure all services, including health, education and youth and community organisations can work together to create a mental health support system for children and young people that best meets their needs; and
- ▶ Gather regular information on mental health need, and information on young people using services.

Accessing Help

Government should:

- ▶ Make sure young people can access the right service as quickly as possible, by removing barriers and making sure professionals have clear instructions about the services that are available and how young people can access them; and
- ▶ Give young people more options about how to make an appointment with Community CAMHS and greater control and choice of appointment times.

Support for Adults Working with Children and Young People

Government should:

- ▶ Give mental health training to all professionals in contact with young people with mental health problems (eg GPs, Teachers, Social Workers, youth workers). The training should focus on making sure they respond in a sensitive, knowledgeable and age appropriate way to young people; and
- ▶ Mental health practitioners who are trained to work with young people should be attached to every GP surgery in Northern Ireland and should also be available to every primary and post primary school in Northern Ireland.

Specialist Support

Government should:

- ▶ Set up a dedicated telephone advice line for statutory CAMHS so that young people, parents / carers can easily access support and information while they are waiting for an appointment or between appointments;
- ▶ A range of community based mental health support must be available to young people after they leave hospital, or once they are no longer seeing Community CAMHS;
- ▶ Children and young people requiring inpatient mental healthcare should never be treated on an adult mental health ward;
- ▶ Children and young people who are having a mental health crisis and are in need of urgent specialist help should be able to access it at any time, all year round;
- ▶ Urgently address the role and response of A&E to children and young people who come in with mental health needs. Basic standards need to be met and monitored; and
- ▶ The care young people receive in a mental health hospital should always be the best form of support and tailored to their needs.

Flexible Treatment Options

Government should:

- ▶ Give young people a greater choice of treatment and support for their mental health problems. This should include a range of evidence based, self-help supports, psychological treatments and alternative therapies;
- ▶ Medication should only be prescribed when all other non-drug based interventions have been considered;
- ▶ Make sure young people are involved in decisions being made about their care and have a range of ways of giving their views on how services are delivered; and
- ▶ Make sure young people and parents / carers are clear about the standard of service they should expect and know how to make a complaint or provide feedback.

Moving from Child to Adult Services

Government should:

- ▶ Make sure young people are properly prepared and supported to move from child to adult mental health services. Specific attention should be given to the support needs of young people who are not accepted for adult mental health services; and
- ▶ 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 Understanding

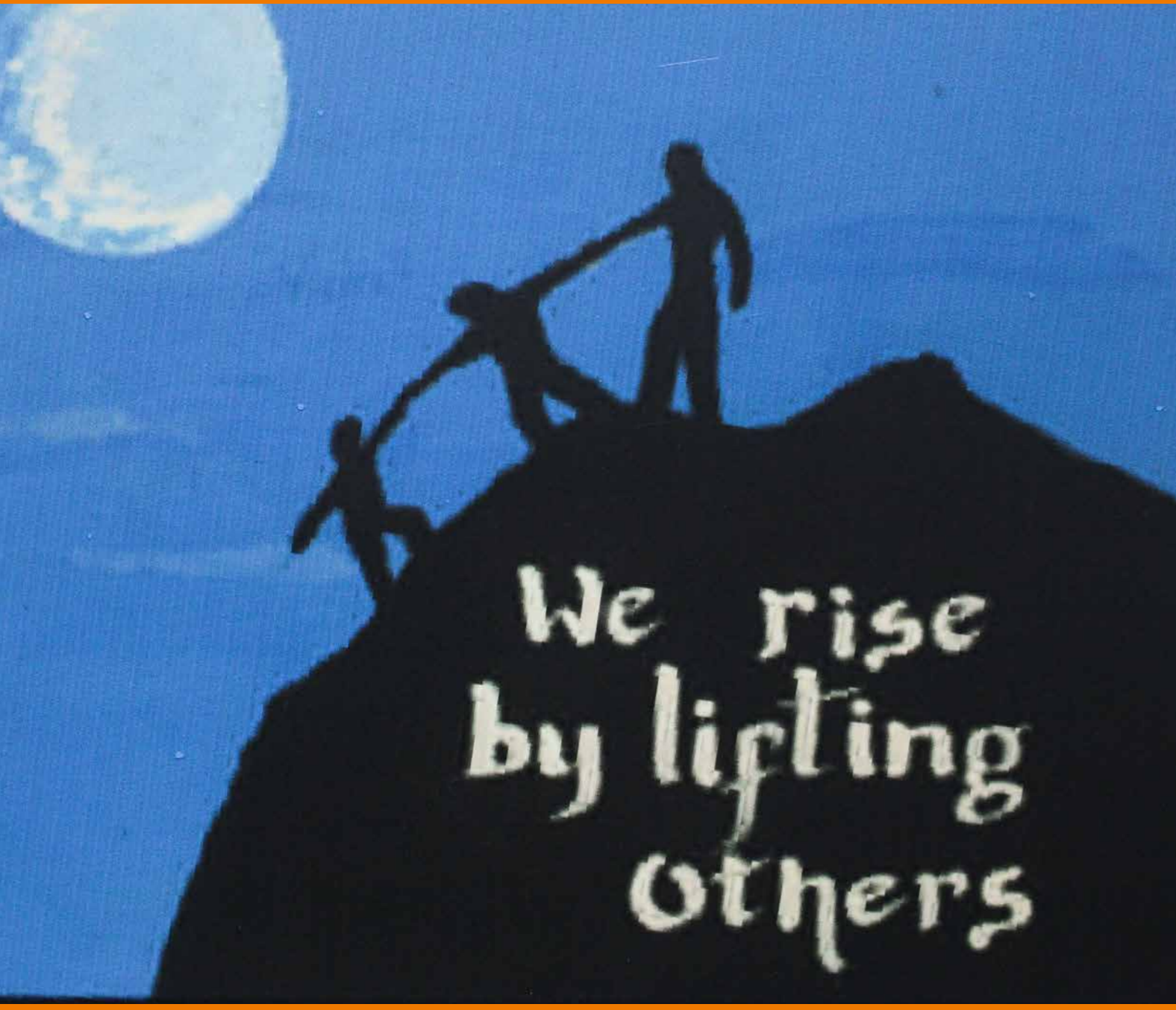
Government should:

- ▶ Make sure children and young people are educated about their emotional well-being and mental health. Children and young people's well-being should be as important to the education system as their academic achievement;
- ▶ Schools, colleges and alternative education should work more closely with mental health services to make sure young people get all the support that they need; and
- ▶ Provide information and training for parents, carers and young people at key stages and transition points across childhood. This should include how to talk about their mental health, how to recognise mental ill health, what types of supports are available and how to access them.

Young People with Additional Needs

Government should:

- ▶ Make sure that young people with a learning disability can access the same range of mental health services and support as young people without a learning disability; and
- ▶ Children and Young People with drug and/or alcohol problems should have access to services that can support them with their mental health and substance use at the same time. This must include specialist intensive community support and inpatient care.



NEXT STEPS

What NICCY will do with this Information?

NICCY will talk to Government and other organisations that support children, young people and families about this report and what it recommends Government should do.

We will also check if the recommendations have been carried out and let you know what action has been taken (you will be able to see this on our website).

How to get help

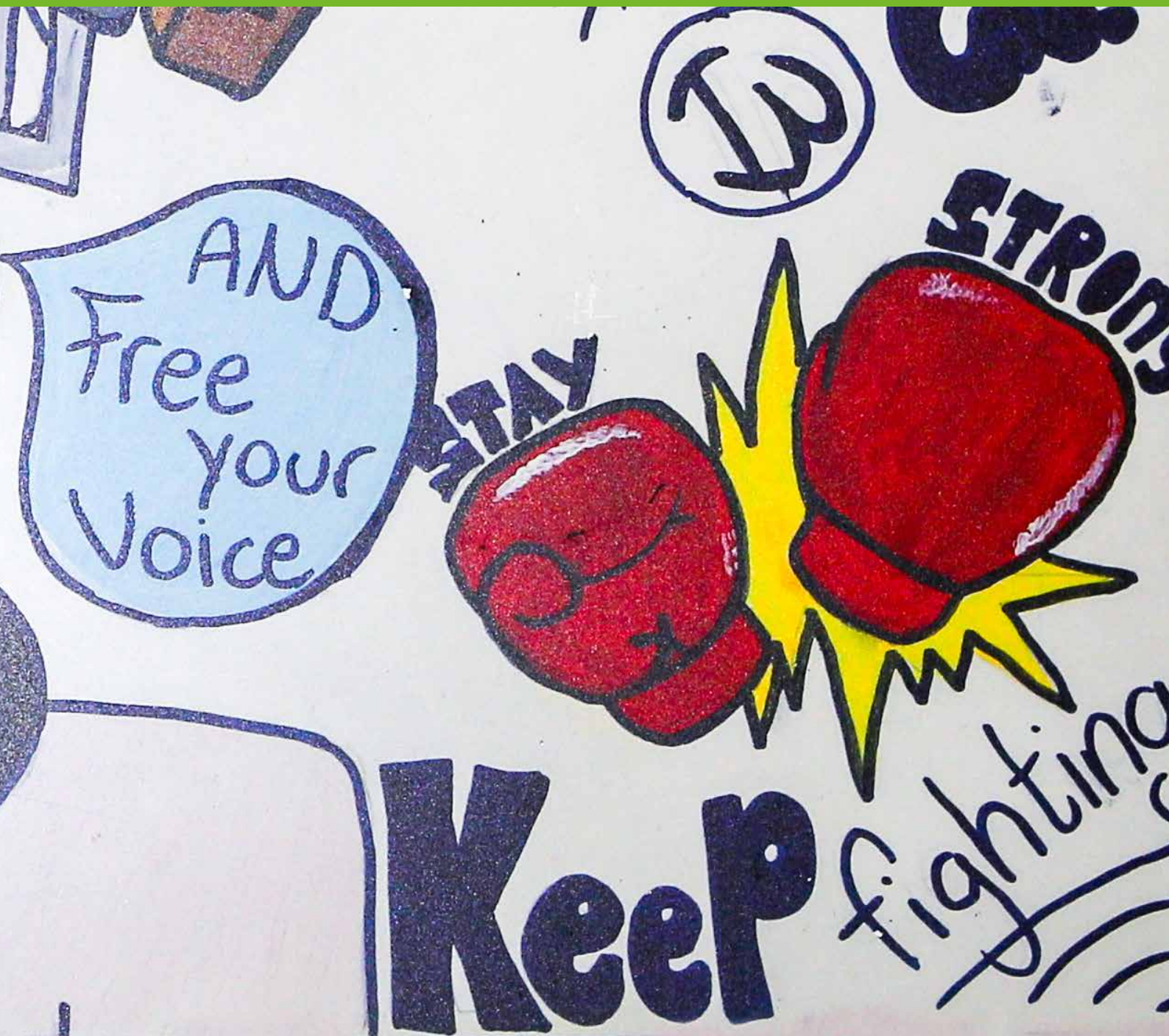
If you need support with your mental health talk to your parents / guardians, GP, teacher or another trusted adult.

In an emergency you can contact the following organisations:

- ▶ **Childline**
T: 0800 1111
W: 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**
T: 116 123
W: 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**
T: 0808 808 8000
W: 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

NICCY is also developing additional resources to increase young people's awareness of their rights on many issues, including mental health. If you would like further information please contact our Participation Team on participation@niccy.org.



For further information:

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Please contact the communications team at NICCY if you require an alternative format of this material.

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