



# **Profiling the Population of Disabled Children and Young People in Out-of-Home Care in Northern Ireland**

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## 1.0 Introduction

Whilst the majority of disabled children and young people live with their birth families, who may draw on the support of health and social services when required, it remains the case that the numbers of disabled children who live away from home proportionally exceeds that of their non-disabled peers (DHSSPSNI, 2012; Stalker & McArthur, 2010). Furthermore, disabled children are less likely to experience permanence in substitute families than non-disabled children (Baker, 2007). Despite these concerns, and with the exception of a few important local studies, there remains a lack of knowledge regarding the numbers, characteristics and experiences of disabled children and young people in out-of-home care. The current study, therefore, aims to examine the profile of disabled looked after children and young people (LAC)<sup>1</sup> in Northern Ireland (NI).

The study has three key stages: (1) a review of policy and research literature on the needs and experiences of disabled children and young people in care; (2) a survey providing demographic data on the population of disabled LAC in NI; and (3) case studies of a sample of this population involving reading case files and interviews with children and young people, carers, birth parents and social workers. Stage 1 of this study is complete and the accompanying reports are available (Dowling et al., 2013; Kelly et al., 2013). The present report is based on stage two of the project, describing the aims, methodology and findings of a survey completed by social workers working with disabled LAC in NI.

The overall aim of this stage of the study is to profile the population of disabled LAC across NI. The key objectives are to:

- Examine the characteristics of the population of disabled LAC in NI;
- Identify the key reasons for their entry to care;
- Investigate disabled LAC'S care experiences and access to services; and
- Establish baseline data on this population to inform future research and practice with disabled LAC.

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<sup>1</sup> In NI, children who live in out-of-home care on a full-time basis are often referred to as 'looked after children' (LAC), reflecting the language of the Children (NI) Order 1995. These children can live in a range of out-of-home care including foster families, kinship placements, residential children's homes or specialist care settings.

## **2.0 Background to the Study**

This section of the report outlines the background to the study including the service context across Health and Social Care Trusts (HSCTs) in NI and the wider childhood disability and LAC population in NI. Examining these contexts allows for consideration of comparisons with wider population cohorts and helps to explain some of the variations in numbers of disabled LAC accessing services across the region.

### **2.1 The Wider Context of Looked After Children Across Northern Ireland**

Health and social care services in NI are delivered through an integrated service model with a commissioning Health and Social Care Board (HSCB) and five Health and Social Care Trusts (HSCTs). Statistics on the population of LAC in NI during the time period of the study are available from the HSCB's Delegated Statutory Function (DSF) data which is collected bi-annually (HSCB, 2013) and the Departmental statistical bulletin on children in care in NI 2013-14 (DHSSPS, 2015). Throughout the findings section of this report, data for the study population will be compared with those provided in both of these statistical reports on the general LAC population, although such comparison is limited by the different time frames for data collection and variances in definitions of disability employed across datasets. The other source of data relevant to this report is the 2011 census information on the wider population of children and young people in NI. According to this most recent census data, there are 456,059 children and young people (0-18 years) in NI and 7% of these are disabled (NISRA, 2011).

In relation to the LAC population at the time of the study, the DSF report on children in care at 30 September 2013 (the end of the data collection period for the current study) identified 2,892 LAC in NI, the highest number recorded in twelve years. In relation to spread across HSCTs, the largest number were recorded in the BHSC (25%) and the smallest number were in the WHSC (17%), to some extent reflecting trends in geographies and childhood populations in each Trust area. There were almost equal proportions of females (48%) and males (52%) in the LAC

population, with most in the 5-11 year age range (33%) and lowest numbers in the 16+ category (18%).

Within the general LAC population, 54% were placed under a Care Order; with over a quarter (28%) being voluntarily accommodated and 16% subject to an Interim Care Order. The length of time in care peaked at 1-3 years (31%), with 27% had been looked after for less than one year (16% for 3-5 years, 17% for 5-10 years and <10% for over 10 years). The majority resided in foster placements (39% non-relative and 32% kinship settings). Other placement types included being placed at home (11%) or in residential care (7%). Most LAC (76%) had not experienced a placement move; 8% had moved once, 4% had experienced two placement changes, and 12% had moved on more than three occasions. Overall, 8% of LAC were on the child protection register, mostly those in the youngest 0-4 age group (46%).

The DSF report identified a total of 333 disabled LAC children, representing 11.5% of the general LAC population and indicating that disabled children are over-represented in the general LAC population in NI (HSCB, 2013). The highest percentages of these were in the BH SCT (42%) and NH SCT (35%) with very small numbers reported in the other three Trusts. The majority of disabled LAC (63.4%) were reported to have an intellectual disability; followed by those assessed as being on the autistic spectrum or having ADHD (18.6%); physical/sensory impairment (11.4%) ; and 6.6% were in the 'other' category. In addition to data on the number of disabled LAC, the DSF report also identified a total of 348 LAC who had a Statement of Special Educational Needs (SEN). There are no further disaggregated figures for disabled LAC as available reports focus on the LAC population as whole (disabled and non-disabled LAC together).

In relation to the mental health needs of the LAC population, the only figure available in the DSF Report (2013) is that 1.1% (n=32) LAC were awaiting assessment or treatment with Child and Adolescent Mental Health Services (CAMHS). Further information is provided in the DSF report on the mental health needs of the leaving care population with 16.8% of care leavers reported to be receiving treatment for mental health concerns and 9.1% receiving treatment for self-harming behaviours.



## **2.2 The Service Context for Disabled Looked After Children in NI**

The HSCB bears the responsibility for commissioning services, managing resources as well as performance management and service improvement. The following five HSCTs have the main responsibility for the delivery of statutory health and social care services in their region: Western (WHSCT), Northern (NHSCT), Southern (SHSCT), South- Eastern (SEHSCT) and Belfast (BHSCT). The geographical spread differs considerably across Trusts, with the NHSCT and WHSCT covering the largest geographical areas. The BHSCT provides for a densely populated urban area, whilst the remaining HSCTs cover the needs of a mixed populous, some in urban zones, others in remote rural locations. The WHSCT has a dual challenge of service provision for a widely spread rural population whilst at the same time serving the needs of the province's second city.

Social service support for disabled LAC is provided across a range of social work teams in each HSCT including: Children with Disability (CWD) Teams, Looked After Children (LAC) Teams, 16+ Teams and Family Intervention/Family Support Teams (FIT or FIS). LAC Teams have the main responsibility for all children in care in NI, including disabled children, in all but one Trust in NI (where CWD maintain responsibility). CWD teams may co-work on cases of disabled LAC held by LAC teams but they also have the main responsibility for disabled children looked after due to short break usage (short break LAC). Under the Children (NI) Order 1995 children in NI who use short breaks for more than 24 hours continuously are defined as LAC. CWD usually hold responsibility for these cases, including the implementation of all LAC procedures for these children. Disabled LAC within CWD teams are likely to have an intellectual, physical or sensory impairment. Whilst some of these children may also have recognised mental health needs, they will not be case worked within CWD on the basis of mental health need alone. The latter group would be referred to CAMHS or LAC Specialist Therapeutic services.

Family Intervention Teams (FIT/FIS) have a remit of supporting children and families and preventing admission to care, if possible. However, in some Trusts they may have a small number of disabled LAC on their caseloads if they do not meet the threshold for CWD support, often those not yet diagnosed or with borderline to mild levels of impairment.

In relation to the service context for disabled LAC within each of the five HSCTs, a number of issues are worth highlighting to provide a context for the findings in relation to the profile of this population.

1. Regional services, such as the Iveagh and Beechcroft in-patient assessment and treatment facilities, have a higher level of usage amongst some Trusts compared with others. This may be because similar services exist within the Trust area or it may be due to the geographical distance and the challenges for young people and their families of out of area placements, heightened at times of particular vulnerability for young people. Residential placements are also available in the Camphill Community which is a regional service located within the South Eastern Trust.
2. There appears to be variation between Trusts in terms of access to CAMHS for children and young people with intellectual disabilities. Some Trusts rely on psychiatric learning disability services, often accessed through adult services. For others, CAMHS is open or partially open to those with an intellectual disability, depending on the severity of the impairment.
3. Greater usage of services in some areas may reflect increased availability of particular services in that locality rather than increased need. For example, more children in the WHSCT have access to residential short breaks due to the launch of a new residential unit. However, this may alter as the service is extended to include more children and young people with physical disabilities and ASD.
4. A limited number of out of area placements in England or Scotland are made across the HSCTs, usually for children and young people with severe levels of impairment, complex health needs and/or challenging behaviours. This is due to the reported lack of suitable residential placement for these children within NI.
5. Within Trusts the availability of some services is variable. For example, a particular service may be available in one part of the Trust, but because of distance, travel logistics and costs is not available or accessible to those residing at a distance from the service. This is particularly relevant to HSCTs

with a wider geographical spread with greater availability of services in urban areas.

### **3.0 Methodology**

This section describes the methodological approach for this survey stage of the study beginning with an outline the aims and objectives of the study and the inclusion criteria for the sample of disabled LAC. The data collection process and procedures are then described in detail, including data collection, management and analysis.

#### **3.1 Study Aim and Objectives**

The aim of this stage of the study is to profile the population of disabled LAC across NI. The key objectives are to:

- Examine the characteristics of the population of disabled LAC in NI;
- Identify the key reasons for their entry to care;
- Investigate disabled LAC'S care experiences and access to services; and
- Establish baseline data on this population to inform further research and practice with disabled LAC.

The approach to data collection and analysis was guided by a Professional Advisory Group and a Young Person's Steering Committee. As part of the process of negotiating access to staff in HSCTs to undertake the survey, a Local Collaborator at senior management level was identified in each HSCT to join the Professional Advisory Group. These individuals also provided a key communication link with the Trusts, helping to facilitate the collection of data from individual social workers.

### **3.2 Inclusion Criteria**

Disabled children and young people were included in the study if they met the study's inclusion criteria for disability and being 'looked after'. In accordance with the UN Convention on the Rights of Persons with Disabilities (2006), the inclusion criteria for disability were those assessed as:

- Having a cognitive, physical or sensory impairment; and/or
- Having a mental illness or either awaiting/receiving mental health services; and/or
- Being on the autistic spectrum; and/or
- Meeting the threshold for receiving services from a children's disability team.

Any child or young person meeting the above disability criteria who was looked after at any time from 30 September 2012 to 30 September 2013 was included in the study. This time period for data collection fitted with the timeframe for the study. The end date for data collection also corresponded with the date for the last DSF return in 2013 (at 30 September 2013) to help social workers identify relevant cases for inclusion in the study and allow for some comparison of findings for disabled LAC.

Children were defined as looked after for the purposes of the study if they were:

- Living in public care due to a court order/being voluntarily accommodated for more than 24 hours; and/or
- Staying in short breaks exceeding 35 days in one year or a continuous period of 28+ consecutive days in one year.

### **3.3 The Survey Approach**

Data was collected using a structured questionnaire completed by social workers for children and young people meeting the study's inclusion criteria. Prior to commencement of data collection, ORECNI and Research Governance Committees in each HSCT approved the study.

### **3.3.1 Designing the Questionnaire**

A number of important factors were taken into consideration in designing the questionnaire. It was important to ensure that it gathered comprehensive information whilst also being relatively quick and easy to complete for social workers who have many demands on their time. It was, therefore, designed in such a way that social workers for children and young people could use their immediate knowledge of the case to complete the survey rather than having to consult case files or spend a lengthy period seeking additional information. The layout of the questionnaire was such that sections could be skipped if they were not relevant to the experience of particular children and young people (for example, sections on siblings or short breaks). The questionnaire was piloted by three social workers working with disabled LAC. Their feedback confirmed it took between 10-15 minutes to complete and had a user friendly format. A few suggested amendments to terminology were incorporated into the final version (see Appendix 1).

Inclusion criteria were checked on the first page of the questionnaire; with social workers selecting at least one criterion in relation to the child/young person's looked after status and impairment type. Having ascertained that the child/young person met the inclusion criteria for the study, the questionnaire then requested information about the child's family background, as well as their ethnicity, religion and country of birth. The questionnaire then requested information on the child's circumstances including reasons for being looked after, looked after status, length of time in care, placement type and stability, and birth family contact arrangements. Information was also collected about school experiences, risk taking behaviour, additional needs and contact with other services. For those children were looked after due to short break usage, or those who were fully looked after and also using short breaks, a section gathered information about the length of time using the service, the type of placement, placement changes and extent of short break usage.

### **3.3.2 Administering the Questionnaire**

The questionnaire could be completed using an online version supported by the Qualtrics software, or in hard copy. The online version was password protected and

once complete uploaded directly to the software, making it both a secure and straightforward process. Survey responses for each Trust could be automatically downloaded as a SPSS file for data analysis purposes. The completed hard copy questionnaires were emailed to the researcher using a secure, password protected email system. Data gathered was held confidentially and securely on a password-protected computer. The researcher manually inputted data from completed hard copy surveys (10% of returns) into SPSS to facilitate data analysis. Although service related numbers (e.g. health or social care numbers) and dates of birth were collected to facilitate selection of case studies for stage three of the study, the research team had no means of identifying children or young people from the information provided.

In order to ensure social workers applied the inclusion criteria for the study, it was necessary to work closely with the full range of social work teams with these children on their caseloads across the five HSCTs. Meetings were held with relevant senior managers, followed by team leaders and social workers in each team to ensure they were fully informed about the research and survey approach. In each Trust, the researcher undertook demonstrations of the online survey to illustrate how to complete it and ensure all questions were clearly understood.

At this stage, the researcher also worked with the team to identify (anonymously) how many children on their caseloads would meet the inclusion criteria for the study. This was an important step in the data collection process as it provided an opportunity to ensure a consistent understanding of the inclusion criteria across the HSCTs. For example, one Trust held an informal register of people with a learning disability and staff in this Trust were unsure if children not on this register should be included in the study sample. Across Trusts, there were also questions about including children who used a range of therapeutic services and careful attention was given to the reason for referral to these services. Those who were receiving therapeutic support to address assessed mental health needs were included however those using these services for reasons other than mental health need (such as general family/behavioural support) were not. Such discussions with social workers allowed an opportunity to discuss these issues on a case-by-case basis to ensure a consistent interpretation of the inclusion criteria across Trusts.

Through this process each social worker identified the number of LAC on their caseloads who met the study inclusion criteria and for whom they would be completing a questionnaire which enabled the researcher to follow up on lower than expected responses from individual social workers. For social workers who were not able to attend the meeting (due to other commitments or leave), the senior or team leader was able to identify children on their caseloads who met the criteria. Interestingly, a common initial reaction from social workers (particularly those in LAC, 16+ and family intervention teams which do not focus on disability) was that they were very few disabled LAC on their caseloads. However, on working through the inclusion criteria with the researcher, they were often surprised at the actual numbers on their caseloads who met the study criteria.

Before leaving the team, a timescale for completion of the questionnaires was agreed, usually within two weeks of the meeting; however, in some instances a slightly longer timescale was agreed (for example, to accommodate leave or particular demands on the team at that time). When the agreed time scale lapsed, the researcher checked the number of returns on the online system and followed up with individual social workers on any missing data or lower than expected returns. Reminders were copied in to team leaders and local collaborators if responses were particularly slow, with any further assistance required from the researcher provided.

In order to bring the process of data collection to a close, it was planned that the online questionnaire would be deactivated by mid-December 2013. On request, this date was extended until the end of January 2014 to allow final entries to be made (still only including those looked after from 30 September 2012 to 30 September 2013). Teams were given several prompts during this time from the researcher, the local collaborator and senior Trust managers to ensure full opportunity for completion. When the extended date was reached and assurances were given that no further responses would be received, the questionnaire was deactivated and no further entries could be made after this time.

### **3.3.3 Survey Response**

Our total sample is 487 disabled LAC with the numbers of fully LAC (n=323) almost twice those who were LAC solely due to short break usage (n=164). The overall

sample includes children and young people with physical, sensory, mental and intellectual disabilities, and those on the autistic spectrum.

The highest number of returns were received from the SEHSCT (n=117); followed by the WHSCT (n=107) and BHSCT (n=105), with lower responses from both the SHSCT and NHSCT (both n=79).

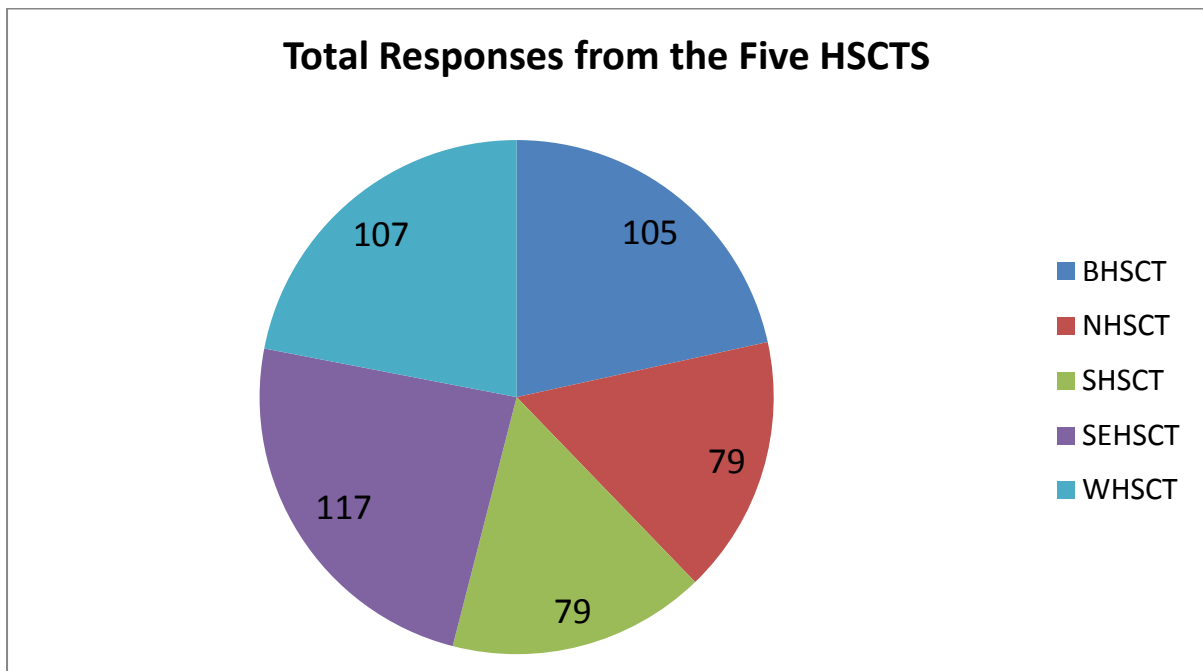


Figure 1. Total number of responses to the questionnaire from the five HSCTs.

Our total sample represents 17% (n=487) of the overall LAC population at 30 September 2013 (n=2892) as reported in the DSF report (HSCB, 2013). However, the study sample differs from the DSF total as it includes those using short breaks (n=164). When those using short breaks are discounted, the total number of disabled fully LAC in the study sample is 323 or 11.2% of the total population. This corresponds to the number of disabled LAC recorded in the DSF report (n= 333 or 12% of the overall LAC population). These figures can be compared with those for the general child population in NI (0-18 year olds) where 7% of children are disabled<sup>2</sup> (although census data was collected at an earlier time period) (NISRA, 2011), indicating that disabled children are over-represented in the fully LAC population in NI.

<sup>2</sup> Taken from taken from the most recent NI census data statistics on children with: 'learning, intellectual, behavioural or social' conditions; 'emotional, psychological or mental health' conditions; 'deafness or partial hearing loss'; 'blindness or partial sight loss'; and 'mobility or dexterity difficulty'.



Figure 2 shows the comparative figures for both datasets, however, this is presented with the caveat that some LAC in our sample are present in more than one category (given the high level of co-existing impairment shown in figure 4), whilst those in the DSF show the main impairment type of each young person.

It is important also to note variations in definitions of disability employed for our sample and the DSF return. In our study sample, the definition of disability does not include ADHD as this is recorded as an 'additional need' (n=67) but does include children with mental health needs (either due to a diagnosis of mental illness or use of mental health services) (n=164; 81 of whom were awaiting/receiving mental health services). By comparison, the DSF return combines ADHD with ASD in the definition of disability (although it is not clear how this is interpreted by those who complete the return as the numbers remain low) and only reports on the number of children who are awaiting assessment or receiving treatment from mental health services which remains low (just over n=32).

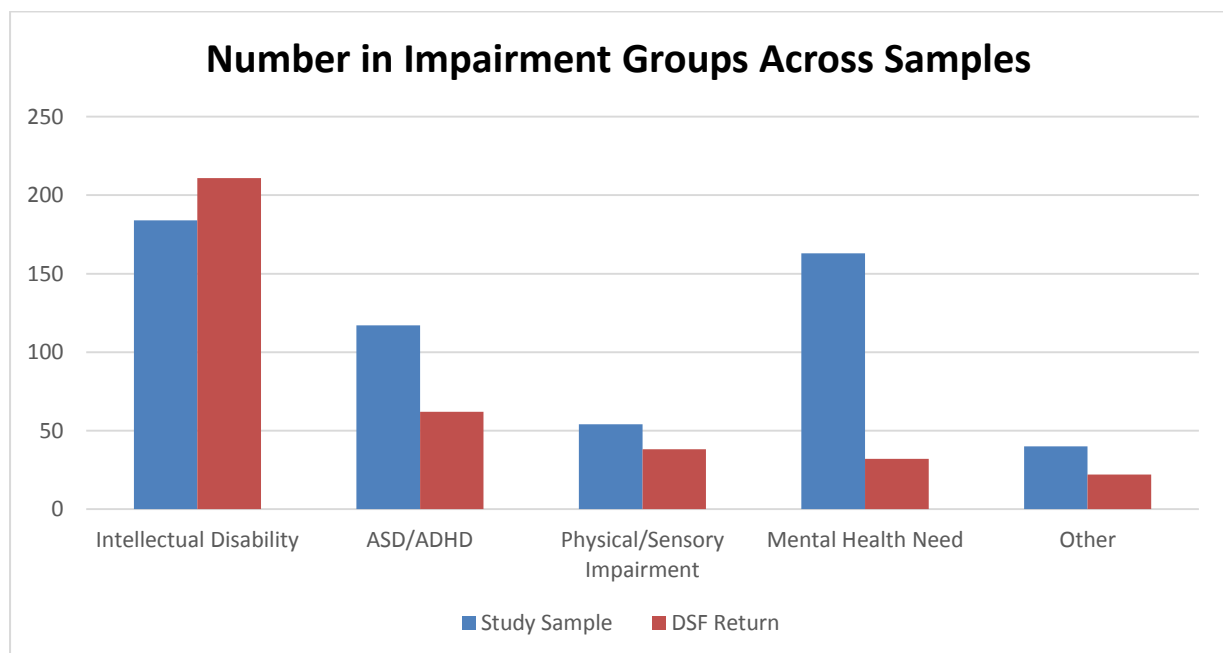


Figure 2. Numbers of disabled fully LAC in each impairment type in study sample and DSF return

There was also variation (see figure 3) in the numbers of disabled fully LAC in the study sample across the five Trusts. The highest numbers were in the SEHSCT (n=92) and BHSCCT (n=90), followed by the NHSCT (n=59), the SHSCT (n=45) and the WHSCT (n=37).

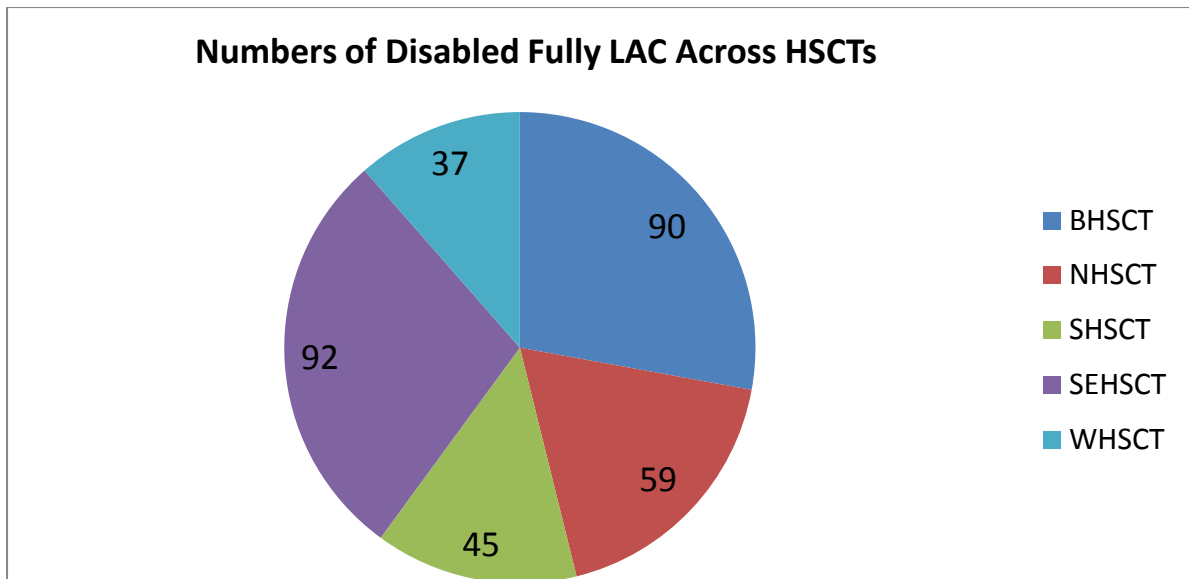


Figure 3. Number of disabled fully LAC across the five HSCTs.

Figure 4 shows the comparison of the study sample with the numbers of disabled fully LAC reported in the DSF return. The study captured almost two thirds of the number of disabled fully LAC in the BHSCT (63.8%) but only half of those in the NHSCT (50.4%), suggesting a lower survey response rate in the latter Trust. In contrast, the numbers of disabled fully LAC in the other three Trusts more than doubled in our study sample (from 37 to 92 in SEHSCT; from 21 to 45 in SHSCT; and from 17 to 37 in WHSCT). These significant increases in numbers suggest that the DSF return did not capture all of the disabled LAC in these Trusts.

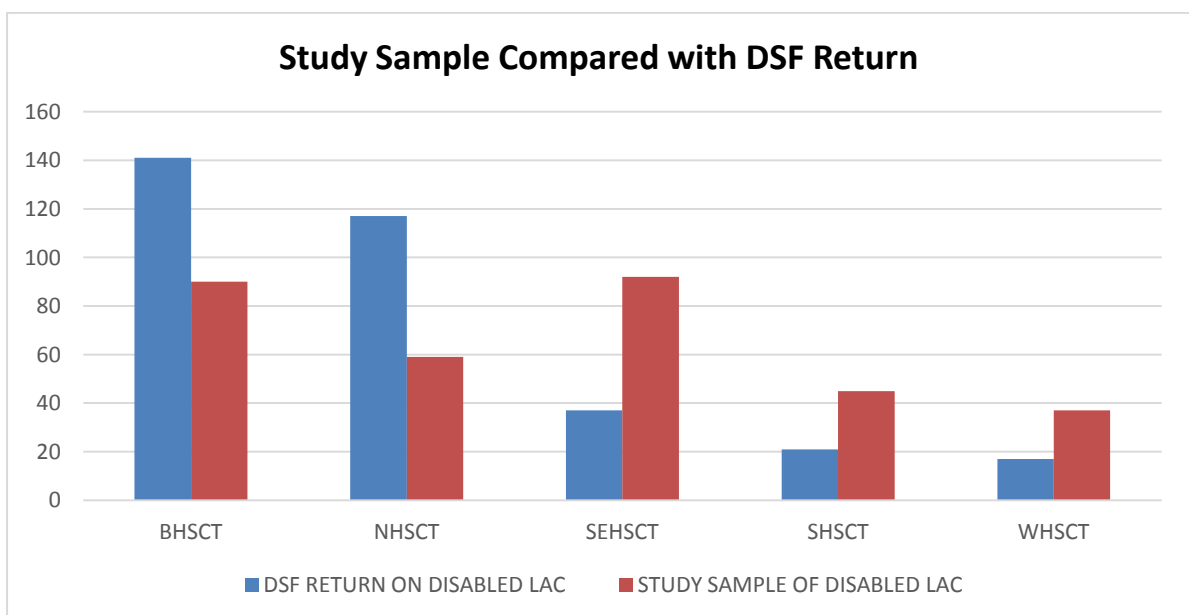


Figure 4. Numbers of disabled fully LAC across Trusts in study sample and DSF return.

Despite this variation, some of the prevalence trends remain the same with the BHSCT having highest numbers of disabled fully LAC (although the NHSCT has the largest child population regionally) and the SHSCT and WHSCT having the lowest numbers. Such prevalence trends may reflect differing service structures across Trusts and the increased availability of preventive services such as residential short break services in some Trusts (highlighted earlier in this report).

### **3.4 Limitations**

Although every effort was made to ensure completion of surveys, it is possible that some social workers did not complete surveys for children who met the study criteria. It is not possible, therefore, to claim that the sample represents a full census of all disabled LAC in NI. However, a substantial response to the questionnaire was achieved indicating a strong response rate matching the prevalence of disability recorded in the DSF return for the same period (12%).

### **3.5 Data Analysis**

Before data analysis commenced, the researcher undertook necessary data cleansing. This process involved sorting labelling systems and collapsing variables, where appropriate, to facilitate data analysis. Data analysis began by running frequencies and cross-tabulations to identify findings across the full range of questions and possible responses. For the purposes of analysis, the database was then split in two for those who were disabled fully LAC and those who were short break LAC as the experience of these two groups was distinct. Relationships between different sub-groups of disabled LAC were identified by conducting cross-tabulation of combinations of variables; for example, impairment and placement type.

## 4.0 Findings: Profile of Disabled Fully Looked After Children

This section of the reports focuses on the profile of the disabled fully LAC population including their demographic characteristics, education, placement experiences, safeguarding issues, additional and unmet needs.

### 4.1 Demographic Characteristics

The survey provided a range of data on the characteristics of the group of disabled fully LAC (n=323) including impairment type, age, gender, religion and ethnicity and the relationships between some of these demographics.

#### 4.1.1 Impairment Type

The two main sole impairment types were intellectual disability (n=87 / 27%) and mental health (n=86 / 27%), followed by those with multiple impairments<sup>3</sup> (n=56 / 17%) (see figure 5). Children in the other impairment category had a physical/sensory impairment, a chronic health condition or a rare syndrome. A total of 39% of the sample were reported to have a co-existing impairment. The combinations of these co-existing impairments are shown in the figure below.

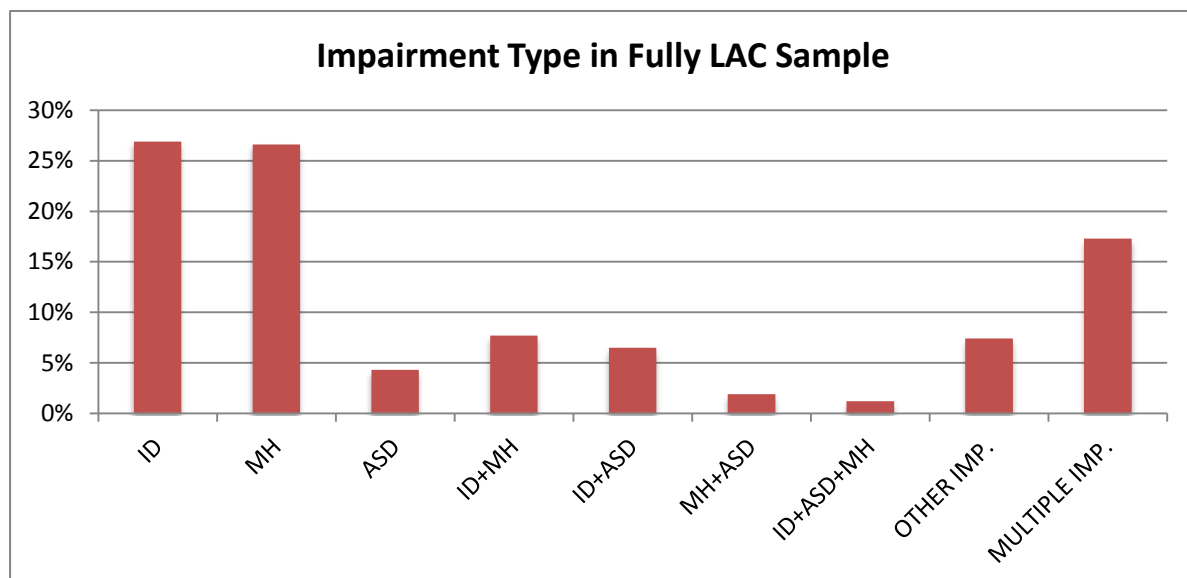


Figure 5. Prevalence of impairment type in the fully LAC sample.

<sup>3</sup> 'Other disability' includes those with physical / sensory impairment or other impairment type. These were collapsed into one category as numbers were small. 'Multiple disability' includes those with a combination of 'other disability' with ASD, mental health and/or intellectual disability.

There was some variation between Trusts (see figure 6) across impairment types. There were no cases of sole ASD in the SHSCT or WHSCT, levels of sole intellectual disability were highest in the NHSCT and levels of mental health were higher in SHSCT and WHSCT. Multiple impairment types were reported more often for BHSCT and WHSCT. Such variation suggests a need to review processes for identifying various impairment types across Trusts to ensure an accurate representation of trends in impairment related needs regionally.

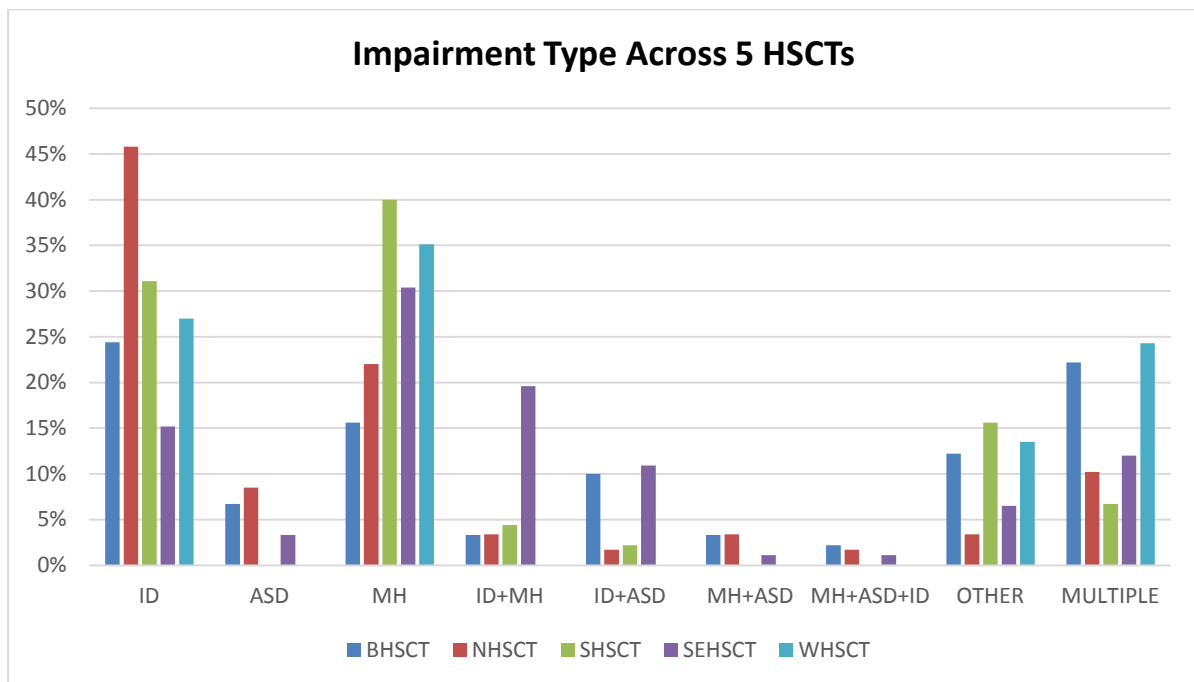


Figure 6. Impairment type of disabled fully LAC across Trusts.

Those with an intellectual disability, with co-existing intellectual disability and ASD and with multiple impairments were more likely to have their impairment identified before they came into care (see Figure 7).<sup>4</sup> Those with with physical disability (included in 'other impairment' group) were also more likely to have impairment identified before their entry to care (72% of those with a physical impairment). In contrast, those in the remaining impairment categories were more likely to have their impairment identified after their entry into care. In particular, LAC with ASD and those with mental health needs were much more likely to have their impairments identified after becoming LAC. Almost three quarters (71%) of those with as assessed mental illness had this identified following their entry to care.

<sup>4</sup> Data was missing for 10.5% of the study sample for this question, and 6.5% of those missing were in the intellectual disability category.

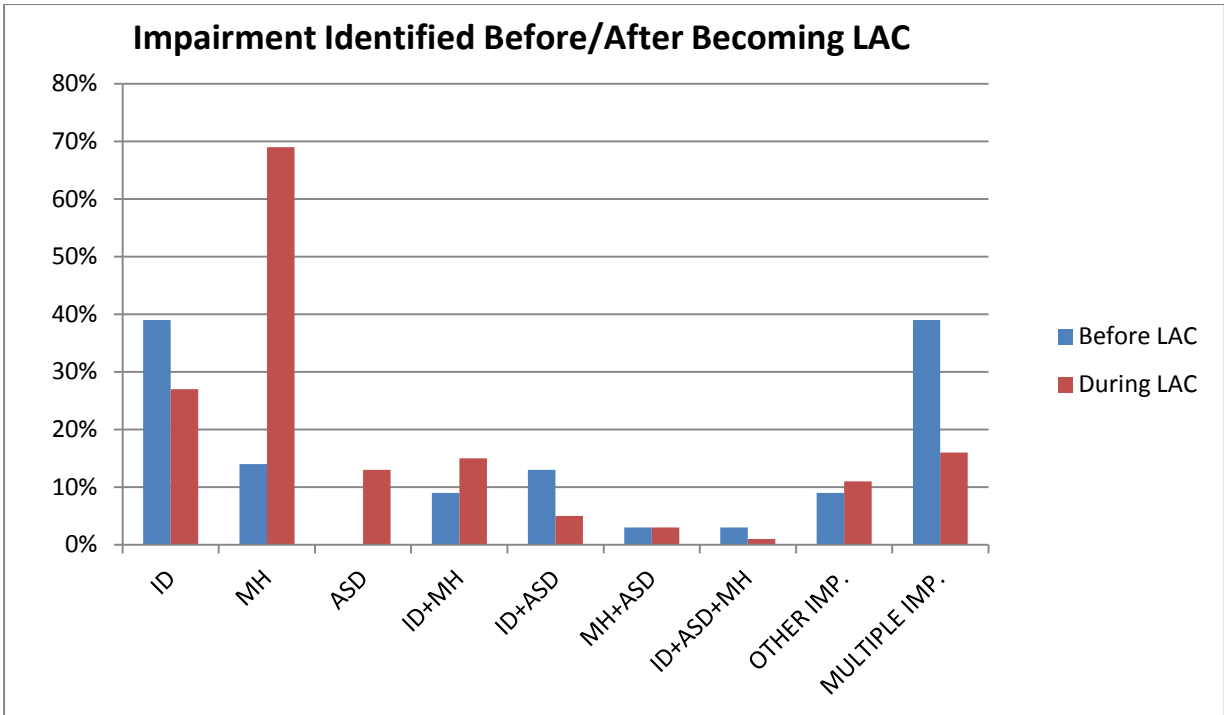


Figure 7. Impairment identified before or after child/young person became LAC.

#### 4.1.2 Gender

In relation to gender, 42% of the study sample were female and 58% were male. By comparison, the gender division in the overall LAC population follows the same trend but with a lower rate of divergence (48% female and 52% male) (DHSSPSNI, 2015). There were some observable differences when comparing gender with impairment type (see figure 8). Reflecting the higher number of males in the study sample, there were more males in all impairment groups. However, the higher number of males is notable in the intellectual disability (61% of young people in this category were male); and all of those with co-existing ASD and intellectual disability were male. Mental health (as a sole impairment) was the exception, in this group females (15%) outnumbered males (11%). Interestingly, this gender gap lessens when the analysis includes those with mental health who also have other co-existing impairments. Almost equal numbers of males and females had an assessed mental illness (17 males and 18 females). However, females were more likely to be engaged with mental health services. Overall, 56% of those engaged in specialist therapeutic LAC services and 56% of those in Tier 3/4 CAMHS were female (compared to 44% males in both categories). This finding may be explained by the higher number of females

in the sole mental health category but may also indicate a greater willingness of females to engage in therapeutic support, or a greater likelihood of referral to therapeutic services for females; points which can be explored in more detail during the qualitative phase of the study.

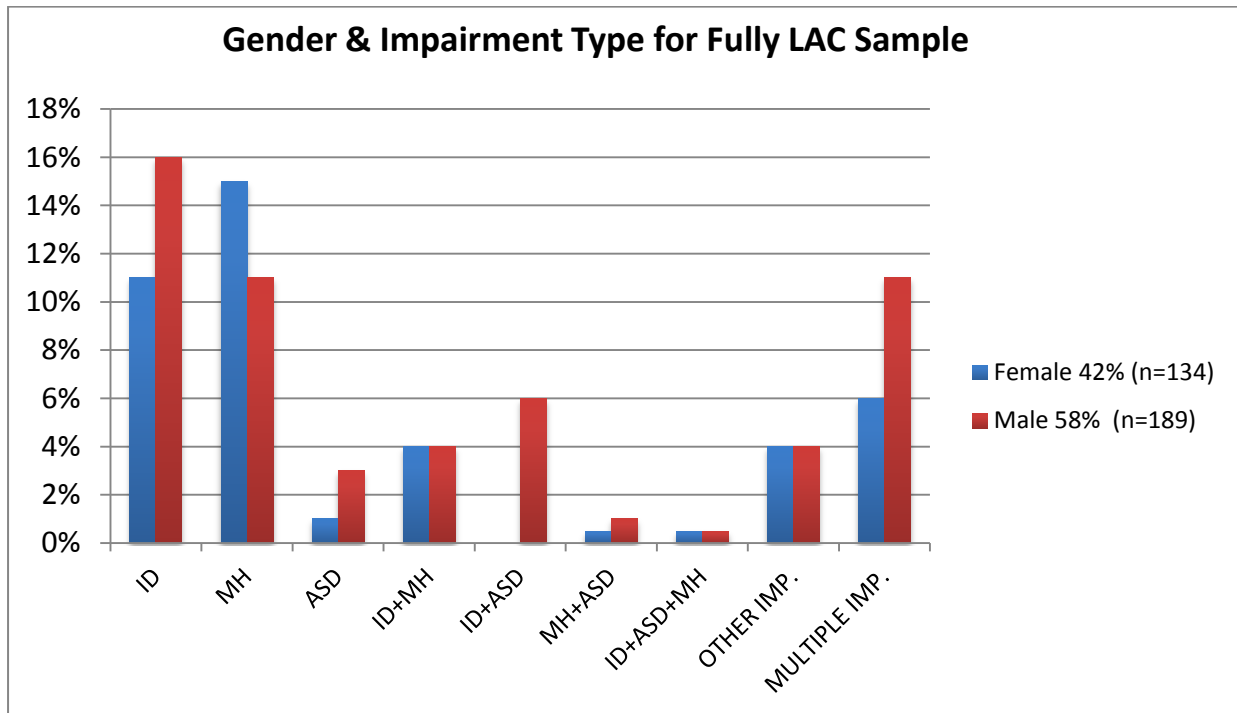


Figure 8. Gender and impairment type for disabled fully LAC.

### 4.1.3 Age

Within the study sample, the numbers of disabled fully LAC increase with age. This is in contrast to the total looked after population where there are substantially more children in the youngest age range and a decline in the numbers of young people aged 12 years and over (HSCB, 2013).

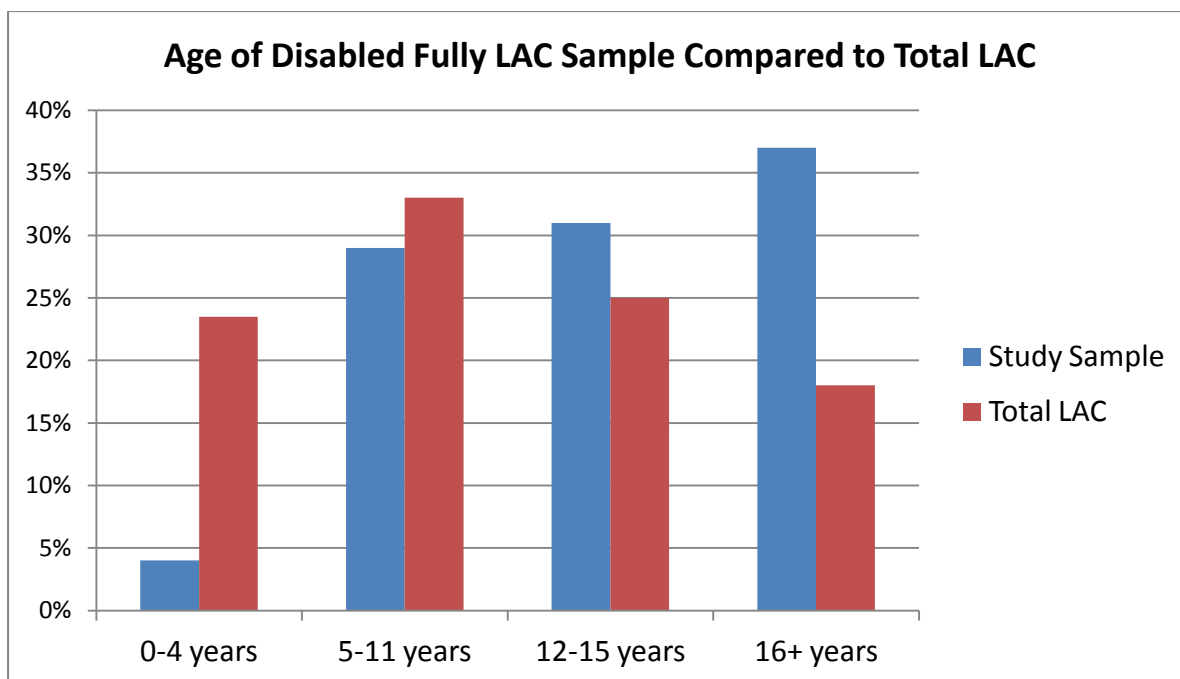


Figure 9. Age groups of disabled fully LAC compared with the wider LAC population.

When comparing impairment type with age group (see figure 10), those in the youngest age range tend to present with multiple impairments or more complex health needs (in the 'other impairment' category). The same prevalence pattern remains for the 4-11 age range but also includes those with ASD. It is also notable that there is a reduction in the numbers of looked after children with an intellectual disability/ASD in the 16+ age group, whilst there is a marked increase in those with mental health needs, suggesting that mental health is the main reason for the increase in numbers in the 16+ age group. This finding may indicate that fewer young people with mental health needs are exiting the care system in late adolescence or that mental health needs are more likely to be identified in teenagers in care. It may also be the case that more young people with mental health needs are entering the looked after system in their later teenage years (however, there were similar patterns in length of time in care for those with intellectual disability compared with those with mental health needs). Whatever the reason, this finding has implications for care planning for different sub-groups of LAC and emphasises the importance of pathway planning and leaving care support for LAC with mental health needs.



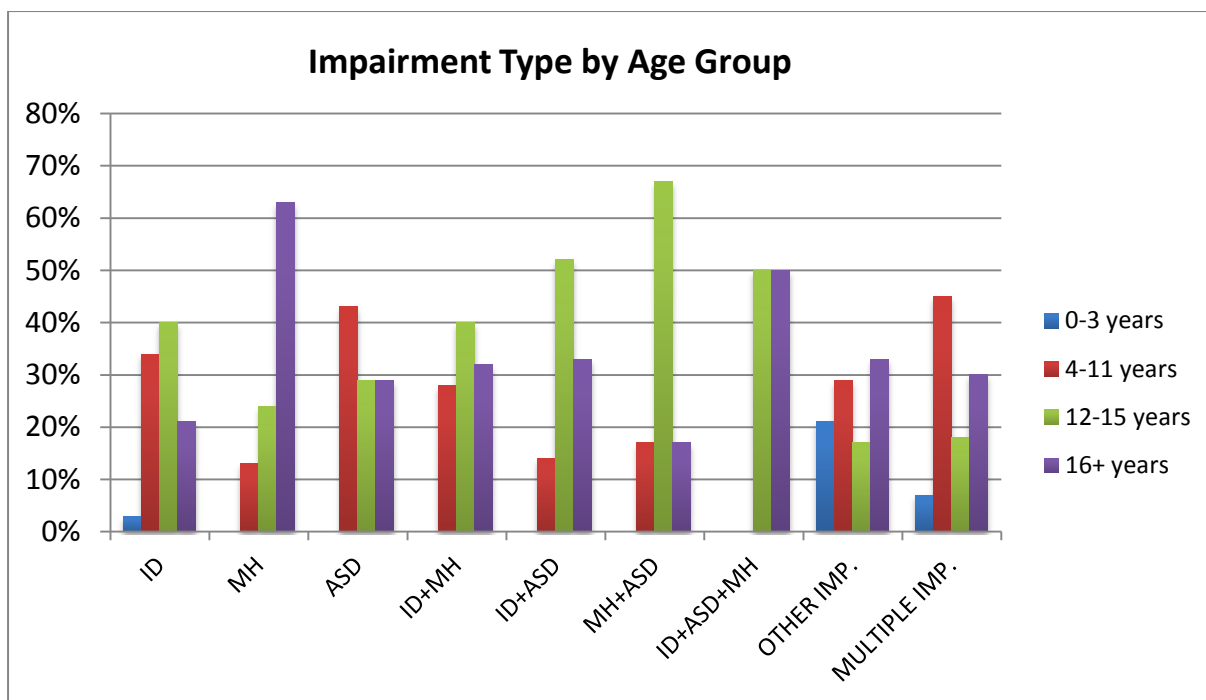


Figure 10. Impairment type by age group.

#### 4.1.4 Religion and Ethnicity

In the disabled fully LAC study sample 47% were reported to be Protestant and 46% Roman Catholic. This contrasts with figures for the general LAC population which indicate a higher prevalence of Roman Catholics (51%) than Protestants (40%) and the general child population in NI (49% Roman Catholic and 33% Protestant (NISRA, 2011). This religious difference in the study sample is likely to relate to the older age range of LAC in the study sample as the census data showed that the Roman Catholic population in NI had a younger age distribution than Protestants. No religious affiliation was indicated for 4% of the study sample and 'other' religion for 3%. However, there were no children or young people in the study sample from the other main religious groups such as, Muslim, Jewish, Hindu or Sikh.

Figure 11 compares the study sample with the overall looked after population across the five HSCTs in relation to the two main religious groupings in NI. It is apparent that there are some differences in the representation of religions in the study sample compared with the overall looked after population in some Trust areas (HSCB, 2013). For example, trends are reversed in the BHSCT and WHSCT with the number

of Protestant children being almost doubled in the study sample than in the general LAC population for the BHSCT and more than doubled in the WHSCT. In the SHSCT there were only small differences however in the SEHSCT Roman Catholic children were over-represented in the study sample.

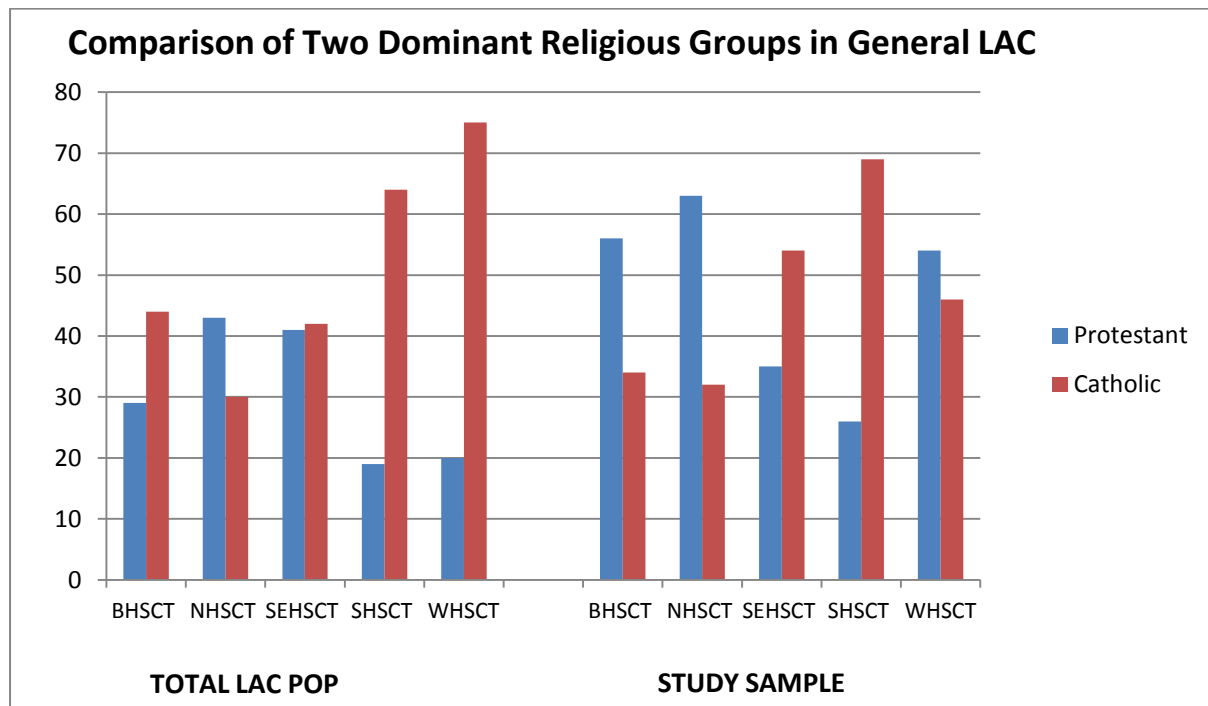


Figure 11. Religious groupings amongst disabled fully LAC and wider LAC population by HSCT.

In terms of ethnicity, 93% were categorised as ‘white’ with the majority of these being white Northern Irish (96%). Other ‘white’ children and young people were reported to be Great Britain (5) or North Eastern European (3). The ethnicity of the study sample does not differ significantly from that for the general population of looked after children and young people and is also close to the ethnic make up of NI as a whole (NISRA, 2011).

#### 4.1.5 Parenting Experience

Two of the young people in the disabled fully LAC sample were parents. Both of these young people had mental health needs and one had a co-existing intellectual disability. The parent with a co-existing impairment was not residing with their child and, in the other case, the child resided with their mother with a mental health need.

Two further young people were pregnant at the time of data collection, both of whom were reported to have mental health needs.

## **Summary**

The total number of disabled fully LAC in the study sample is 323 which represents 11% of the total LAC population (and corresponds with the number of disabled LAC recorded in the DSF report). Comparison of this figure with census data reports that 7% of the general child population in NI (0-18 year olds) are disabled (NISRA, 2011) shows that disabled children are over-represented in the LAC population in NI.

The two major impairment categories of disabled fully LAC were intellectual disability and mental health need, representing over half of the study sample (27% in each category). There was also a high incidence of co-existing impairments (39%).

Those with an intellectual disability, physical disability, co-existing intellectual disability and ASD or multiple impairments were more likely to have their impairment identified before they came into care. In contrast, those solely with ASD or mental health needs were much more likely to have their impairment identified after becoming LAC.

Males were more prevalent across all impairment groups, particularly intellectual disability with the exception of the mental health category where there was a higher number of females. The numbers of disabled fully LAC in the study group grew as they aged in contrast to the general LAC population where there is a drop in numbers in the 16+ age group. The incidence of mental health need was highest in the 16+ age group for both genders. There are some differences in representation between the two main religious groups across Trusts comparing the study sample with the overall LAC population. However, the study population does not differ from the wider looked after population or regional ethnic mix, with the majority being reported as white Northern Irish.

## 4.2 Family Background

The majority of disabled fully LAC came from a single parent household (60%). Of the 222 responses to the question of whether birth mothers were care experienced, 25% were reported to have a history of being in care. There were 175 responses to the same question for fathers and 10% of these were reported to be care experienced. In relation to parental impairment, 43% of fathers were reported to have no impairment compared with 49% of mothers (see figure 12). Of those with impairment, the most commonly reported was an intellectual disability (16% mothers and 8% fathers). The 'other' impairment category was selected for 21% mothers and 30% fathers, most commonly mental illness or alcohol dependency. In seven instances one or both parents were deceased. Information gathered directly in relation to parental mental health status revealed that 48% had known mental health needs. We do not know from our data whether the highest prevalence of mental health need was amongst fathers or mothers as the survey question on parental mental health need and did not differentiate mothers from fathers however, our sample is weighted towards information about mothers as they represented 60% of the parents as single parent households. There is also some evidence of co-existing impairments amongst parents, most commonly co-occurring mental illness and intellectual disability.

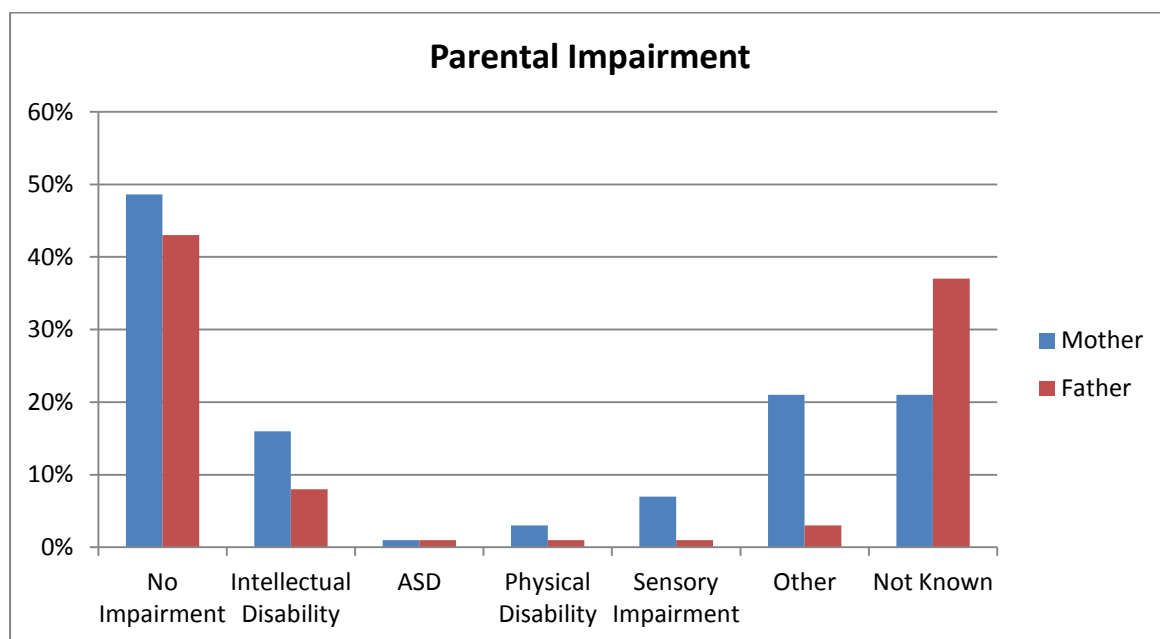


Figure 12. Presence of impairment type amongst birth parents.

## Sibling Looked After Status

Amongst siblings (9% had no siblings), 55% were also looked after and 36% were not. Of those siblings who were looked after, 39% resided in a different location to the disabled LAC with only 16% residing in the same location as their sibling(s) (see figure 13).

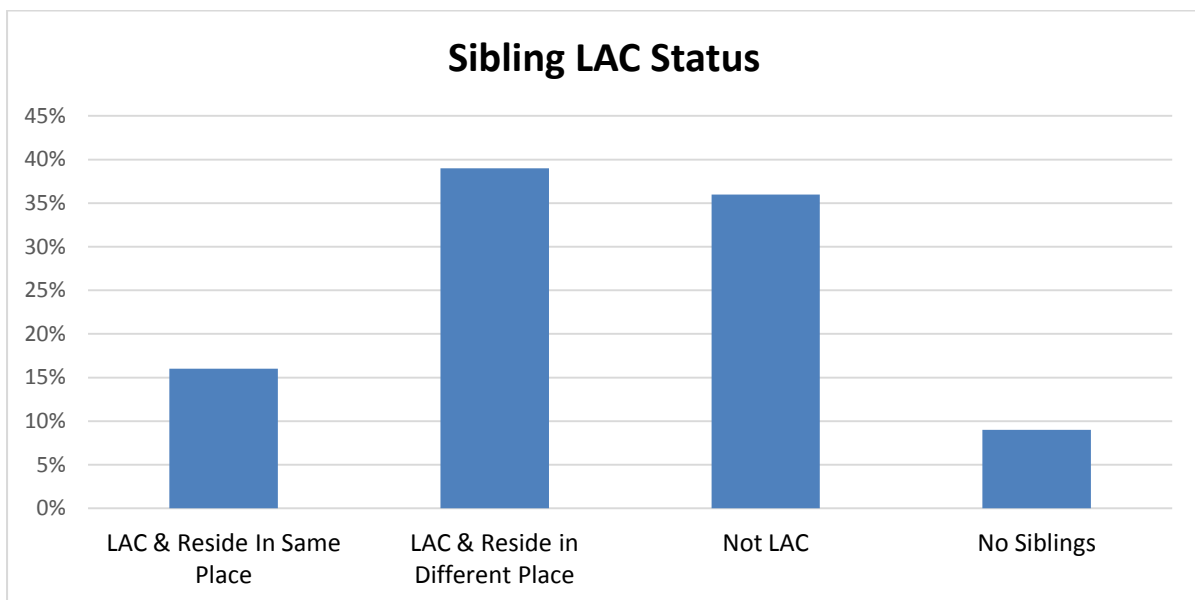


Figure 13. Sibling looked after status.

Overall, disabled fully LAC were more likely to reside away from their siblings than they were to reside in the same location, and this trend remained the same across impairment types. It is interesting to note that over one third of disabled fully LAC had siblings who were not looked after. This was particularly the case for those with co-existing mental health, intellectual disability or ASD (see figure 14).

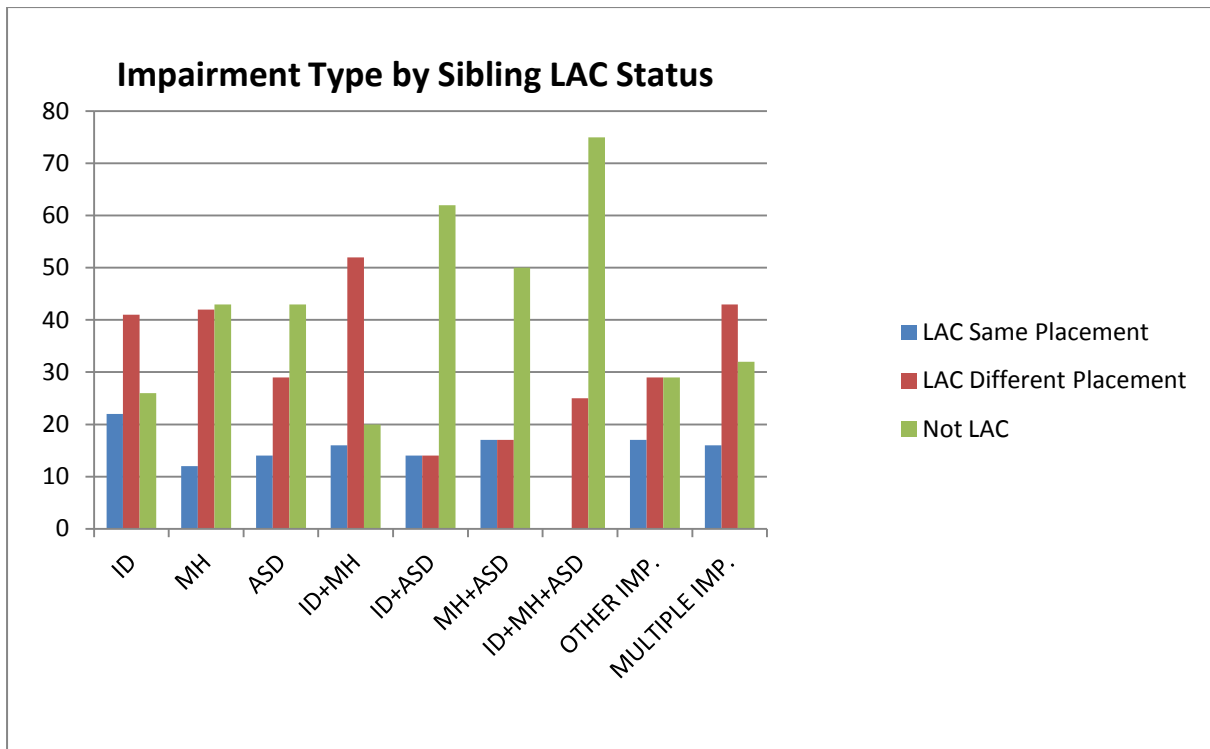


Figure 14. Child's impairment type by sibling LAC status.

### Birth Family Contact

Findings regarding contact with birth families show that 63% had regular (daily, weekly, fortnightly or monthly) contact with their mother and 35% with their father (see figure 15). A fifth of children had only irregular contact with their mother (20%) and father (21%), whilst 17% of children had no contact with their birth mother and this figure rose to 44% in relation to birth fathers. In addition, 62% had regular contact with their siblings (in 52 cases they lived in the same placement), and 27% had contact with grandparents. Overall, 10% (n=31) of children had no contact with siblings. Of these, 12 had looked after siblings in a different placement and 18 had siblings who were not looked after (the age/impairment status of these siblings is not known). More than half of the study sample (53%) had no contact with grandparents.

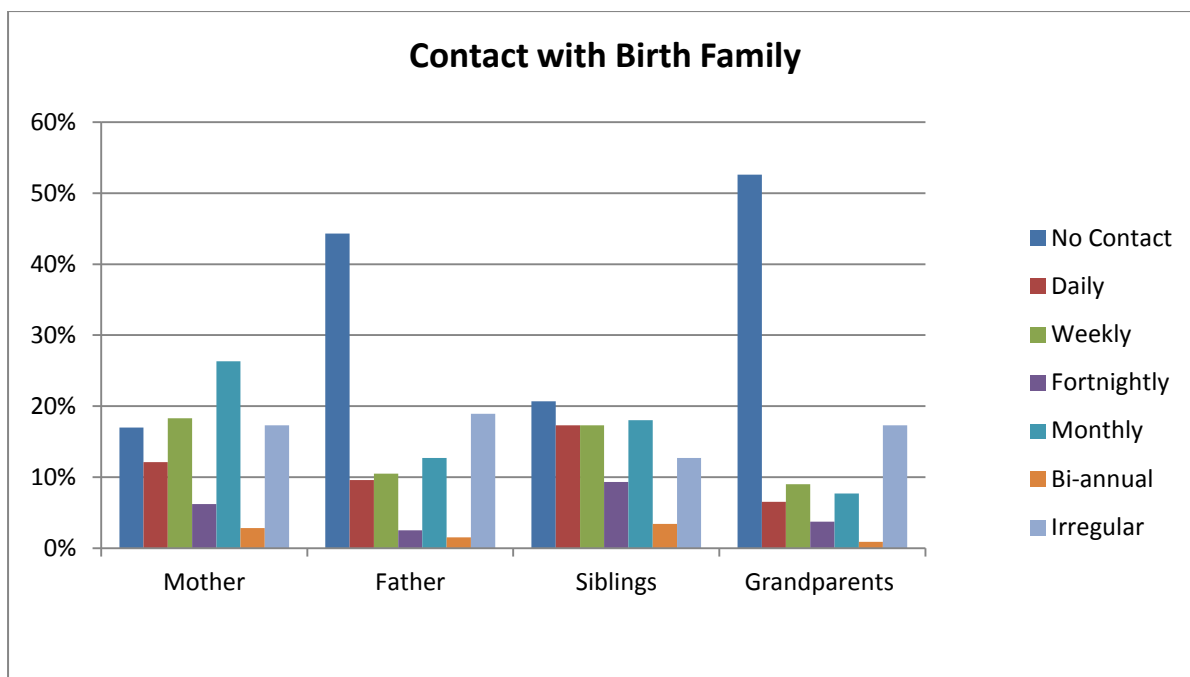


Figure 15. Fully disabled LAC contact with birth families.

## Summary

More than half of all the disabled fully LAC came from a single parent household. A quarter of mothers were found to have a history of being looked after, although this information was not always known. From the data available on parents, 16% of mothers and 8% of fathers were reported to have an intellectual disability. Almost half of the sample were reported to have one parent with a mental health need.

Just over a third of the sample children and young people had siblings who were not looked after, with the highest incidence found amongst LAC with co-existing intellectual disability, ASD or mental health need. Siblings who were looked after were more than twice as likely to live in a different place than their disabled brother or sister.

Just over three quarters of disabled fully LAC had regular contact with their birth mother and just over one third with their birth father. However, 17% only had irregular contact with their birth mother and a further 17% had no contact. Whilst 19% had irregular contact with their birth father, 44% had no paternal contact. Almost two thirds (62%) had regular sibling contact whilst 10% had no contact with

siblings. Over a quarter remained in contact with grandparents whilst just over half had no grandparent contact.

### 4.3 Looked After Experience

This section will profile the disabled fully LAC's experience of care including: the reasons for being in care; legal status; length of time in care; and placement type and change. Where possible, comparisons will be drawn with the general LAC population based on the DSF report (HSCB, 2013).

#### 4.3.1 Reason for Entry to Care

Social workers reported on all of the reasons that each child or young person had become looked after (see figure 16). Neglect was the most commonly selected reason (70%) followed by emotional abuse and parents not coping (both representing 53% of reasons given). One third had witnessed domestic violence and just over a quarter had been subject to physical abuse (27%), with 19% reported to be beyond parental control. A smaller proportion (9%) had experienced sexual abuse.

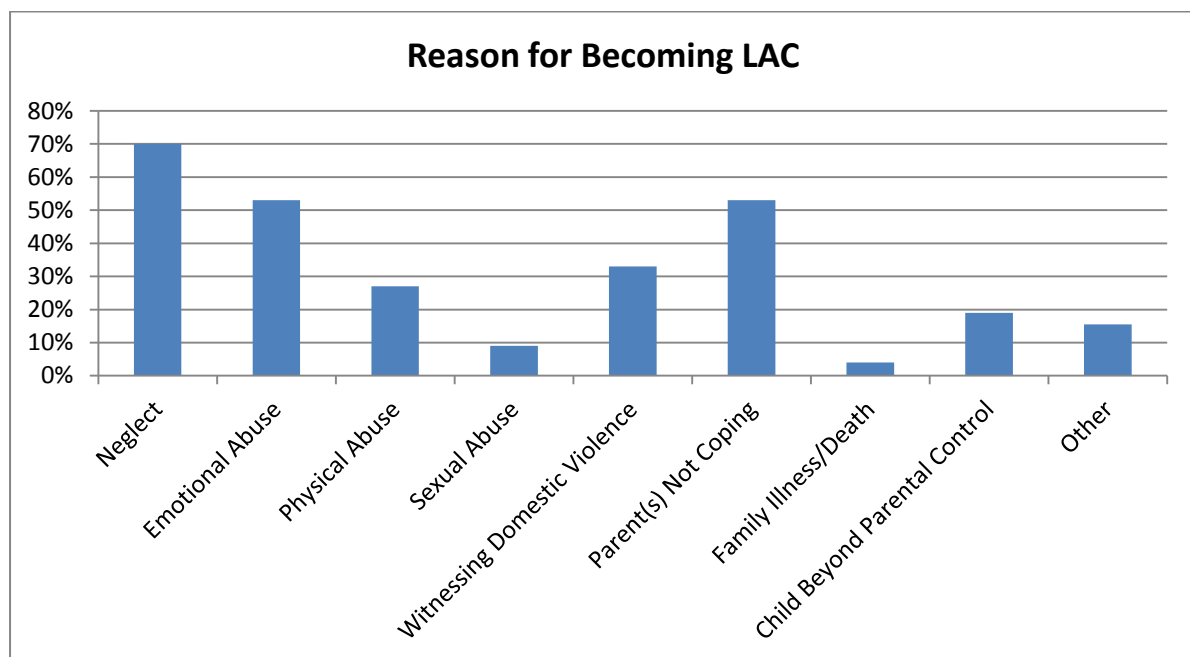


Figure 16. Reasons for coming into care for disabled fully LAC.



There are interesting trends emerging (see figure 17) when comparing the reasons for becoming looked after with age group. After the 0-4 age group where overall numbers were relatively low; reasons of neglect, being beyond parental control and emotional abuse declined slightly as the child aged, whilst there was a marked increase in sexual abuse amongst older young people, and this was twice as likely amongst teenage females compared to teenage males (although numbers are small with the total number of LAC recorded in sexual abuse category at n=30 / 9%).

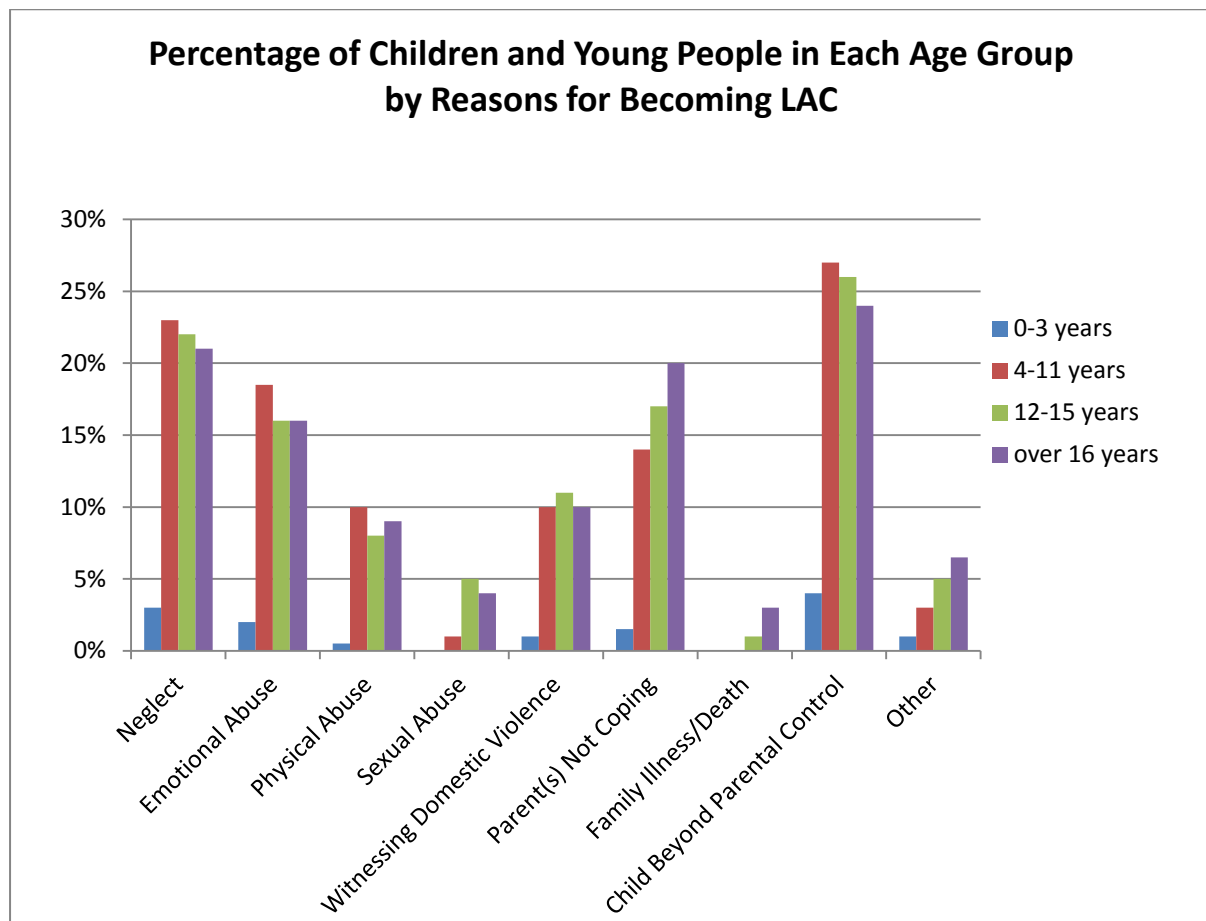


Figure 17. Reasons for becoming LAC and age group.

There were some differences in the reasons for becoming looked after in relation to impairment type (see Table 1). Neglect featured most highly across most impairment groups, with the exception of those with co-existing ASD, mental health and/or intellectual disability for whom 'parents not coping' was reported most often. Whilst the overall numbers of children and young people who had experienced sexual abuse were smaller than most other categories, those with mental health needs were more likely to have this reason reported, followed closely by those with 'other'

impairments (including physical/sensory impairments) or intellectual disability. Physical abuse and being beyond parental control was reported more often for those with mental health and/or intellectual disability.

Reason LAC Impairment	Neglect	Emotional Abuse	Physical Abuse	Sexual Abuse	Witness Domestic Violence	Parents Not Coping	Family Illness/ Death	Beyond Parental Control	Other
ID	73	52	19	7	32	50	1	6	7
MH	58	50	25	11	32	43	8	30	15
ASD	8	4	2		3	3		2	1
ID+MH	22	20	18	2	13	24	1	10	6
ID+ASD	5	2	1	1	1	7		2	7
MH+ASD	6	4	1		1	8	1	2	
ID+ASD+MH	4	3	2		2	4		3	5
OTHER	25	21	12	8	14	16	1	5	3
MULTIPLE	25	16	10	1	10	16	1	2	6
TOTAL	226	172	89	30	108	171	13	62	50

Table 1: Numbers in each reason for becoming LAC by impairment type.

#### 4.3.2 Legal Status

The majority of children and young people in study sample (see figure 18) were under a Care Order (66%), greater than in the general LAC population with 54% under a Care Order. The second most common legal status was being voluntarily accommodated (23% compared to 28% in the general LAC population). Males were more likely than females to be voluntarily accommodated, and these were more likely to be in the older age group and to have an intellectual disability or mental health need. Interestingly, those with ASD were almost as likely to be voluntarily accommodated as being subject to a Care Order; neither age nor gender were found to have a significant affect on LAC status amongst those with ASD. It is not clear why there are a greater number of young people looked after under an Interim Care Order (ICO) in the wider LAC population in comparison with the study sample, however, this is likely to relate to the longer period of data collection for the present study. This will be explored during case study phase of the study. A small number of disabled fully LAC (n=21 / 6%) were reported to have an 'other' legal status. These LAC were under the Mental Health NI Order (1986) (n=6), freed for adoption (n=5) or had just turned 18 and were no longer looked after (n=10).

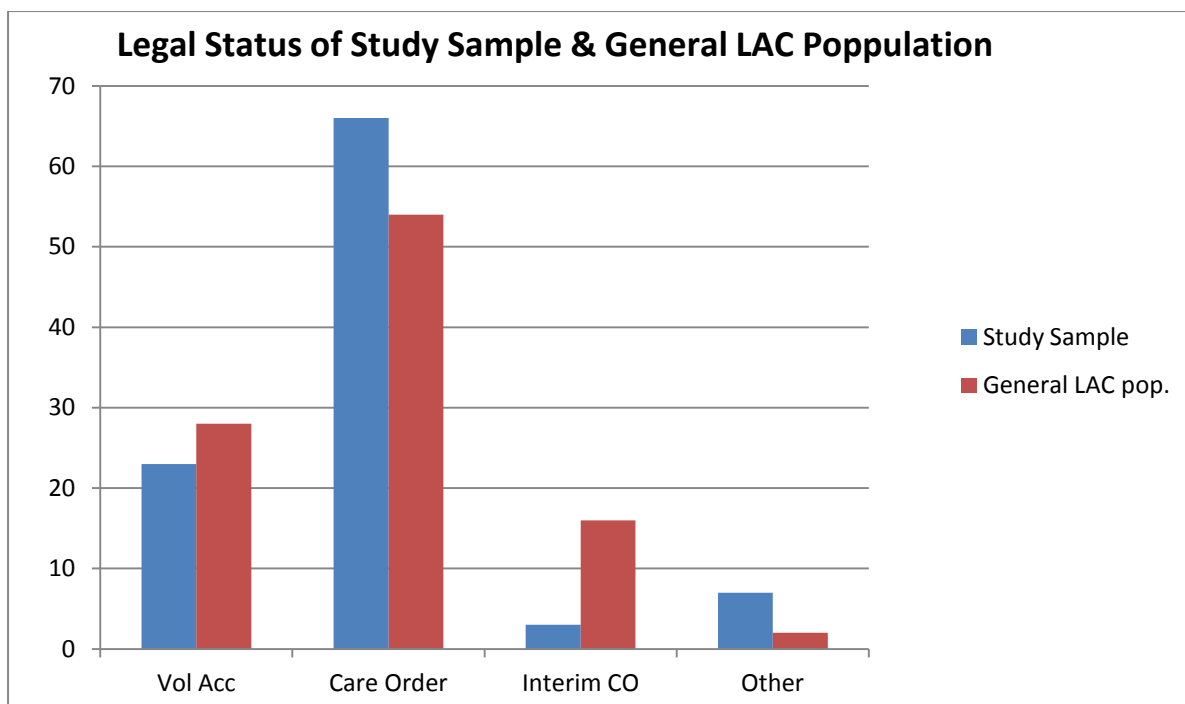


Figure 18. Legal status amongst disabled fully LAC sample and general LAC population.

There were some differences in LAC status relating to age and gender. Whilst overall there are more males in the sample (n=189) compared to females (n=134), there were more than twice as many males as females who were voluntarily accommodated. None of the voluntarily accommodated females were in the younger age ranges (0-3 / 4-11), with nine in the 12-15 age range and 15 in the 16+ group. For voluntarily accommodated males, two were in the 0-3 age range and six in the 4-11 age range. These numbers rose to 15 aged 12-15 and 26 in the 16+ age range.

For those who were looked after in a Care Order there was a different trajectory for males and females. In the 4-11 age group there were 45 males on a Care Order, with fewer in the 12-15 age group (n= 34) and 33 in the 16+ age group, thus a decreasing trajectory with age increase. With females the numbers of those on a Care Order was highest in the 12-15 age group (n= 35) with fewer in the 4-11 age group (n=28) and the 16+ age group (n=29).

When comparing impairment type with LAC status, (see figure 19) it is apparent that children with combinations of ASD, intellectual disability and/or mental health need were more likely to be voluntarily accommodated than those in sole impairment or other /multiple impairment groups where the trend was towards children being on a Care Order.

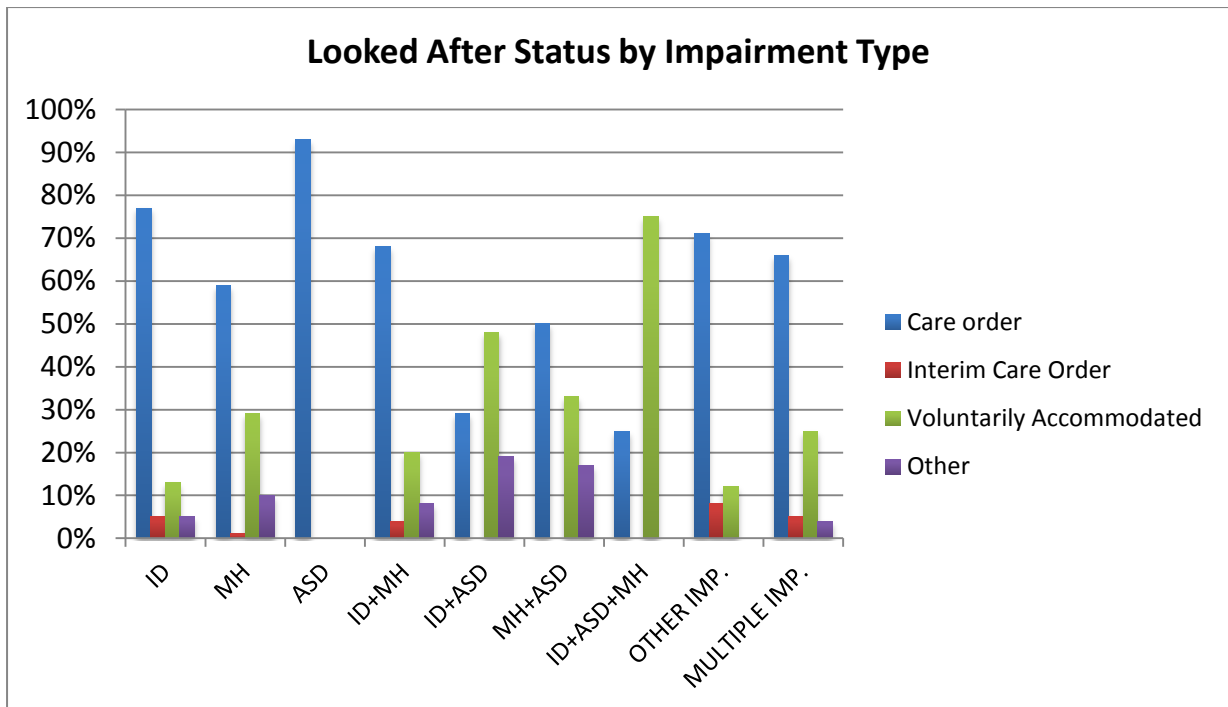


Figure 19. LAC status of disabled fully LAC by impairment type.

### 4.3.3 Length of Time in Care

In the study sample there is an upward trajectory in terms of the length of time in care, with the majority being in care for more than five years (39%), followed by 3-5 years (25%) and 1-2 years (23%). The general LAC sample differed in that there was a higher number of children looked after for less than 12 months (27% compared with 12% of the study sample) and lower numbers of children spending between 3-5 years and more than five years in care (see figure 20).

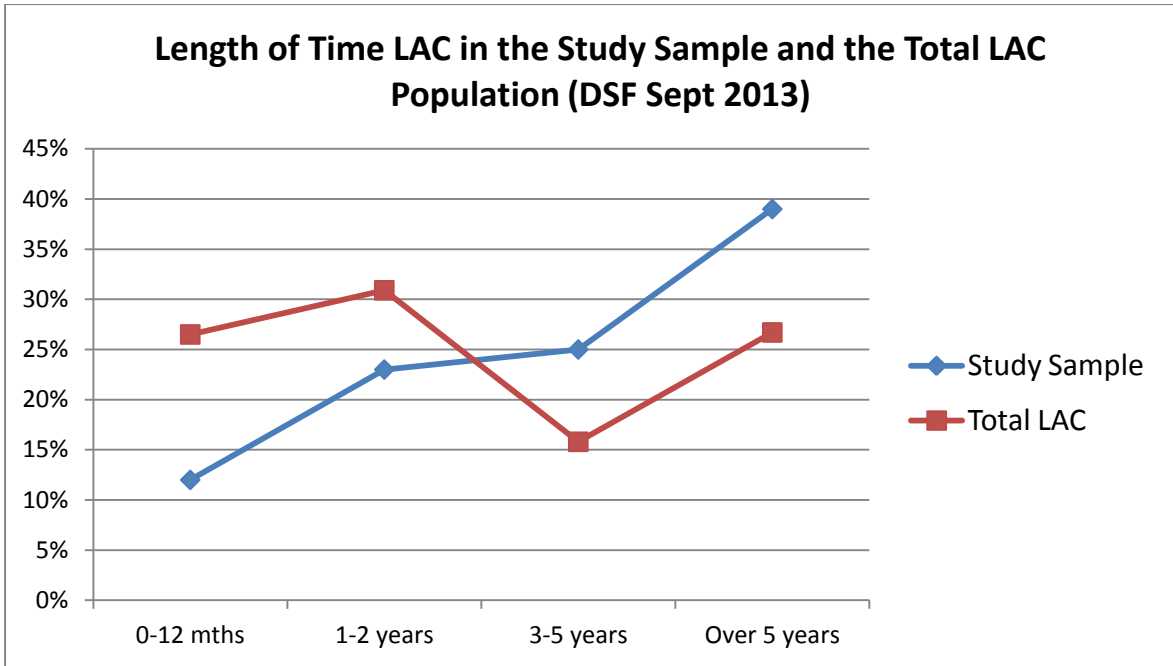


Figure 20. Length of time LAC.

The increase in the length of time being looked after is evident across almost all impairment types, with a particular rise in those with ASD and multiple impairments (which includes those with physical and sensory impairments) (see figure 21).

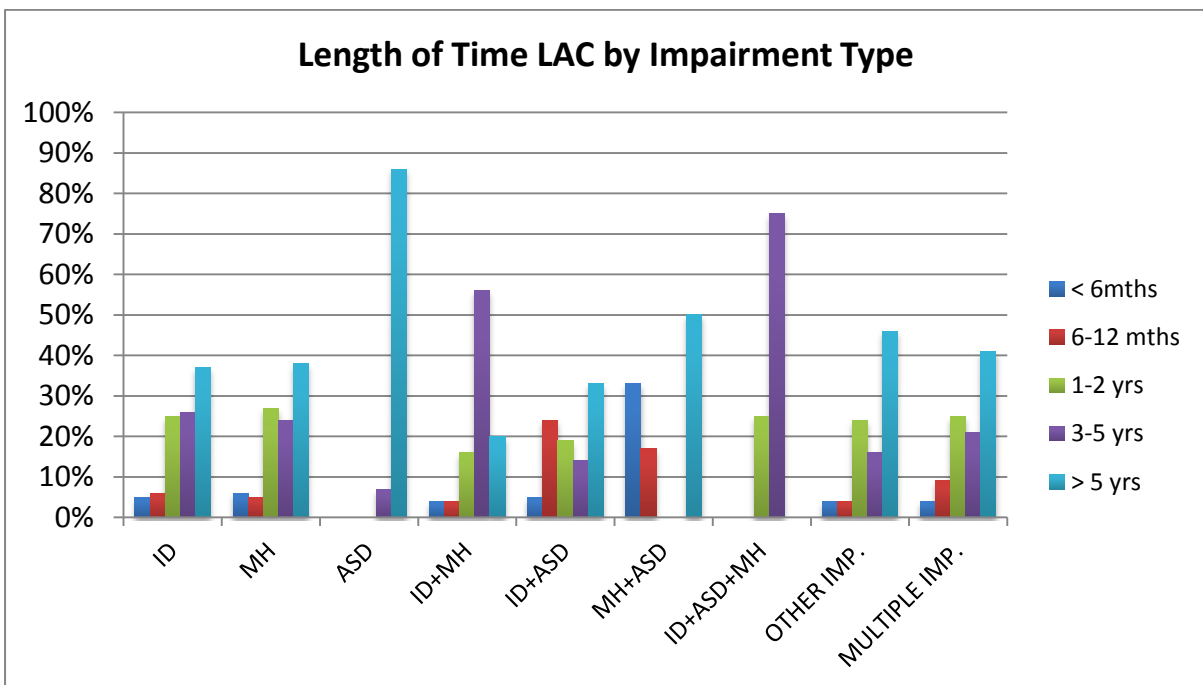


Figure 21. Length of time LAC by impairment type.

#### **4.3.4 Placement Type**

The most common placement type for disabled fully LAC was in non-relative foster care (40%), which is very similar to that of the general looked after population (39%) (see figure 22). There is a contrast, however, in relation to kinship foster care. In the study sample this accounted for only 17% compared to 32% of the general looked after population. Similar trends are observed for placement at home with birth parents (5% of study sample but 12% for general LAC population). Therefore, whilst 62% lived in a home-based foster setting, much fewer were accommodated within their own family in kinship care or at home with their birth parent.

Children in the study sample were also more than twice as likely than those in the general LAC population to be placed in a communal residential setting, either a children's residential home or a specialist residential placement, (17%), compared with just 7% of the wider LAC population. The 'other' category in figure 22 included supported placements in the community, pre-adoptive placements, the Camphill Community, intensive support units, residential placements out of jurisdiction and unregulated placements such as bed and breakfast accommodation. The higher number in the 'other' category may reflect the higher numbers of older disabled young people in the study sample who were at the stage of leaving care.

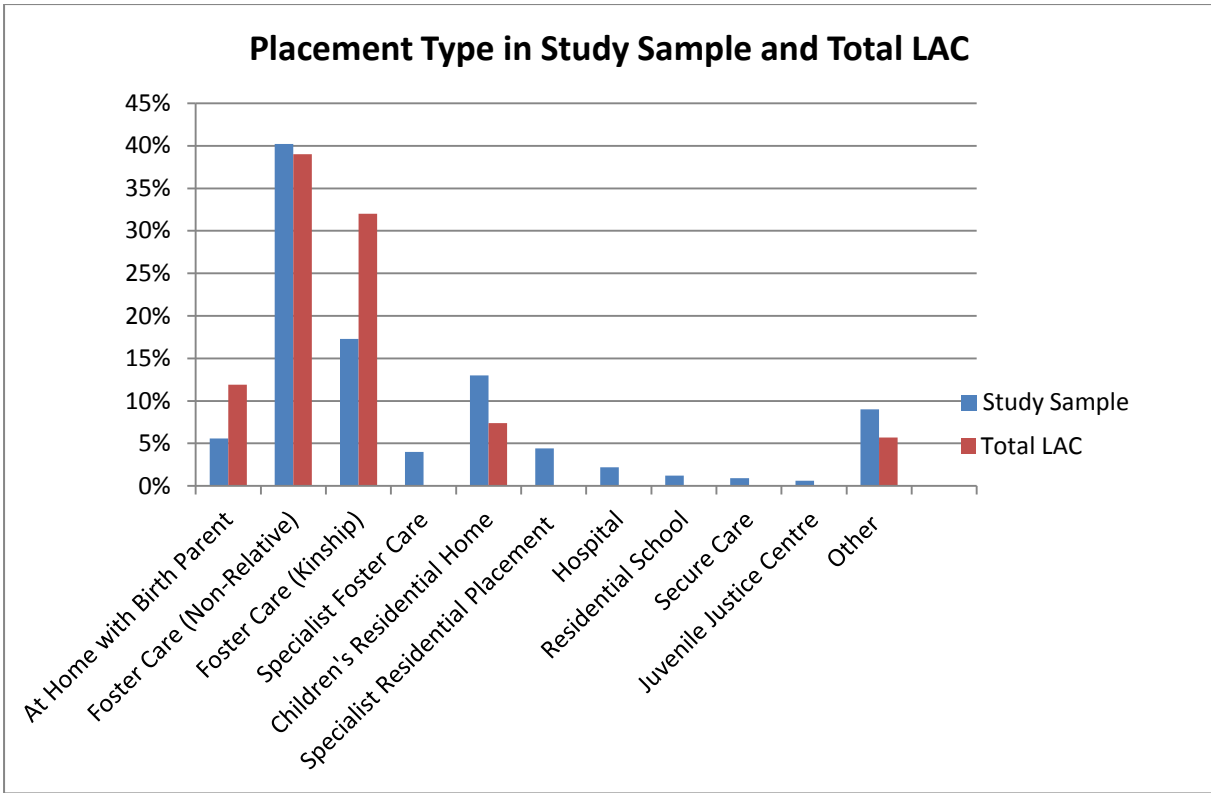


Figure 22. Placement type for disabled fully LAC sample and total LAC population.

Although not a high proportion, still a concerning number (n=14), mostly older males, were reported to be in an out of area specialist residential placement or residential school. Of the 14 children living in placements out of jurisdiction, 10 had an intellectual disability. The young people placed in residential schools were reported to present with complex needs and challenging behaviours, with their parents requiring additional support to meet their needs. Those placed in other specialist residential settings were living in intensive support units, secure accommodation and specialist residential centres for young people with intellectual disabilities and/or mental health/ASD, often combined with challenging behaviours.

Three of these 14 young people (from two HSCTs) were placed out of jurisdiction in Scotland or England because no suitable residential option was available within NI. These young people had intellectual disability/mental health needs or multiple impairments and also presented with challenging behaviours and/or additional health needs. Only one of these young people was in care because they were beyond parental control; the other two were categorised under reasons related to abuse or neglect. Out of jurisdiction placements present additional difficulties of distance from family and community and can also impact on the transition from care.

When considering the relationship between age group and placement type, it is apparent that older children (12-15 and 16+ ages) were more likely to reside in congregate residential settings than younger children. These figures correspond with statistics for the wider LAC population which also show that older LAC are more likely to be in residential care (DHSSPSNI, 2015).

Table 2 shows the number of disabled fully LAC in each placement type according to impairment type (data was missing for four cases; some placements (hospital, school, secure care, juvenile justice centre) are not shown in table as numbers are too small (less than eight). Children with an intellectual disability were less likely to reside in a children’s residential home than other settings with foster care being the most likely alternative. However, children with intellectual disabilities were more than three times as likely to reside in non-relative foster care than in relative foster care and the likelihood of relative foster care decreased as the child aged.

Children with ASD were more likely to live in congregate settings and less likely to live in foster settings, in particular, kinship foster settings. For those with mental health needs, foster care was the most common residential option, and this was much more likely to be non-relative foster care than kinship foster care. A significant number of children with mental health needs resided in a children’s residential home and these were all in the teenage age ranges. As noted above, those in specialist residential placements were more commonly those children and young people with an intellectual disability, a mental health need or ASD. Those in specialist foster care settings tended to be in mental health, ASD or multiple impairment categories. These young people tended to be male and in the 12+ age range.

Placement Impairment	At home	Non-relative FC	Kinship FC	Specialist FC	Children’s Residential	Specialist Residential	Other
ID	5	48	18	1	6	2	4
MH	5	22	13	3	18	4	16
ASD		4	4	2	2		1
ID + MH		13	3	1	3	3	
ID + ASD	2	3	2	1	3	3	1
MH + ASD		2	3		1		
ID+ASD+MH					2	1	1
Other	2	12	4	1	1		3
Multiple	4	26	9	4	6	2	3
TOTAL	18	130	56	13	42	15	29

Table 2. Number of disabled fully LAC in each placement type by impairment.



All of those who lived in hospital settings (not shown in table as numbers are small) had an intellectual disability (n=7); three had co-existing ASD and two had multiple impairments. All except one were male and five were in the 16+ age group (one aged 12-15 and one in 0-3 age group). Our data does not record the length of time young people have resided in a particular setting, but we do know that of these seven children, two had been in care for less than 6 months, four for between 1-2 years and one for more than 5 years. There were differences across Trusts in the use of hospital placements, with four of the young people being under the care of the SEHSCT, two in the BHSCT and one in the SHSCT. There were no children residing in hospital placements in the NHSCT or WHSCT.

#### **4.3.5 Placement Change**

The data suggests (see figure 23) that disabled fully LAC are more likely to experience instability in their placement than their counterparts in the general LAC population. Just over one third (35%) of disabled fully LAC in the study sample experienced no placement changes compared with over three quarters (76%) of the general looked after population (HSCB, 2013).

Over one third of the study sample (34%) had been subject to 1-2 changes<sup>5</sup> of living situation (which is in itself a significant disruption in a young person's life) compared with only 12% of the general LAC population. Further instability was experienced by 29% of the sample population who had experienced between three or more placement changes, compared with 12% of the total LAC population. Further, significant disruption was evident for 9% of the study population who had moved on six or more times and for 10 young people (3%) this was upwards of 10 placement moves.

Whilst placement change was generally linked with older children and those who had been in care for longer periods, there was also evidence of significant disruption for younger children and those in care for short periods. In relation to age, 38 children (12%) in the 4-11 age group experienced 1-2 placement changes and 16 (5%) had

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<sup>5</sup> Placement change refers to a change in full-time care placement and does not include change of short break placement which are likely to be more short-term and frequent.

3-5 placement moves. In terms of length of time in care, 48 (15%) of those who experienced 1-2 placement changes had been looked after for less than two years. Of those who experienced 3-5 placement moves, 13 (4%) had been in care for less than two years and 22 (7%) had been in care for between 3-5 years. In addition, three of the 10 young people who experience more than 10 placement moves had been in care for less than two years (the remaining seven were looked after for over five years).

It is worth noting that a placement move not only means a new physical environment, but also new carers, neighbourhood and perhaps accompanying change of school or day time activity which may be substantially challenging for some disabled children and young people.

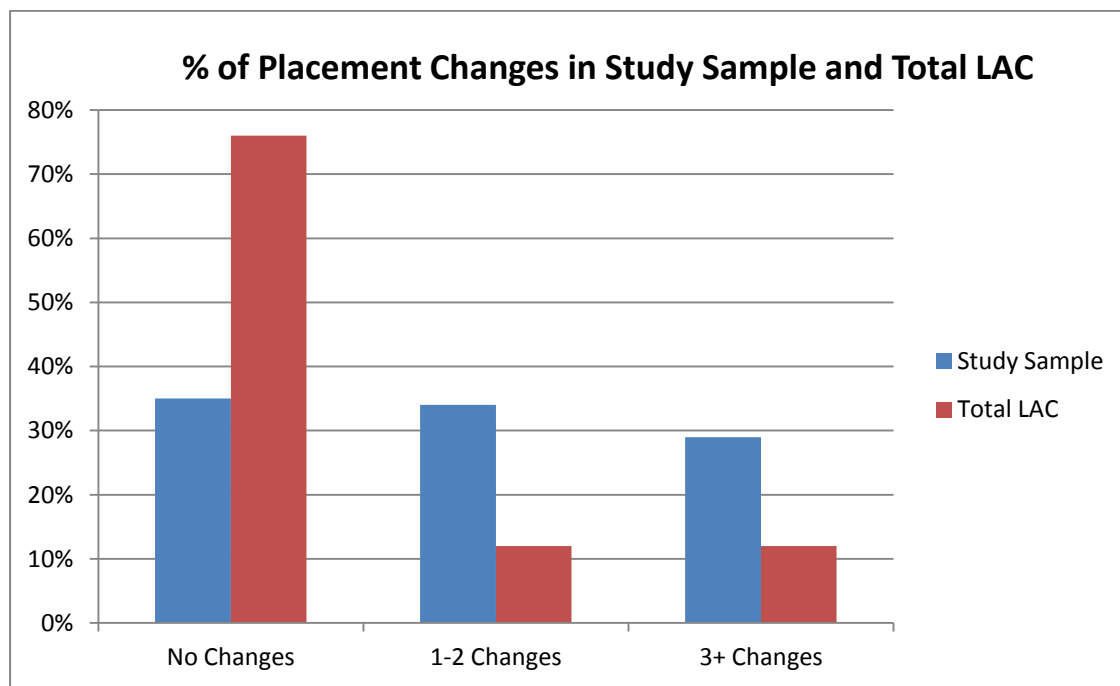


Figure 23. Comparing placement change for disabled fully LAC and general LAC population.

Figure 24 shows placement changes across impairment groups. Children with mental health needs including those with co-existing impairments appear to experience greater placement instability. Children with ASD were also reported to experience significant levels of placement change, which may result in particular challenges for these children in relation to change of routine and structure for

children with ASD. Children with intellectual disabilities had also experienced high levels of placement change.

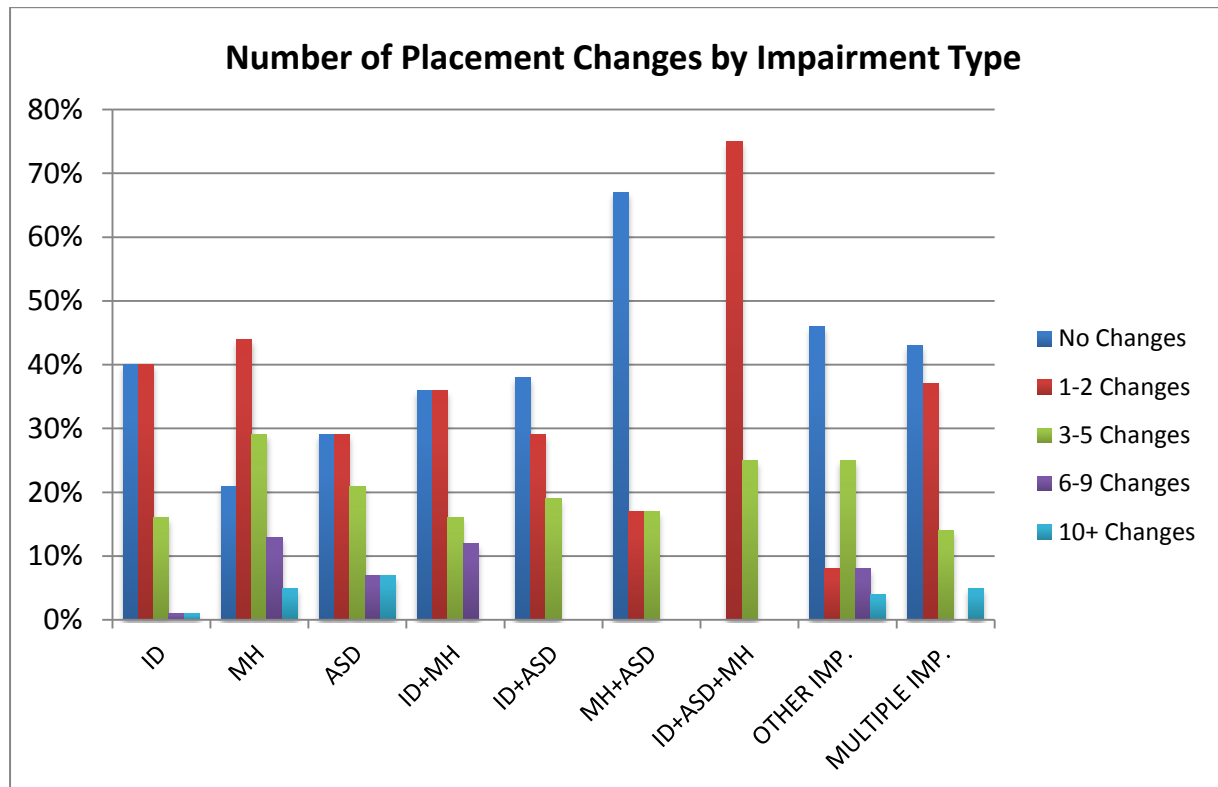


Figure 24. Placement changes by impairment type.

## Summary

The majority of disabled fully LAC had been in care for more than a year and over one third (39%) had been looked after for over five years. There was a particular rise in the length of time looked after for those with ASD or mental health needs. Most commonly children became looked after due to neglect, often combined with emotional abuse and parents not coping. There was some relationship between reason for becoming looked after and the age of the child, with decreasing reports of neglect and emotional abuse and increasing reports of sexual abuse (although remaining small in number) as children aged. Parents not coping and children being beyond parental control were cited more frequently for older children and young people. Children with mental health needs were more likely to be identified as being beyond parental control.

Two thirds of the study sample were reported to be looked after under a Care Order, with just over one fifth being voluntarily accommodated (mostly male with a combination of ASD, mental health and/or intellectual disability). A very small number of disabled fully LAC had been placed on an Interim Care Order by comparison with the general LAC population for whom the number increased five fold, perhaps reflecting the period of data collection for the present study or a trend towards more permanent placement decisions for disabled LAC.

Overall, 62% of the study sample were living in a home based placement. However, the majority of these were in non-relative foster care (40%) with much lower levels of kinship care and placement at home with birth parents in comparison to the general LAC population. Older disabled LAC with mental health needs (38%) were more likely than any other group to live in a children's residential home, though this was closely followed by those with ASD (29%). A number of children and young people with complex needs, usually older males, were living in specialist residential placements out of jurisdiction and, for some, these were outside of NI. It was reported that there was no service provision to meet the high level needs of these particular children within NI. Disabled fully LAC were found to experience greater disruption to their placement than those in the general LAC population. Those with mental health needs, ASD or co-existing impairments were found to be more likely to experience placement change.

#### **4.4 Short Breaks**

In addition to time spent in care, 32% of the sample of disabled fully LAC also availed of short breaks. The majority of disabled fully LAC availing of short breaks were placed in non-relative foster care (51%) or kinship foster care (19%), followed by residential children's homes (14%). Few children in the youngest age group used short breaks (3%), with the highest usage found amongst those who were in the 12-15 age group (38%), followed by those aged 4-11 years (31%). The use of short breaks then dropped in the 16+ age group to 26%. Almost twice as many males (63%) as females (37%) were found to use short breaks.

Figure 25 shows the breakdown of short break usage by impairment type, although the numbers in some categories are very small. Young people with ASD were most likely to use short breaks (50%, n=7), followed by those with co-existing mental health and ASD (33%,n=2), multiple impairments (31%, n=17) and intellectual disabilities (30%, n=26). A quarter of those in the 'other impairment' category (n=6) used short breaks, mostly physically disabled LAC.

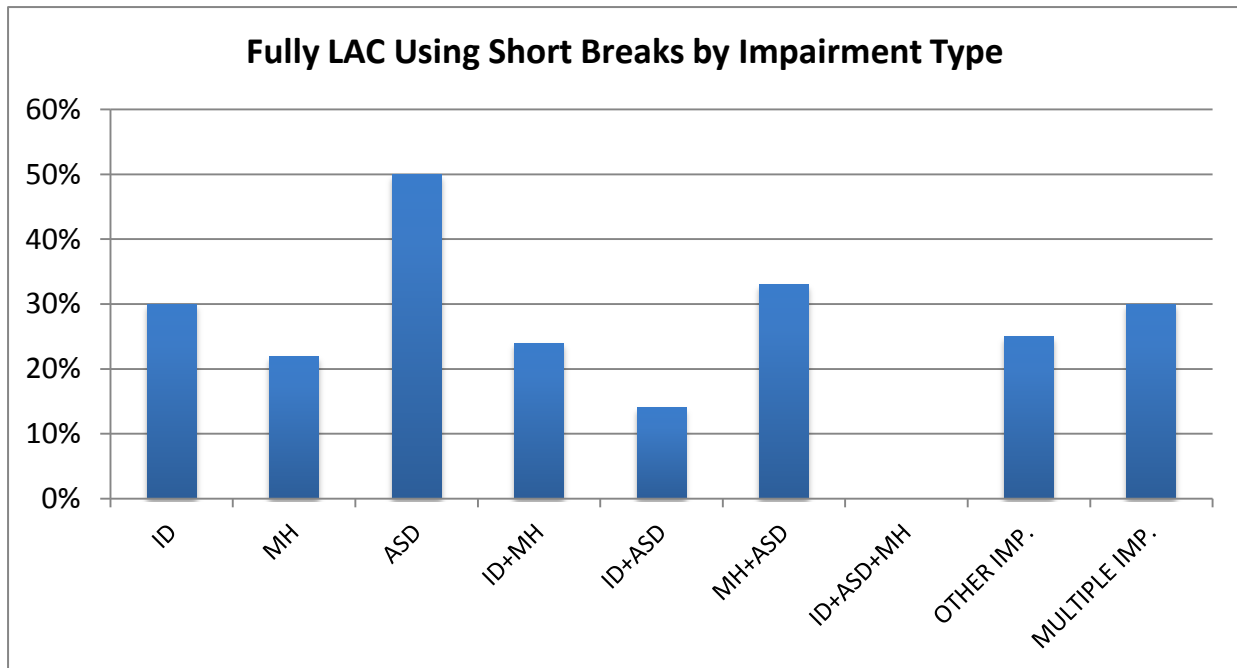


Figure 25. Percentage of disabled fully LAC using short breaks by impairment type.

Short breaks were largely reported to offer a planned break for the carer (15%) or to support the current placement (11.5%) (see figure 26). In only 6% of cases was the short break viewed as a social opportunity for the child or young person and rarely had it been used in response to crisis (1.5%). The number of short breaks was relatively low overall, with only one young person exceeding 35 days of short breaks.

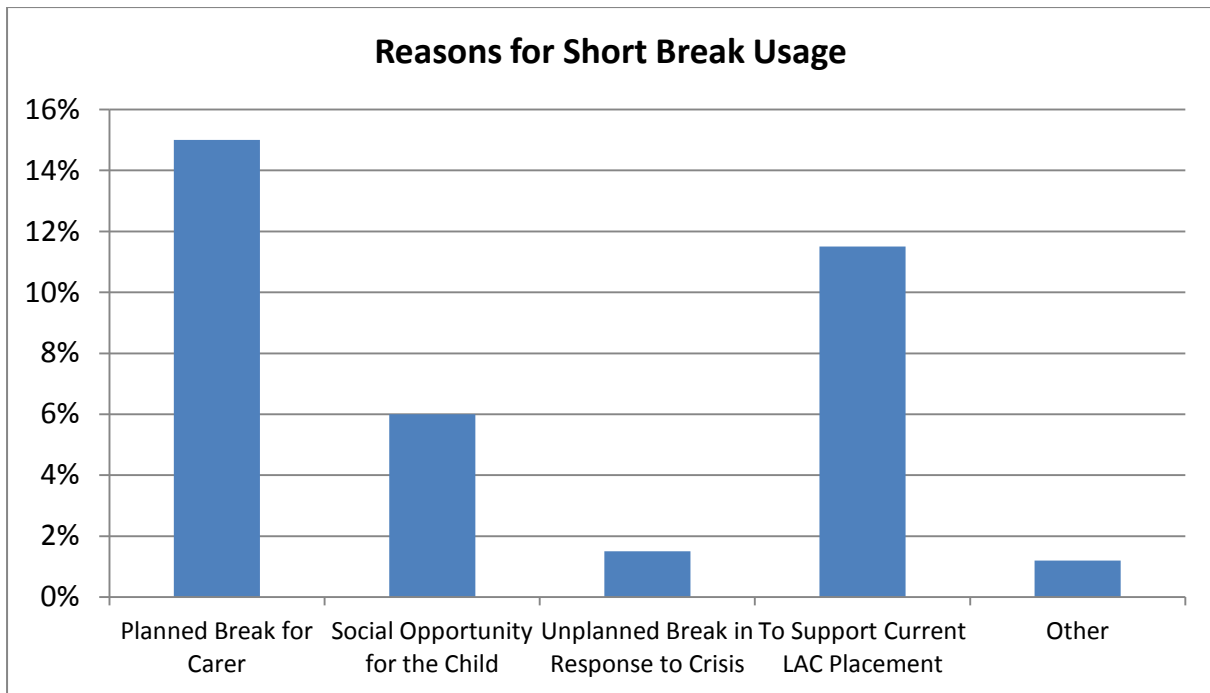


Figure 26. Reasons for short break usage.

The majority of short break placements were in non-relative foster settings (28%) (see figure 27) or specialist residential settings (21%). In addition to residential short breaks a number of other options such as short term domiciliary care or befriending schemes are available to support LAC placements. These are allocated on the basis of assessed need and service availability and form another element of the total package available to these children and young people. Although only 4% of the sample (n=12) were reported to have a domiciliary carer.

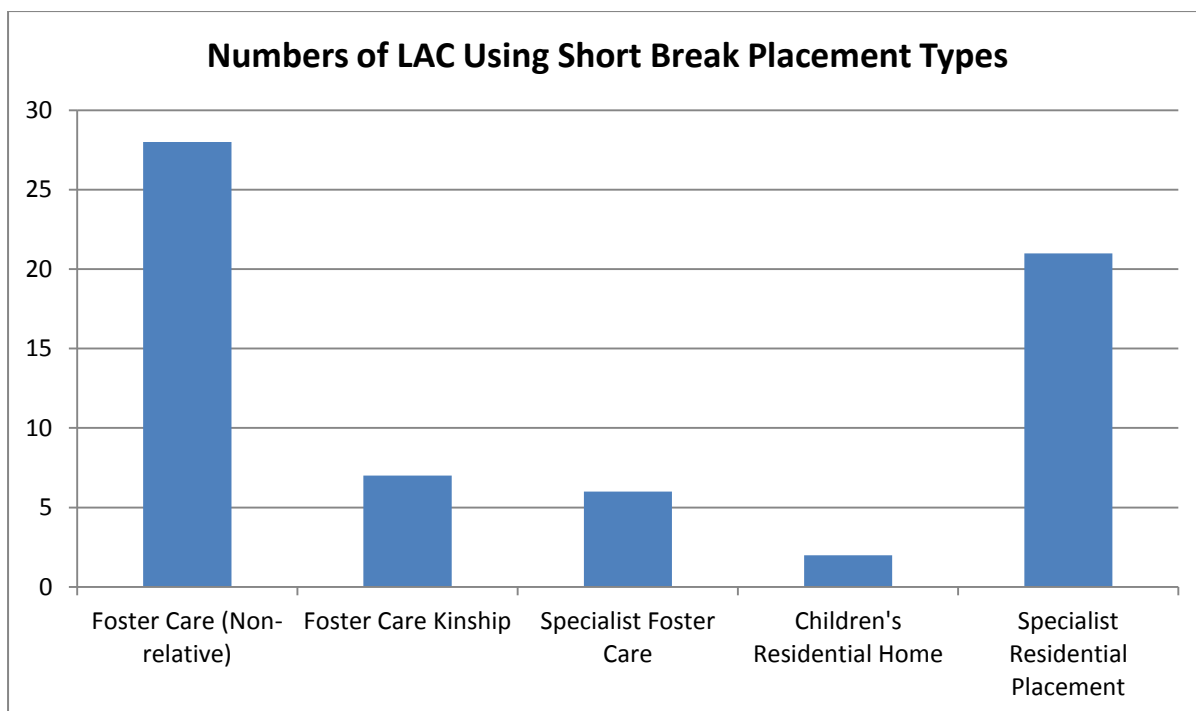


Figure 27. Short break placement type.

Analysis of the disabled fully LAC using the two main short break placement types shows that of those using non-relative foster care, those with mental health needs were most prevalent (32% / comprising 11% of the total with mental health needs), followed by those with intellectual disability (21%) and those with multiple impairments (18%). Those with multiple impairments were most likely to use specialist residential short break placements (42%), followed by equal numbers of LAC with intellectual disability, mental health needs and co-existing ASD and intellectual disability.

## Summary

Within the fully LAC sample, 32% also used short breaks, mostly males and those aged 4-15 years. The two main short break placement types were with non-relative foster carer and specialist residential placements. Those with mental health needs were most likely to avail of non-relative foster placements, followed by those with intellectual disabilities and multiple impairments. Those using specialist residential placements mostly presented with multiple impairments. The reasons for short break usage was more commonly attributed to supporting the child's carer or current

looked after placement and less likely to be viewed as a social opportunity for the child.

## **4.5 Safeguarding and Risk**

This section reports on disabled fully LAC's engagement with the child protection processes, followed by findings related to risk taking behaviour and contact with criminal justice.

### **4.5.1 Child Protection Processes**

A substantial proportion of the study sample had been subject to child protection proceedings before they became looked after. Almost three quarters (74%) had been subject to a child protection investigation and case conference prior to entry to care; and 70% had been placed on the child protection register.

Interestingly, although the number of child protection proceedings reduced when children became looked after, they were still significantly higher for disabled LAC in comparison to the general LAC population. In the study sample, 20% were placed on the child protection register whilst LAC in comparison to only 8% of the general LAC population (HSCB, 2013).

These higher numbers of disabled fully LAC on the child protection register whilst in care was unexpected as all of the Trusts follow a 'dual process' policy which aims to avoid bringing looked after children through child protection processes if the concerns can be addressed within looked after child review and planning procedures (DHSSPSNI, 2010). Therefore, spot checks were carried out with social workers to enquire about the reasons for the higher rate of engagement in child protection processes. Their responses indicated that these young people were subject to case conferencing or registration whilst in care because: they were at home on a Care Order with ongoing child protection concerns (19% of those registered whilst LAC were at home on a Care Order); there were concerns regarding child sexual exploitation; or there was a high level of engagement in risky behaviour which necessitated a child protection response. Of those on the child protection register



whilst LAC, 40% were reported to present with risky sexual behaviour, 33% with risk of suicide and 36% with risk of substance misuse.

In relation to the impact of placement type on child protection registration whilst in care, differences were noted in two categories: half of those at home on a Care Order were registered whilst LAC; and 38% of those in specialist foster care.

Figure 28 shows that, across age ranges, the majority of disabled fully LAC were engaged in case conferences or placed on the child protection register before entry to care. Those aged 4-11 years were most likely to be engaged in these child protection proceedings pre-care (89% brought to case conference and 83% registered) and those aged 16+ were least likely, however, the figure remains high (66% brought to case conference and 61% registered). Whilst contact with the child protection system reduced across age groups after entry to care, those in the 4-11 age category were still most likely to be engaged in child protection proceedings whilst LAC (28% brought to case conference and 24% registered), followed very closely by those aged 16 or over (21% brought to case conference and 23% registered). These trends are interesting as those aged 12-15 years are the second largest age group overall in the fully disabled LAC sample (21%, with 37% aged 16+ and 28% aged 4-11 years), yet those in the 12-15 age group were much less likely to be engaged in child protection proceedings whilst in care (16% brought to case conference and 13% registered).

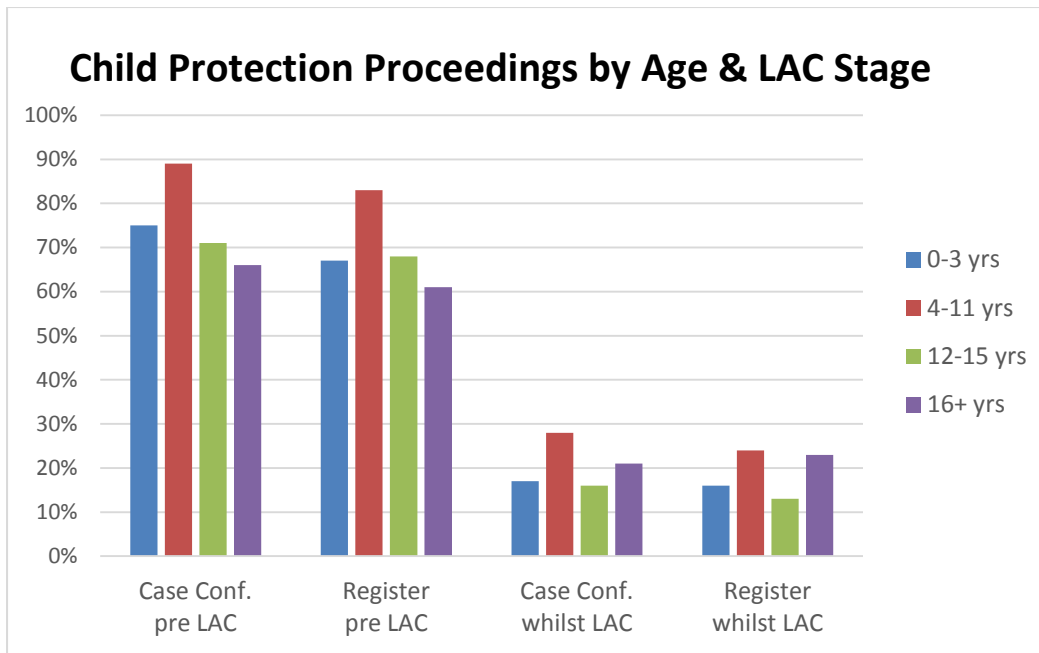


Figure 28. Child protection proceedings for disabled fully LAC before and whilst LAC by age.

Within the 4-11 age group, males were three times more likely to be subject to a child protection case conference and four times more likely to be placed on the child protection register whilst in care. In contrast, within the 16+ age range, females were twice as likely to be subject to a child protection case conference whilst in care, although this gender difference reduced in relation to child protection registration (57% females and 43% males).

Generally, there was drop in involvement in child protection proceedings across impairment types after coming into care. However, whilst there were slight differences for those with intellectual disability co-existing with mental health needs/ ASD and those with other/multiple impairments, there was a marked increase in case conferencing and registration for those with mental health needs (see figure 29). For example, of those placed on the child protection register pre-care, 26% had mental health needs, however 41% of those registered whilst in care were reported to be in the mental health category.

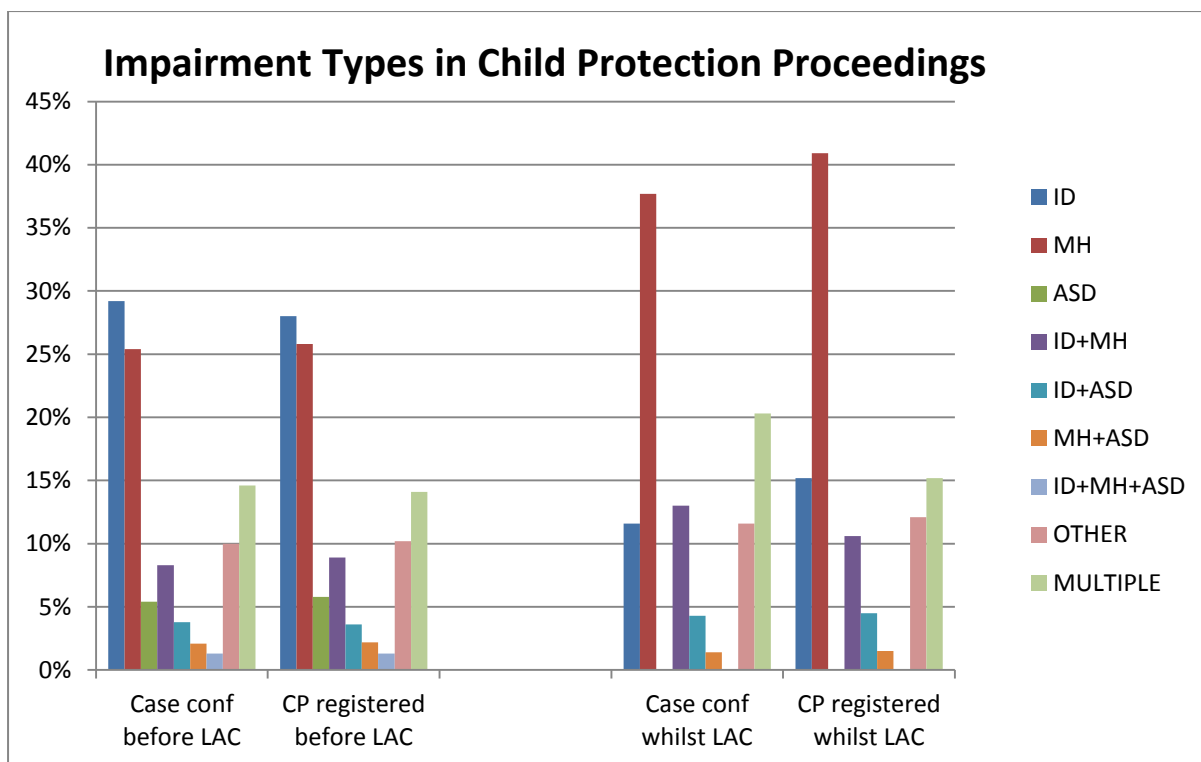


Figure 29. Child protection proceedings before and whilst LAC by impairment type.

#### 4.5.2 Risky Behaviours

The survey asked social workers to indicate whether disabled fully LAC were involved in a range of risky behaviours and to rate whether this risk was high, medium or low (the former two categories requiring service intervention). Figure 30 shows that across these risk levels, more than one third (39%) of the disabled fully LAC were found to be engaged in risky sexual behaviour, more than a quarter at risk of attempted suicide (28%) and substance misuse (27%). Just under one fifth (18%) presented with 'other' risks which included self-harm, being vulnerable in the community and risk of absconding.

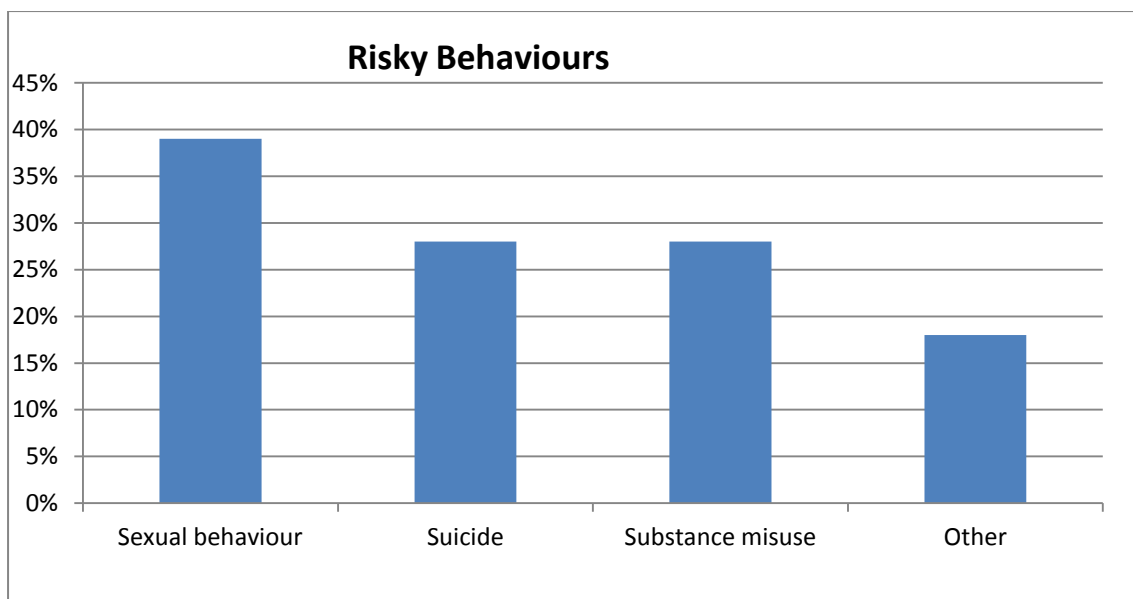


Figure 30. Risky behaviour amongst disabled fully LAC.

Figure 31 shows the impairment groups for those reported to be at high risk across the risk categories. Those with mental health needs were clearly considered to be at highest risk across all risk categories, forming the majority of cases reported to be at risk of substance misuse, risky sexual behaviour, suicide and other risks. Proportionally, the risks for those with intellectual disabilities and ASD were low, with those with multiple impairments being slightly higher, particularly the risk of substance misuse. Young people with intellectual disabilities featured highest in the 'other' category where they were reported to be vulnerable in the community.

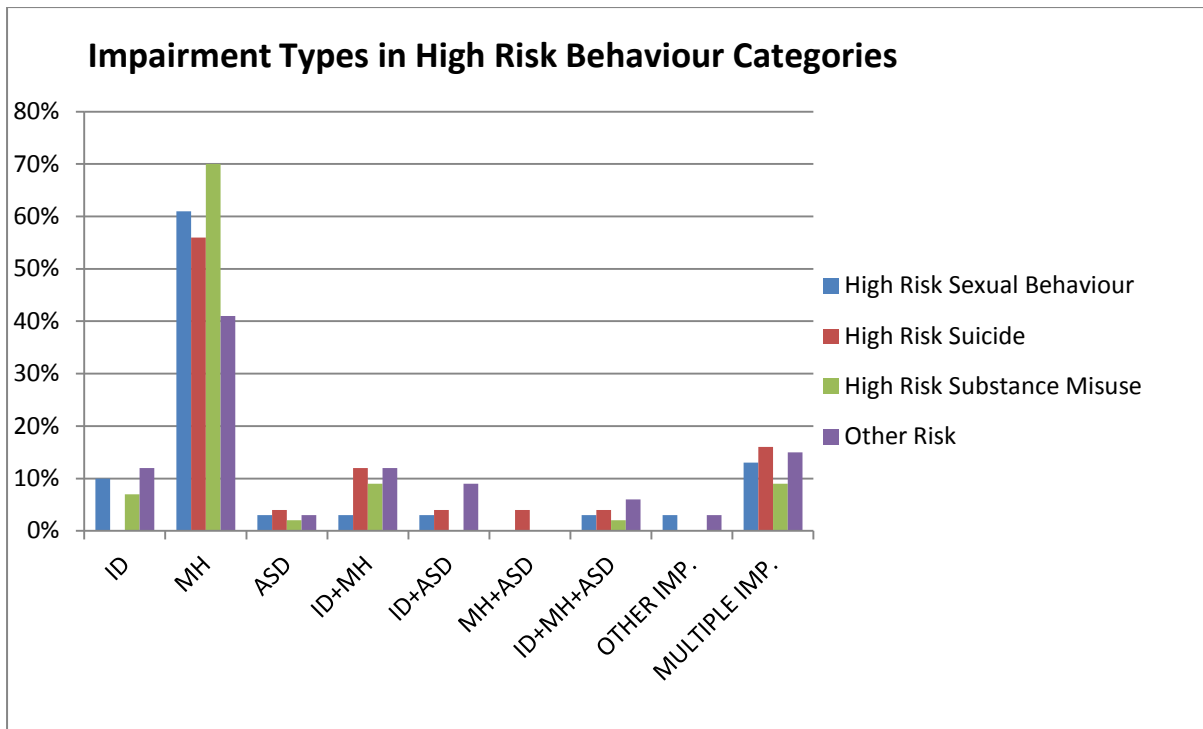


Figure 31. Risky behaviour and impairment type amongst disabled fully LAC.

A significant association is evident between increased age (from 4 to 16+ years) and levels of risk (see figure 32). Levels of risk decreased in all age categories across risk categories apart from the 16+ age group, with the exception of the 'other' risk category where the 16+ group are also prevalent the low level of risk. The trend towards a higher level of risk for the oldest age range is particularly notable in the substance misuse category.

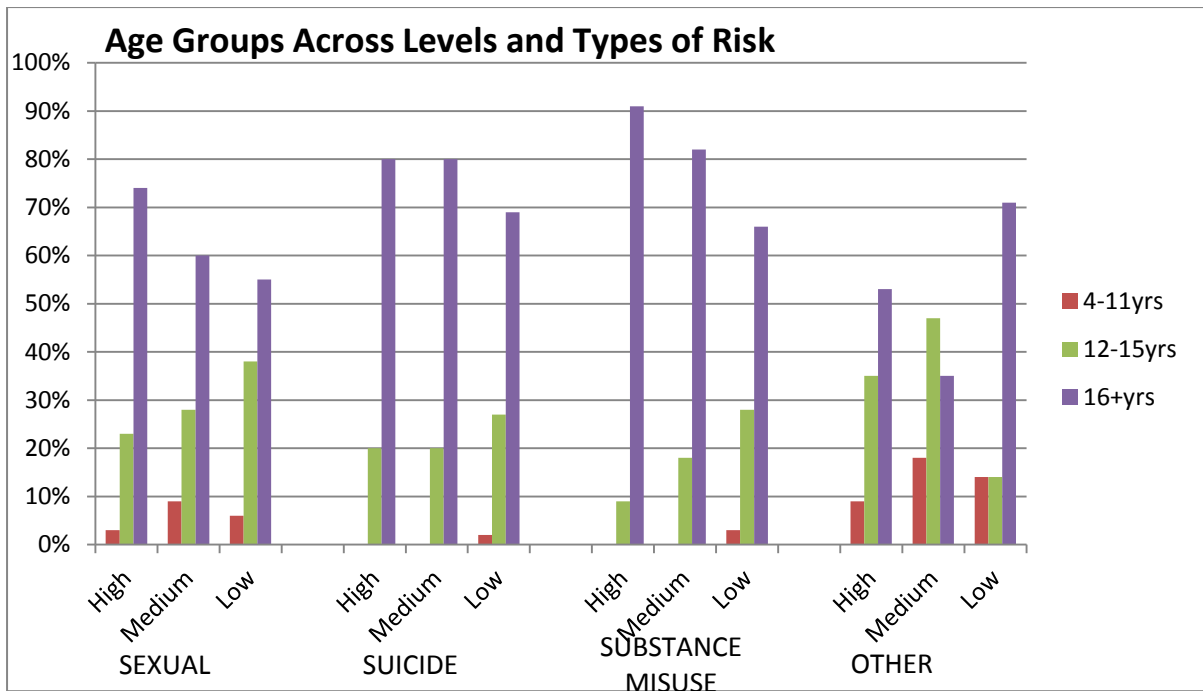


Figure 32. Association between disabled fully LAC's level of risk and age.

In relation to gender, females were most prevalent in the higher risk categories for risky sexual behaviour and risk of suicide (see figure 33). However, the gender divide at high risk levels lessened for risk of substance misuse (48% male, 52% female) and reversed in the 'other' risk category with more males than females (69% male, 31% female).

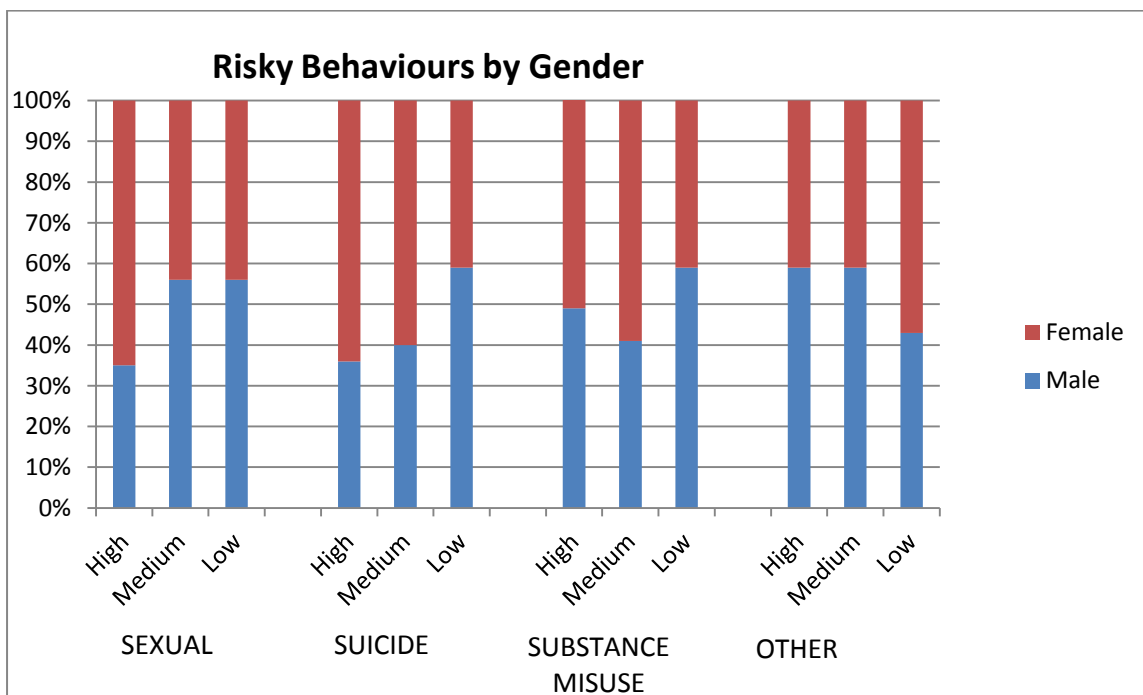


Figure 33. Association between disabled fully LAC's level of risk and gender.

### 4.5.3 Cautions and Convictions

Overall, 19% (n=62) of the disabled fully LAC sample had received a police caution and 11% (n=35) had a criminal conviction. These findings compare with the figures for the general LAC population where almost 3% have been cautioned and almost 2% had a conviction (HSCB, 2013). Those in the older age groups were most likely to have been cautioned by the police, with 81% (n=50 / 16% of disabled fully LAC sample) of those cautioned in the 16+ age group. Of those who had a criminal conviction, all but four were in the 16+ age group (see figure 34). All criminal convictions and the majority of police cautions (74%, n=46) occurred after young people had become looked after. More males than females had a caution and conviction, however, this gender difference was most notable in conviction rates (52% male and 48% females with cautions; 66% male and 34% females with convictions).

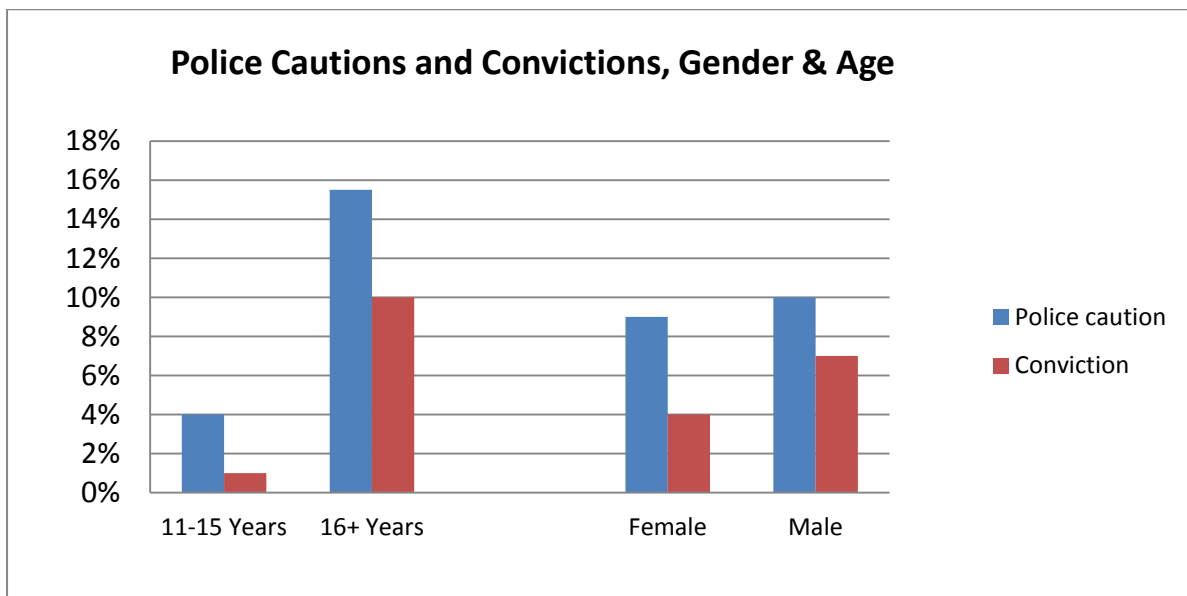


Figure 34. Police cautions and convictions by age and gender

Young people with mental health needs and/or ASD were more likely than others to have a police caution or criminal conviction (see figure 35). For example, 45% of those solely in the mental health category received a police caution and 22% a conviction. In relation to ASD, 21% of those in this sole impairment group had a caution and conviction.

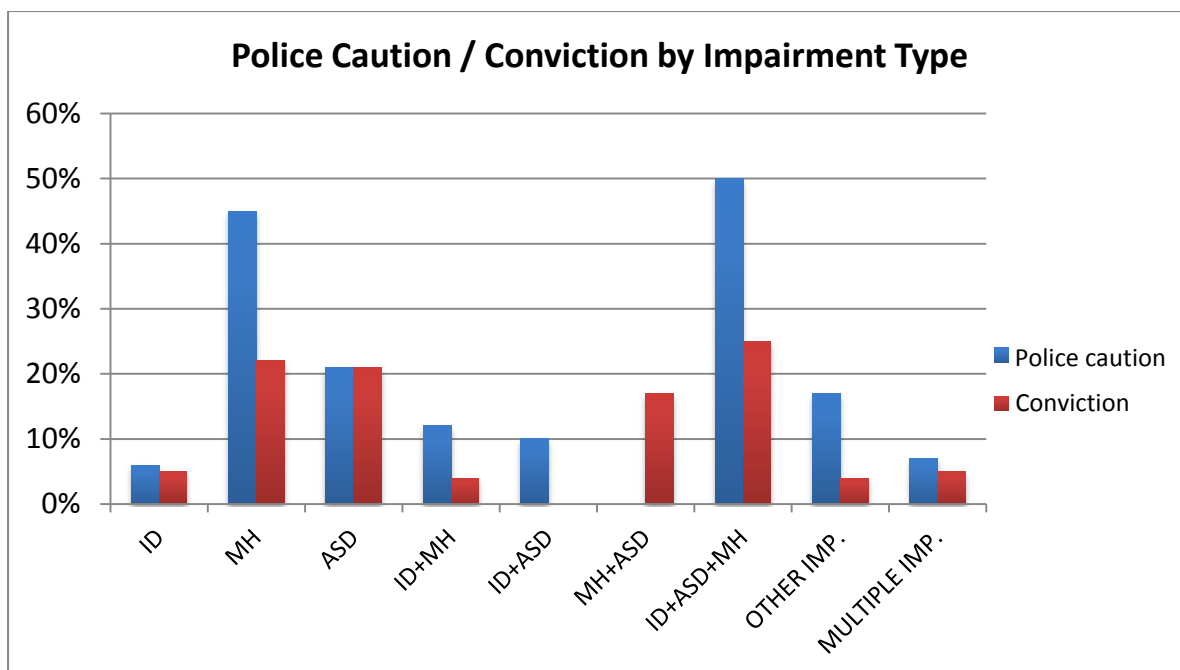


Figure 35. Police cautions and convictions by impairment type.

## Summary

Reflecting the trend for the general LAC population, the majority of the study sample had been subject to child protection proceedings before they became looked after. However, in contrast to the general LAC population (8%), 20% of the disabled fully LAC sample were on the child protection register whilst in care. Half of those at home on a Care Order were on the child protection register whilst LAC; and 38% of those in specialist foster care. The two main age groups for those brought to case conference/registered whilst LAC were 4-11 and 16+; with mental health being the dominant impairment category. In the 4-11 age group, males were most likely to be subject to a case conference and registration whilst in care; a trend reversed for the 16+ age range.

More than one third (39%) of the disabled fully LAC were found to be engaged in risky sexual behaviour, more than a quarter at risk of attempted suicide (28%) and substance misuse (27%). Those with mental health needs and those in the 16+ age group were at highest risk across all risk categories. Females are most prevalent in the higher risk categories for risky sexual behaviour and risk of suicide.



Almost one fifth (19%) of the disabled fully LAC sample had received a police caution and 11% a criminal conviction. These figures are much lower for the general LAC population (3% cautioned and almost 2% convicted (HSCB, 2013). Those in the 16+ age group and those with mental health needs and/or ASD were more likely than others to have a caution or criminal conviction. Males were also more prevalent, most notably in conviction rates, with two thirds of those with convictions being male.

#### 4.6 Education

Overall, 64% of the sample of fully disabled LAC were reported to have a Statement of Special Educational Need (SEN), compared with 26% in the general LAC population (DHSSPSNI, 2015). The majority of these had sole ASD (93%) or intellectual disability (92%), co-existing ASD and intellectual disability (95%) or multiple impairments (86%) (see figure 36); followed by those with co-existing mental health and intellectual disability (76%) or in combination with ASD (75%). However, only 14% of those solely with mental health needs were identified as having a SEN.

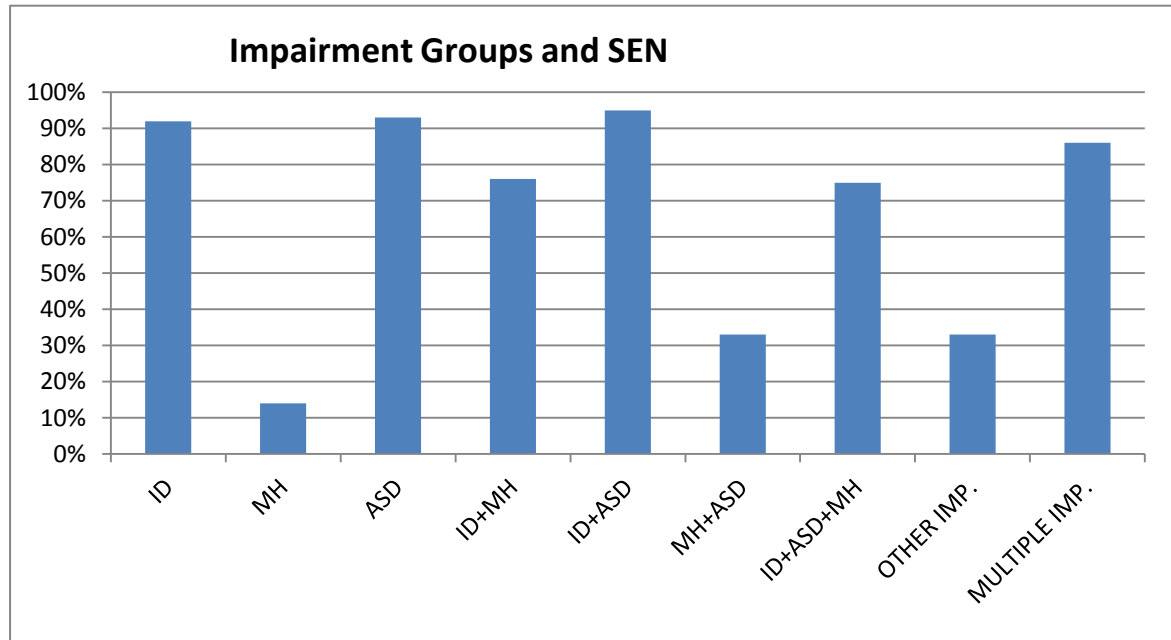


Figure 36. Disabled Fully LAC with a Statement of Educational Needs.

Of those attending mainstream school (26%, n=83), most had mental health needs (43% in sole mental health category), followed by those in the 'other' impairment category (12%). Those attending special units within mainstream schools (8%, n=26)

mostly had a sole intellectual disability (42%), co-existing mental health and intellectual disability (19%) or ASD (15%). Amongst those attending a 'special school' (34%, n=110), the majority had a sole intellectual disability (45%), followed by those with multiple impairments (29%). Seven children with an intellectual disability attended a residential school and three with ASD.

Half of the study sample had no school change, 38% (n=123) had between 1-2 changes, 8% (n=26) between 3-5 changes and two young people experienced between 6-9 school changes. School change in a similar way to placement change impacts on young people's sense of stability and belonging. School change may be a result of placement change bringing increased instability and additional upheaval. Children who were most likely to attend special school were least likely to experience school change. In some of these cases, special schools may already have been some distance from the child's birth family home to attend special schools which are fewer in number than mainstream schools. Smaller class sizes and higher staff ratios within special schools may also mean that they are better equipped to cope with challenging behaviour and less likely to seek alternative educational placement for children presenting with more complex, challenging behaviours.

Figure 37 shows that those with mental health needs and/or ASD were more likely to experience significant disruption to their education. For example, of those experiencing 3-5 school changes, more than one third had sole mental health needs (35%), followed by those with ASD (15%) and those with co-existing mental health and intellectual disability (15%). The two children experiencing 6-9 school changes both had sole mental health needs.

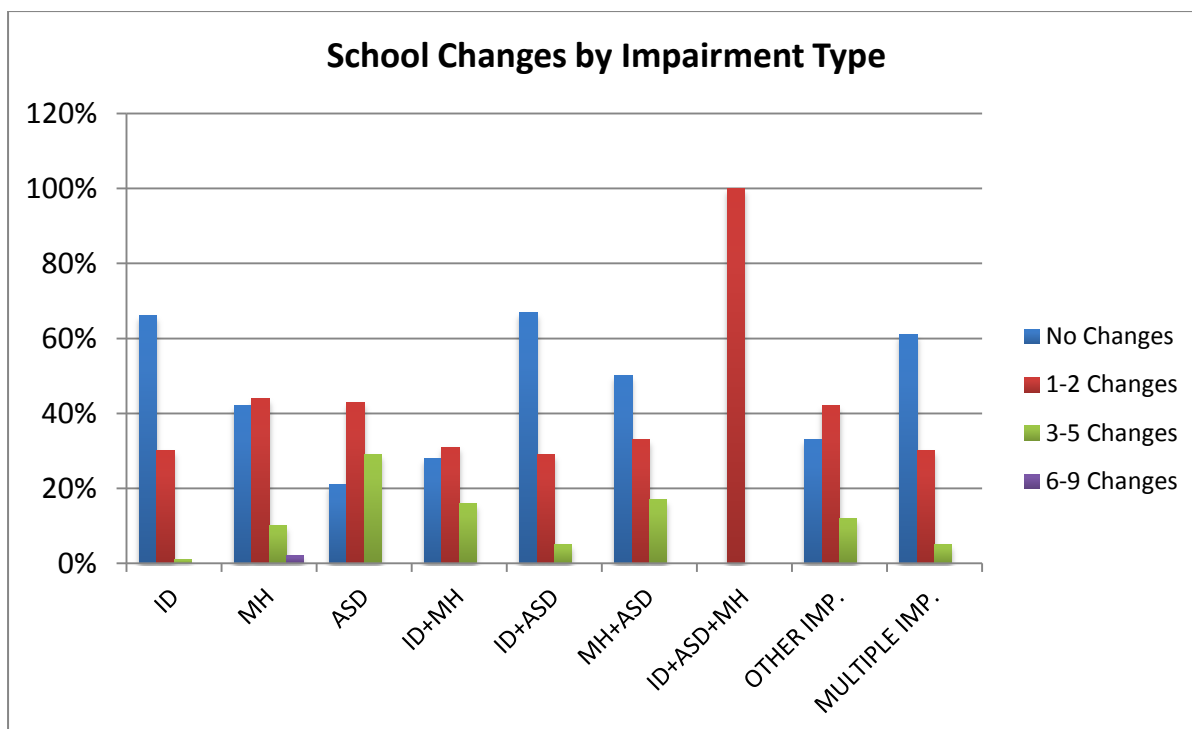


Figure 37. School changes by impairment type amongst disabled fully LAC.

Some young people were no longer at a mainstream/special school and were classified in an 'Other' category (13%, n=42) which included apprenticeships, intensive support units, home tuition and alternative education settings. Those with sole mental health needs were mostly likely to be 'other' settings (38%), followed by those with sole intellectual disability (21%) and those with multiple impairments (19%).

Those 'Not in Education, Employment or Training' (NEET) were exclusively in the 16+ age range (8%, n=27). Those with sole mental health needs comprised 48% of this group, followed by those in the 'other' impairment group (22%) and those with multiple impairments (15%). Only two young people with an intellectual disability and one with ASD were classified as NEET.

## Summary

Almost two thirds (64%) were reported to have a Statement of Special Educational Need (SEN), mostly those with ASD, intellectual disability or multiple impairments. Those with an intellectual disability, ASD, or multiple impairments were most likely to

attend a special unit/school. School change was more likely for those in mainstream schools and those with mental health needs and/or ASD. Those who were availing of alternative education mostly had mental health needs, intellectual disability or multiple impairments. All of those the NEET category were in the 16+ age range and mostly had mental health needs.

#### 4.7 Additional Needs and Access to Services

Social workers also reported information about the additional health needs of the sample of disabled fully LAC (see figure 38). The most commonly cited 'additional need' related to challenging behaviours (53% of the total). Speech and language disorders (23%) and ADHD/ADD (21%) also featured relatively frequently (see figure 39), followed by anxiety (16%). Smaller numbers (not on the graph below as numbers were less than 10% of the sample) of other health related needs were also reported. For example, asthma (5%), dental problems (7%), encropesis (6%), stomach/digestive problems (5%), eczema (4%) and glue ear/grommets (4%). In addition, 3% (n=9) had an acquired brain injury and a further 3% (n=11) required high level medical intervention (e.g. tube fed).

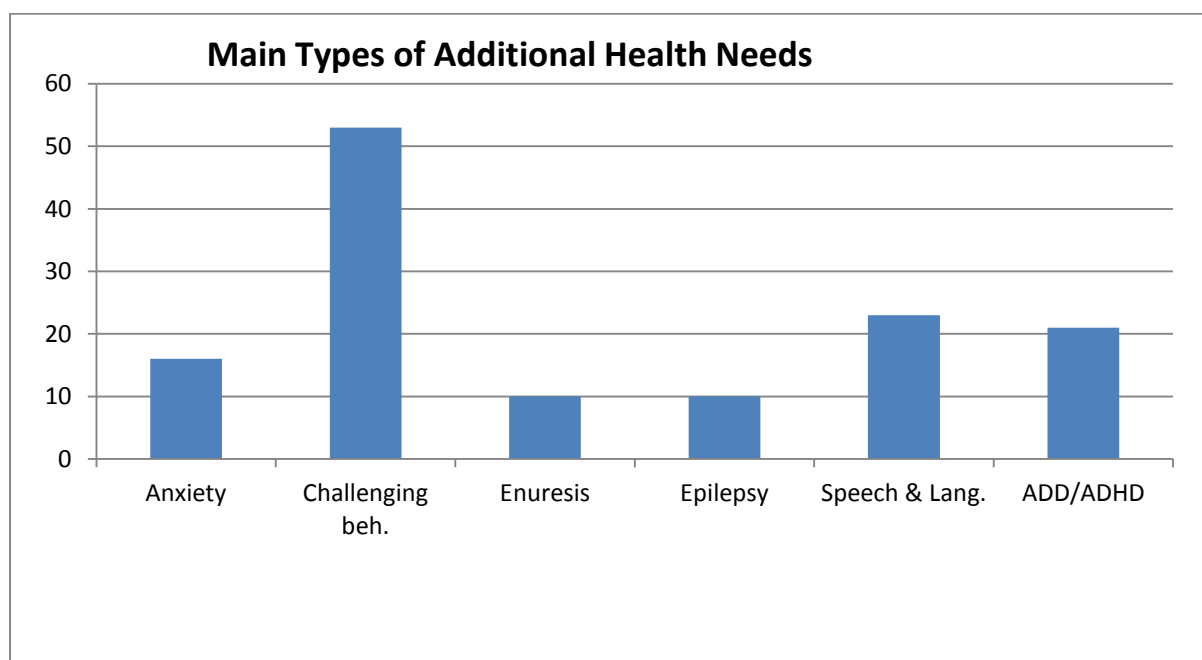


Figure 38. Main type of additional health needs amongst disabled fully LAC sample.

The purpose of drilling into the data to explore the additional health needs of the sample population, is not to seek to present these children and young people as having a range of medical labels, but rather to consider the complexity of their needs and related service requirements.

Some of the reported additional health needs were more commonly reported for children and young people with particular impairment types. For example, those reported to have anxiety were more likely to have a mental health need. Encopresis, enuresis and epilepsy were most prevalent amongst those with intellectual disabilities. Speech and language difficulties were associated with intellectual disability, whilst ADHD/ADD was relatively equally applied to each of the majority impairment types (22% intellectual disability and 23% mental health need). Challenging behaviour was most commonly reported amongst young people with mental health needs (63%) followed by those with an intellectual disability (53%).

#### **4.7.1 Access to Mental Health Services**

A quarter of the total sample had access to Tier 3/4 CAMHS. Figure 39 shows that, of these, 61% were reported to have a mental health need as a sole impairment, followed by those with multiple impairments (11%). Overall, 23% of the total sample accessed LAC Specialist Therapeutic Services. Of these, 57% were reported to have a mental health need as a sole impairment, followed by those with co-existing mental health and intellectual disability (17%) and those with multiple impairments (12%).

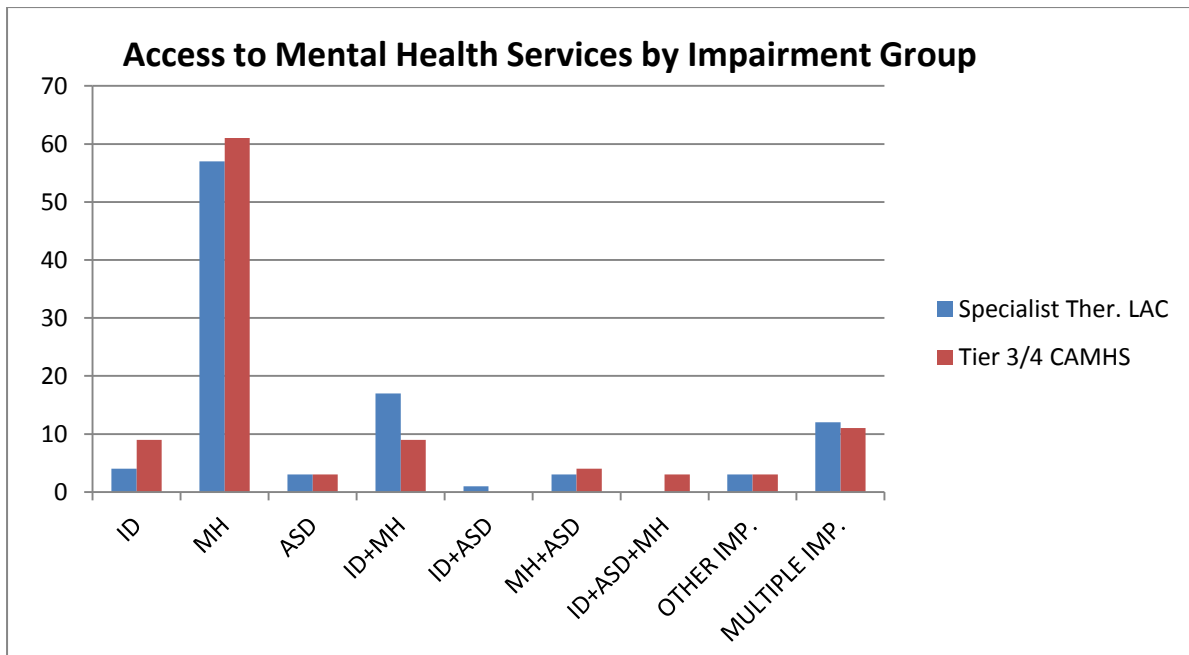


Figure 39. Percentage of those receiving mental health services by impairment type.

Of those with sole mental health need, 57% had accessed Tier 3/4 CAMHS and 50% LAC specialist therapeutic services. A high proportion had also accessed psychology services (62%) and psychiatric support (35%).

Of those with co-existing mental health and intellectual disabilities, 28% had accessed Tier 3/4 CAMHS and 52% LAC specialist therapeutic services. Within this group, 56% had accessed psychology services and 36% psychiatry.

Of those with sole intellectual disability, 8% had accessed Tier 3/4 CAMHS and 3% LAC specialist therapeutic services. Only 23% of those with an intellectual disability received psychiatric services (9% of these were not reported to have a mental health need), and over a third (37%) psychology services (16% of these these were not reported to have a mental health need).

Of the total of disabled fully LAC with an assessed mental illness (n=35), only six had multiple impairments, four with an intellectual disability and two with ASD. Two thirds (66%) of those with an assessed mental illness had access to psychology and 60% psychiatry; 63% were receiving Tier 3/4 CAMHS but only 20% receiving LAC specialist therapeutic services.

Comparison of these findings on access to mental health services (including psychiatry, psychology, Tier 3/4 CAMHS and LAC Specialist Therapeutic Services)

across mental health and/or intellectual disability indicates that those with intellectual disabilities have reduced access to Tier 3/4 CAMHS, even when they have co-existing mental health and intellectual disabilities. Although the percentage of those with co-existing mental health and intellectual disabilities accessing psychology and psychiatry remained relatively high, it is likely these services were from the learning disability programme of care rather than specialist mental health services. As a result, those with intellectual disability may be less likely to have their mental health needs identified or have access to specialist mental health services for children and young people.

#### **4.7.2 Access to Transition support**

Although 37% of the total sample were aged 16+ and 31% were in the 12-15 age range, low levels of engagement with transition services were reported with only 14 (4%) accessing a transition co-ordinator. Of these, four were young people with an intellectual disability, four with co-existing intellectual disability and ASD and six with multiple impairments.

In terms of preparing to leave care, just over a quarter (26%) were accessing 16+ social work services. Of these, the majority (54%) solely had mental health needs, followed by those with sole intellectual disabilities (10%) or multiple impairments (10%).

Only 7% (n=23) had accessed an employment officer with more than half of these reported as solely having a mental health need (57%), followed by sole intellectual disability (13%). A higher number (18%, n=59) was reported in relation to access to a Personal Advisor, with a similar pattern of the majority having sole mental health need (51%) or intellectual disability (18%).

#### **4.7.3 Access to Other Professional Support**

Figure 40 shows that the majority of disabled fully LAC had access to a dentist (70%). A high percentage were still involved with community paediatric (41%), health visitor (35%) and specialist hospital (25%) services. Interestingly, 14% of those with

involvement of a community paediatrician and health visitor were aged 16 or over (only two of these young people were parents). The majority of those accessing these services had multiple impairments or intellectual disabilities.

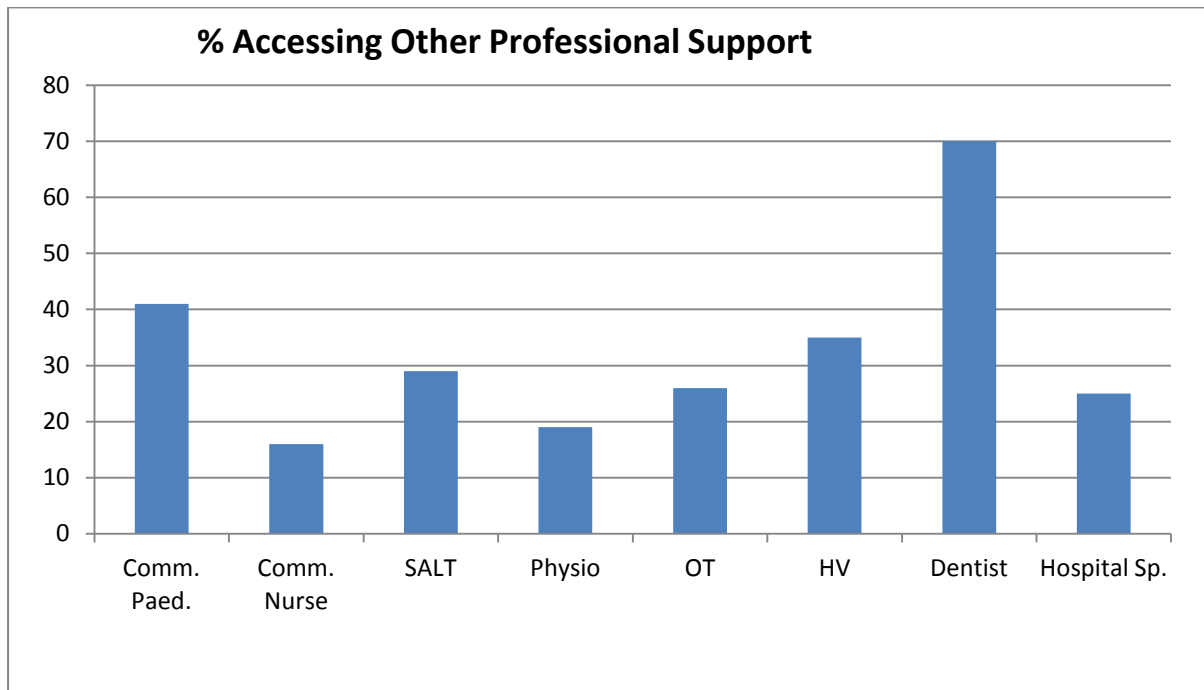


Figure 40. Other professional support.

Just over a quarter had access to speech and language therapy (29%) and occupational therapy (26%) with lower numbers reported for physiotherapy (19%) and community nursing (16%). Again, the majority of those accessing these services had multiple impairments or intellectual disabilities, although a higher percentage of those in the 'other' impairment category were recorded for physiotherapy (12% compared with 4% speech and language therapy and 7% occupational therapy). The latter finding is to be expected as those with physical impairments were classified under the 'other impairment' category. In consideration of the overall prevalence of access to speech and language, occupational and physiotherapy, it should be noted that these services are often available through special schools and 34% of the study sample were attending special schools.

Only 10% (n=32, 48% of these were 16+yrs and 45% 12-15yrs) were reported to have access to an independent visitor and a similar number had access to an independent advocate (n=31, 69% of these were 16+yrs and 31% 12-15yrs). A slightly higher number had access to a Guardian ad Litem (14%, n=45), with the



majority of these aged 4-11 yrs (44%), followed by 12-15yrs (33%) and 16+ yrs (16%). Overall, these findings indicate a lack of independent advocacy and support for the fully disabled LAC population.

## **Summary**

Challenging behaviour was the most commonly cited additional need reported by social workers, followed by speech and language disorders, ADD/AHD and anxiety.

A quarter of the total sample had access to Tier 3/4 CAMHS and 23% accessed LAC Specialist Therapeutic Services. There is some indication that those with intellectual disabilities had lower levels of access to Tier 3/4 CAMHS and LAC therapeutic services. For example, 28% of those with co-existing mental health and intellectual disability accessed Tier 3/4 CAMHS compared with 57% of those solely with a mental health need. Only 3% of those solely with an intellectual disability, accessed LAC specialist therapeutic services.

The disabled fully LAC population also had access to a range of other professionals including community paediatricians (41%), health visitors (35%), speech and language therapy (29%), occupational therapy (26%) and hospital specialists (25%). The majority of those accessing these services had multiple impairments or intellectual disabilities. A surprisingly low number of young people were accessing transition support (4%), however a quarter of the sample were accessing 16+ social work services and 18% were engaged with a personal advisor (mostly those with mental health needs). Low numbers of disabled fully LAC were accessing an independent visitor (10%), independent advocate (10%) or Guardian ad Litem (14%), indicating a lack of independent support and advocacy for the fully disabled LAC population.

## **4.8 Unmet Need**

At the end of the survey, social workers provided additional qualitative comments on unmet need for the disabled fully LAC population and the reasons why the need was not met. The most commonly cited unmet needs included access to CAMHS and disability services. There was also a reported lack of supported housing for care leavers and challenges in finding appropriate training or educational opportunities for

this group. Support for children and young people engaged in substance or alcohol abuse was also reported to be inadequate.

Social workers provided reasons why identified needs remained unmet. In some instances children and young people were not considered to meet the threshold for CAMHS or disability services. In other cases, the service to which a child had been referred had been refused. For example, one young person was unable to access CAMHS because they were using drugs or alcohol, even though the substance use was deemed to be related to their presenting mental health need.

Limited availability of some services often meant that an assessed need could not be met immediately or at all. In some instances lengthy waiting lists meant that young people had a considerable delay in access to services to which they had been referred. Finally, in some instances, assessed need could not be met as young people themselves refused to engage with a service which had been offered and made available.

#### **4.9 Conclusion**

The following key themes can be drawn from the findings reported for the disabled fully LAC sample.

1. A total of 323 disabled fully LAC comprised the study sample, representing 11% of the total LAC population. Comparison of this figure with census data shows that disabled children are over-represented in the LAC population in NI (7% of the general child population in NI being disabled).
2. Intellectual disability and mental health need are the two major categories of disabled fully LAC, followed by those with co-existing impairments. Those with ASD or mental health needs are much more likely to have their impairment identified after becoming LAC in comparison to other impairment types.

3. Reflecting the higher number of males in the study sample, there were more males in all impairment groups. However, the higher number of males is notable in the intellectual disability category (61% male); and all those with co-existing ASD being male. Mental health (as a sole impairment) was the exception, where there was a higher number of females than males.
4. The numbers of disabled fully LAC in the study group grew as they aged in contrast to the general LAC population where there is a drop in numbers in the 16+ age group.
5. Disabled fully LAC are more likely to be under a Care Order (66%) than voluntarily accommodated 23%. Males are more than twice as likely as females to be voluntarily accommodated, and these are more likely to be in the older age group and to have an intellectual disability or mental health need.
6. In comparison with the wider LAC population, disabled fully LAC have spent more time in care, with the majority being in care for more than one year and one third for more than five years.
7. Disabled fully LAC are less likely to experience placement stability than their non-disabled peers, with many experiencing more than three placement changes, some greater than six and for a few more than ten placement changes. Those with mental health needs as well as older children are at greater risk of placement disruption.
8. Although 40% were in foster care, disabled fully LAC were less likely than their non-disabled counterparts in the wider LAC population to reside in a kinship foster setting. Disabled fully LAC were also more than twice as likely than those in the general LAC population to be placed in a communal residential setting.
9. A small number of disabled fully LAC with complex needs were placed in an out of jurisdiction placement outside NI. In addition to the increased cost of these placements, there were associated difficulties of distance from family and likely impact on transition from care.

10. A larger proportion of disabled fully LAC are subject to child protection proceedings whilst in care compared to the general LAC population (20% compared with 8%), suggesting ongoing safeguarding concerns.
11. A sub-sample of the disabled looked after population were found to also use short breaks. It was notable that the broad reason for short break usage was to support carers or the LAC placement. Short breaks were rarely viewed as a social opportunity for the child.
12. High levels of risky behaviour are concerning, particularly in relation to those with mental health needs.
13. Higher numbers of police cautions and convictions for the disabled fully LAC sample are also notable, particularly for older males with mental health needs and/or ASD.
14. There is evidence of instability of educational placement for children and young people who have mental health needs, where increased numbers of school changes were reported. These may coincide with placement changes also high in this group.
15. There are indications that CAMHS may be less available to children and young people with co-existing intellectual disabilities and mental health needs.
16. Low levels of independent support and advocacy were reported for the study sample. Limited transition supports were also reported for those in the older age ranges, particularly for those with intellectual disabilities.

## **5.0 Profile of Disabled Children Looked After Due to Short Breaks**

Under current legislation in NI children who use short breaks (formerly referred to as respite care) for a period exceeding 24 hours are defined as looked after children and are subject to all LAC procedures. This is a contentious issue for many parents of disabled children who use short breaks for family support reasons and may feel their parenting role is being challenged. In addition, under the Children (NI) Order 1995, no single short break placement should exceed four weeks and the total time spent by a child in short breaks should not exceed 90 days. For the present study, disabled children and young people met the inclusion criteria for the study if they were using short breaks for more than 35 days or a continuous four week period in short break care in one year. Including those who were at this higher end of short break usage allowed for consideration of cases exceeding four weeks and also those making more intensive use of short break support, possibly preventing admission to full-time care.

A total of 164 disabled children and young people met this criteria of being looked after due to short breaks (short break LAC). There was considerable variation in the numbers reported in each Trust (see figure 41) which contrast with the census data on childhood population trends across Trusts indicating that the NHSCT has the highest numbers, followed by SHSCT, SEHSCT, BHSCT and WHSCT. In contrast, the high numbers in the WHSCT in this short break LAC sample are likely to reflect the increased availability of short breaks in the area due to the recent opening of a new residential short break service for disabled children and young people. The lower numbers in the BHSCT and NHSCT may reflect the lower childhood population in the BHSCT, insufficient capacity to offer children and young people a higher level of short break provision in these areas, or a lower survey response rate in these Trusts.

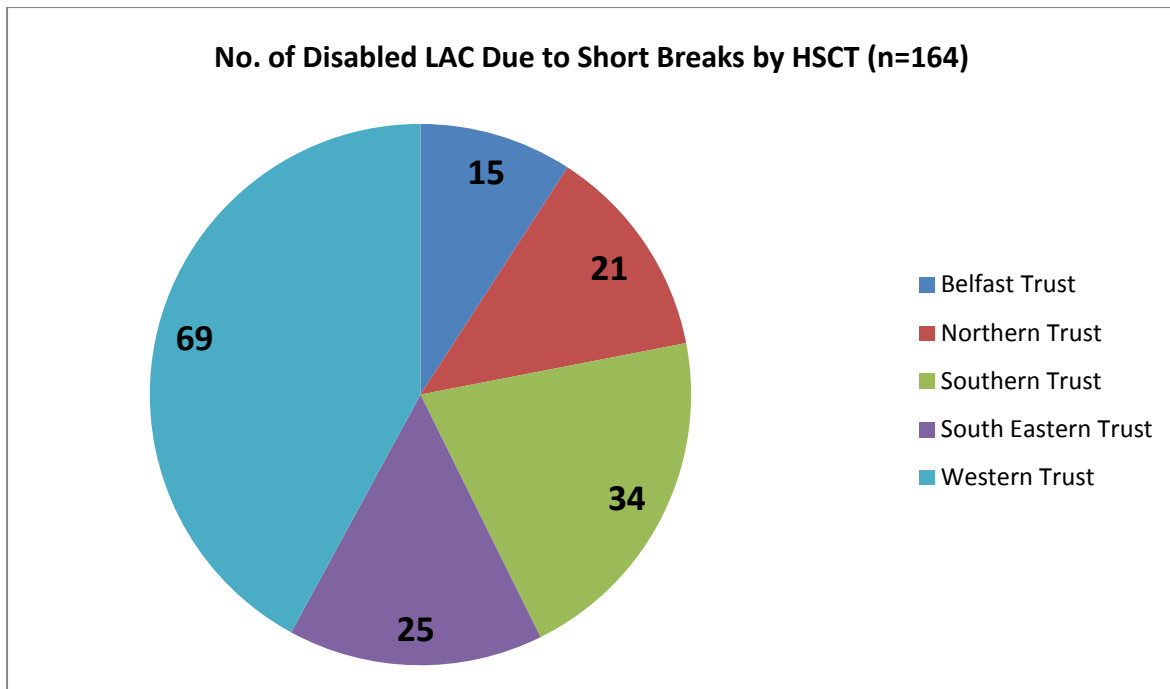


Figure 41. Distribution of short break LAC sample across the five HSCTs.

Figure 42 shows that the majority of children and young people were allocated to between 35-50 days per year (66%, n=108). A further 15% (n=24) received between 51-65 short break days. In total 10 children were reported to have a higher allocation, seven of these between 81-90 days annually (data was missing for 18 cases in the sample). Those at the higher end of short break usage were much more likely to be male and in the older age range. In terms of impairment type, all those using the higher numbers of short breaks (66-80/81-90) had an intellectual disability which co-existed with ASD in all but one case.

Four young people (all aged 12+yrs, three males and one female) were reported to have exceeded the 90 day rule having in excess of 90 days of short breaks in a one year period. One of these young people breaching the 90 day rule had co-existing physical, intellectual and sensory impairments, and epilepsy. The remaining three young people were reported to present with co-existing ASD, severe intellectual disability and challenging behaviours. One of these three young people had also been in a single short break placement for more than 28 days. This young person was also reported to present with epilepsy and severe challenging, self-injurious behaviour.

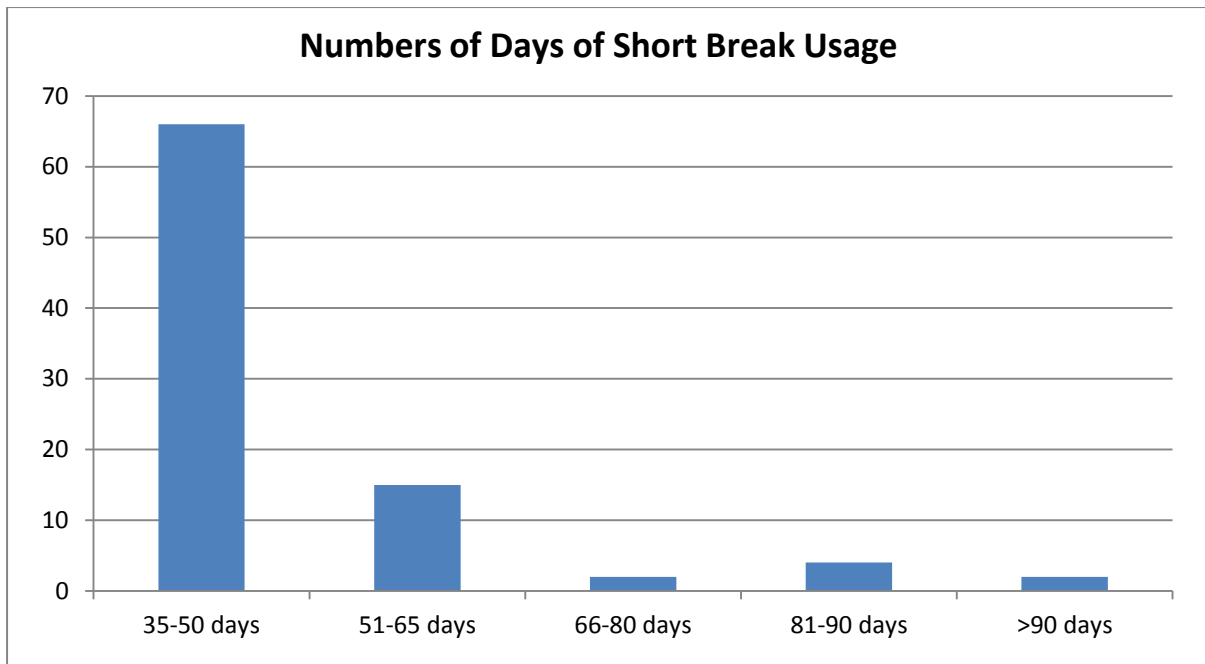


Figure 42. Number of days of short break usage.

The WHSCT offered the highest level of short breaks, with more availability in both the 35-50 day usage category (29% compared to 6-13% in other Trusts) and 51-65 day usage (7% compared to 1-3% in other Trusts). Within the NHSCT, SHSCT and SEHSCT slightly more children were accessing a higher number of short break days in the 66-80 days and 81-90 days groupings (see figure 43). Two children who exceeded 90 days short breaks were in the WHSCT, one in the SEHSCT and one in the NHSCT.

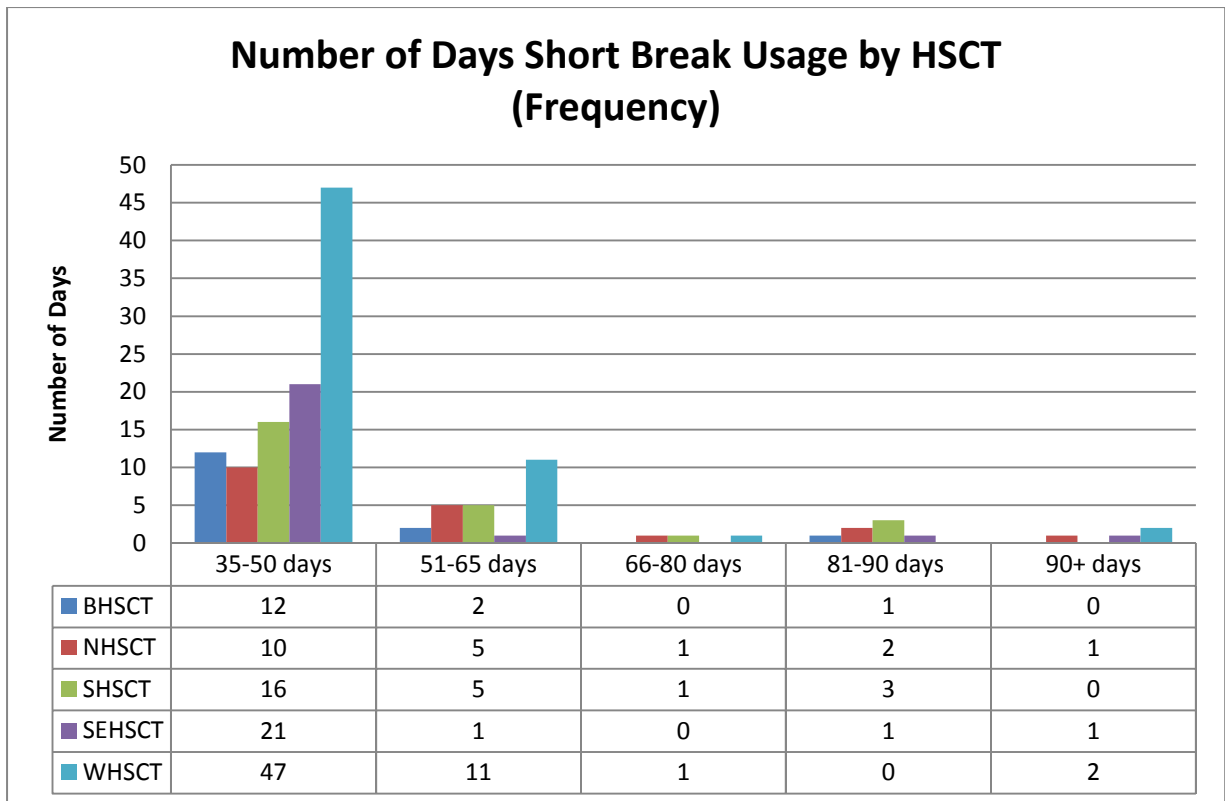


Figure 43. Number of days of short break usage in the five HSCTs.

## 5.1 Demographic Characteristics

All but one of the short break LAC sample (n=163) were reported to have an intellectual disability, often co-existing with other impairments. The one child without an intellectual disability was reported to have a physical disability co-existing with mental health need (see figure 44). Intellectual disability was the only sole impairment reported, others were reported to have intellectual disabilities co-existing with mental health needs (4%), ASD (26%) or both (4%). Almost half of the sample (47%) were in the multiple impairment group and all but one of these had multiple impairments (including combinations of mental health, ASD and physical/sensory impairments) co-existing with intellectual disability. The high percentage of multiple impairments is an indication of the complexity of need within the short break LAC group. Only one child was reported to have an assessed mental illness, an additional six were in receipt of Tier 3/4 CAMHS and none were receiving support through LAC therapeutic services, although 15% of the sample were reported to have a mental health need (co-existing with either intellectual disability/ASD or other multiple



impairments). Support for this group was, therefore, more likely to be accessed through learning disability psychiatry services than specialist mental health services.

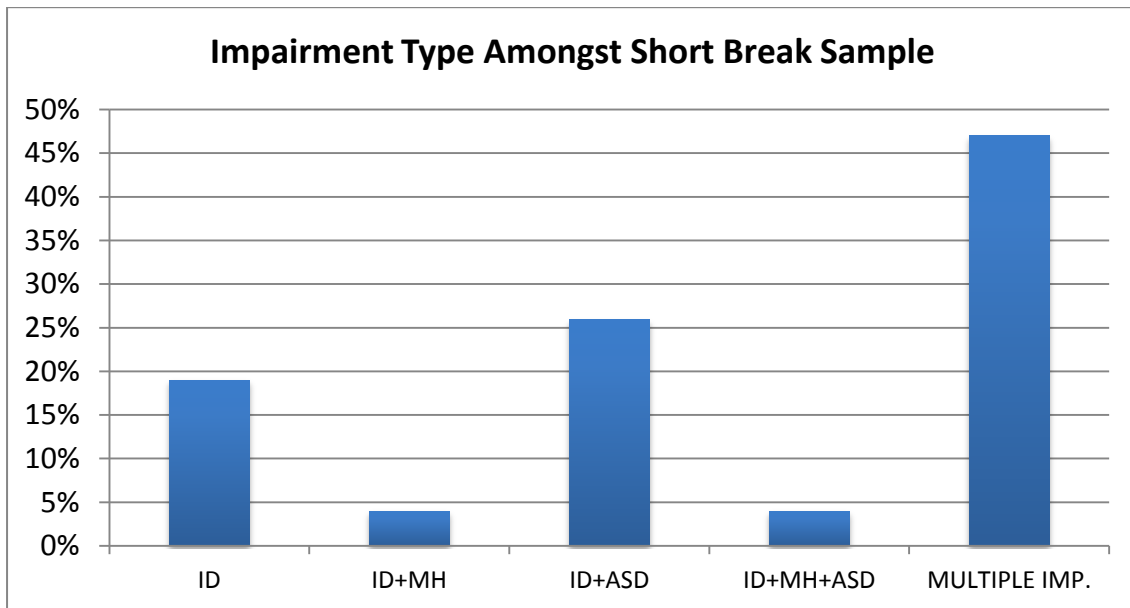


Figure 44. Impairment type amongst short break LAC.

Of the children and young people reported to have an intellectual disability, the majority (75%) were recorded having a 'severe' level of impairment, whilst just under a fifth (19%) were 'moderate' and just 4% 'mild'. There were 35 short break LAC reported to be wheelchair users, 34 of whom also had an intellectual disability. All of these wheelchair users were placed in residential short break settings rather than foster placements. A large majority, 94% of the short break sample (n=154) were reported to require assistance with personal care needs.

None of the short break LAC were in the youngest age category (0-4 years) and only 19% were aged between 5-11 years. There was a substantial increase in the 12-15 year age group who represented the highest proportion of short break users (45%), with slightly fewer in the 16+ age group (36%). Overall, 67% of the short break LAC were male and 33% were female. The highest numbers of short break users were males aged 12-15 years (28%) and males in the 16+ age group (25%).

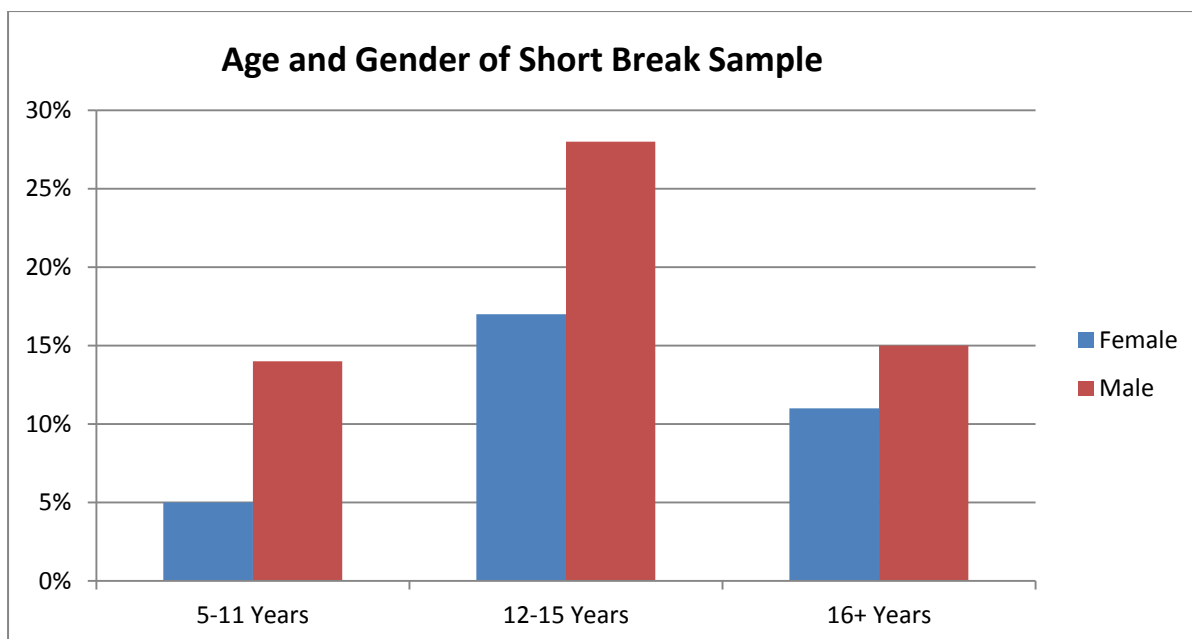


Figure 45. Age and gender of children and young people using short breaks.

Children from a Roman Catholic background represented a greater proportion (56%) of the short break LAC than those from a Protestant background (31%). This contrasts with the more balanced proportions of religious background of the fully disabled LAC (47% Protestant and 46% Roman Catholic), however, these figures are more aligned with those for the general LAC population (40% Protestant and 51% Roman Catholic) and the general child population in NI (49% Roman Catholic and 33% Protestant (NISRA, 2011)). The higher number of short break LAC from a Roman Catholic background also reflects Trust variance as there are higher numbers of short break users in the WHSCT where there are more children and young people from a Roman Catholic background in the general population (NISRA, 2011). No religious affiliation was indicated for 9% of the short break LAC sample, 1% Muslim and 6% 'other' religion (see figure 46). Reflecting the general population in NI (NISRA 2011), the majority (95%) of disabled children and young people using short breaks were white Northern Irish.

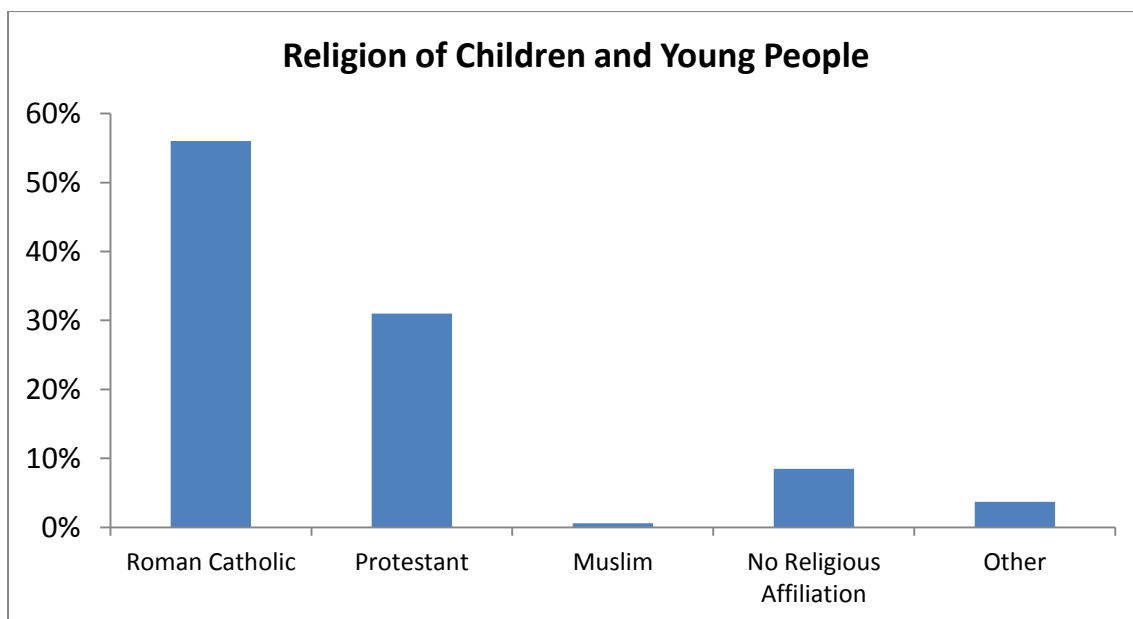


Figure 46. Religion of children and young people using short breaks.

## Summary

All but one of the children and young people in the sample of those looked after due to short break usage were reported to have an intellectual disability and for the majority this was categorised as severe. However, many of the short break LAC also had intellectual disability co-existing with another impairment (34%) or multiple impairments (47%), highlighting the complexity of need within the short break LAC group. There were 35 wheelchair users (all placed in residential short break settings) and a large majority (94%) required assistance with personal care needs.

The most commonly reported service accessed in response to mental health need was consultant psychiatry within learning disability services. Only six (4%) had access to CAMHS and none were receiving LAC therapeutic services. Around two thirds of the sample were male and most were in the older age ranges.

More than half of the short break LAC were from a Roman Catholic background (56%) compared with those from a Protestant background (31%), reflecting trends for the wider LAC population and general child population in NI (NISRA, 2011) and the higher number of short break LAC in the WHSCT where Roman Catholic children are more prevalent (NISRA, 2011).

## 5.2 Family Background

The majority of short break LAC came from a two parent family (61%), with 39% living in a single parent household. This is in contrast to the disabled fully LAC sample where almost two thirds came from a single parent household.

Within the short break LAC sample, only one mother was known to have a history of being in care and none of the fathers, however, it should be highlighted that this information was not known for 26 (16%) of mothers and 28 (17%) of fathers.

The vast majority of parents were reported to have no impairment (81% mothers, 73% fathers) (see figure 47). Nine mothers were reported to have an intellectual disability and five of mothers and fathers had a physical disability. The 'other' category highlighted for nine mothers and three fathers included physical health difficulties and terminal ill health.

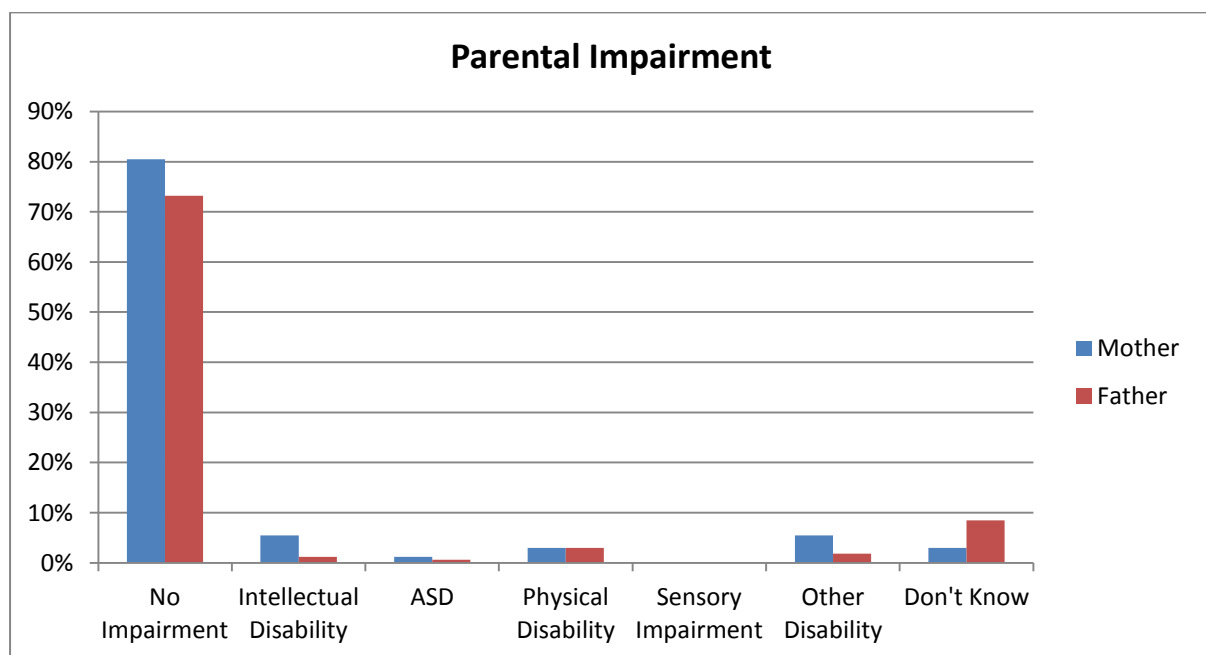


Figure 47. Parental impairment.

A total of 22% (n=36) of parents in the short break sample were reported to have mental health needs (although data was missing for 10% of cases and it is not known whether this figure related to mothers or fathers). Within this group, a quarter accessed a higher level of short break support, with eight accessing between 51-65 days and one availing of short breaks for between 81-90 days.

For the majority of the short break LAC sample, their siblings were not looked after (73%) and a further 12% children were only children (data on the LAC status of siblings was missing for two cases). Only 13% had siblings who were also looked after. Although our data does not directly report on impairment or short break usage for siblings, figure 48 shows that 10% of those with siblings used the same short break placement as their brother or sister and a further 3% had siblings who used alternative short break accommodation (indicating that at least one in ten of the short break LAC sample had siblings with a disability who also used short breaks).

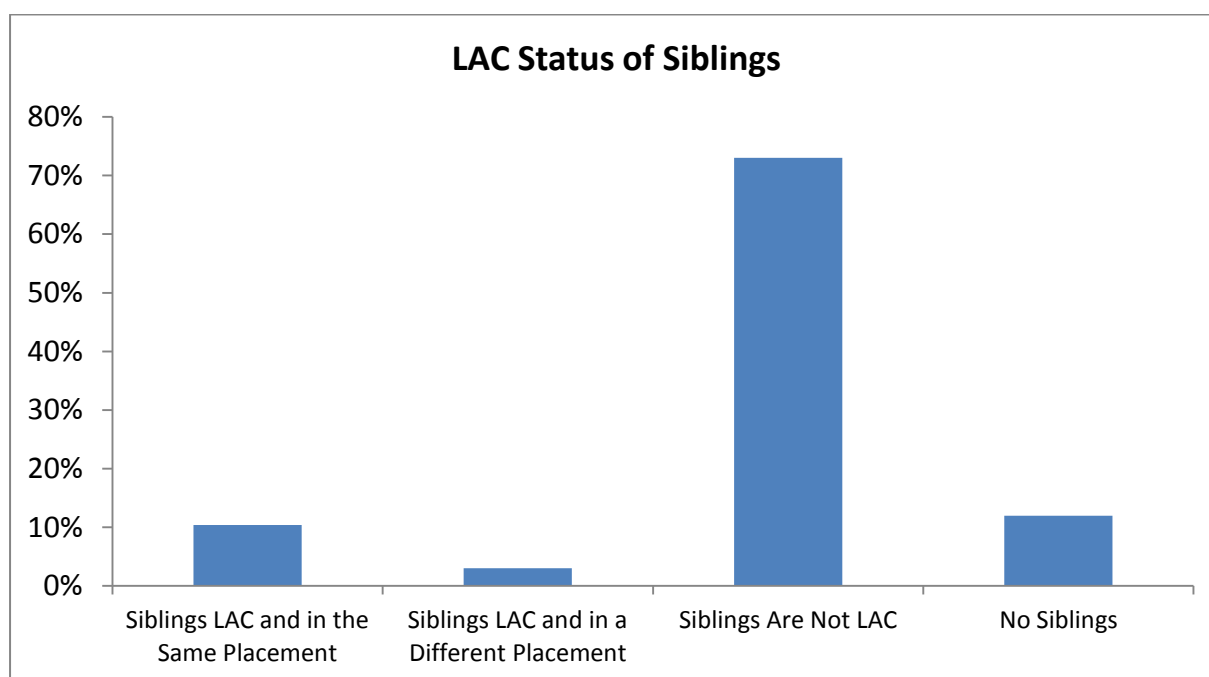


Figure 48. LAC status of siblings.

## Summary

More than half of the children and young people in the short break sample came from a two parent household with just over one third coming from a single parent household. This stands in contrast to those children and young people who were fully looked after who were more likely to come from a single parent household. Whilst few parents of short break LAC were identified as having an impairment, over one fifth (22%) of short break LAC had one parent (the primary carer) with a mental health need and the majority of these children and young people had more extensive short break usage (58% for 35-50 days and 22% for 51-65 days). Most siblings of

short break LAC were not looked after. For those siblings who also used short breaks, these were usually in the same short break placement.

### 5.3 Short Break Experience

A small number of the short break LAC sample (11%) had been using short breaks for less than one year, although only two of these were in the youngest age group. The majority (45%) had been using short breaks for more than five years, and the remaining 43% for between 1-5 years (see figure 49).

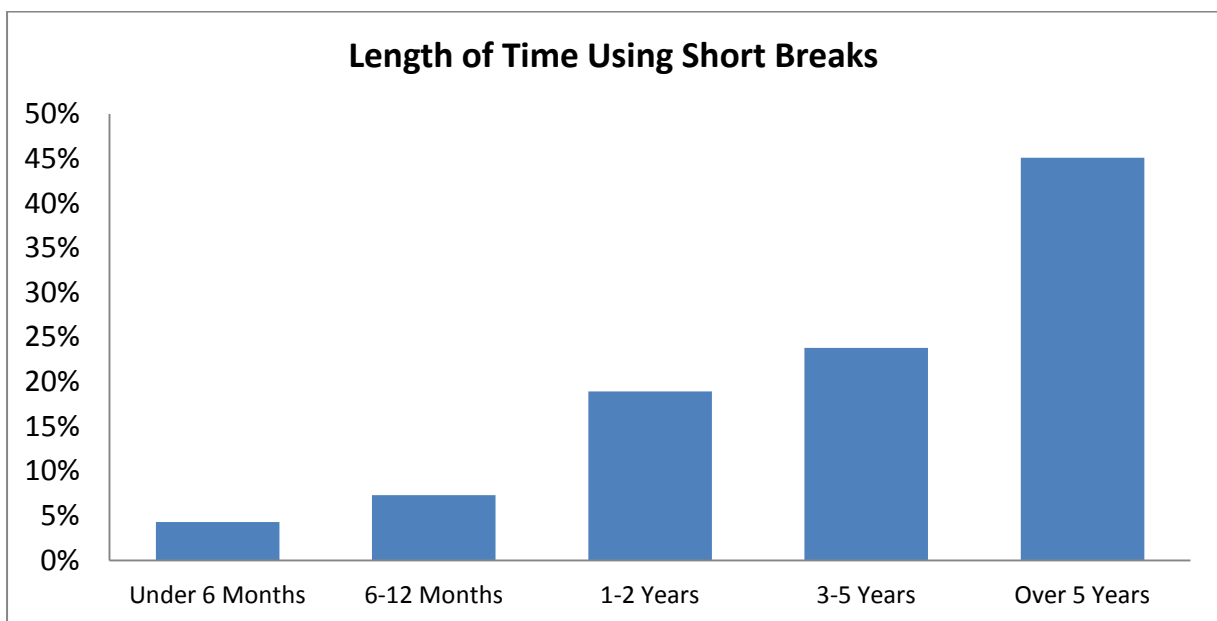


Figure 49. Length of time using short breaks.

The most common reason for short break usage was to provide a planned break for the carer (96%) (see figure 50). In 68% of cases the short break was also viewed as a social opportunity for the child. This stands in contrast to those who used short breaks in the disabled fully LAC sample where there was limited focus on the direct benefits to the child or young person. In a smaller number of cases in the short break LAC sample, short breaks were used in response to a crisis (9%, n=15) or to prevent the child becoming fully LAC (12%, n=20).

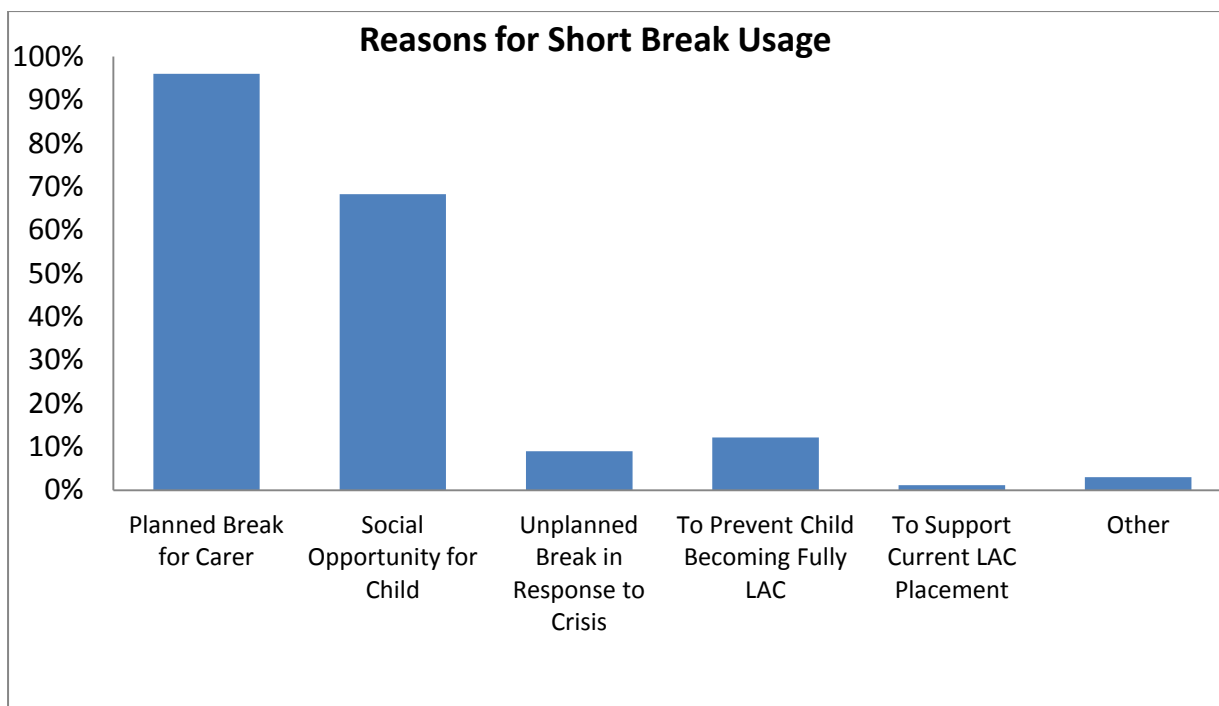


Figure 50. Reasons given for short break usage.

Of those accessing short break services to prevent the child becoming fully LAC, 65% were male and 35% female; the majority were in their teenage years (75%) with the remaining were in the 4-11 age group and the majority (75%) had siblings who were not LAC. Of these, 20 short break LAC, 40% had been subject to child protection case conferencing and registration prior to becoming short break LAC and 30% remaining subject to a child protection investigation whilst short break LAC (a quarter were still registered). None of these short break LAC had a single impairment type (60% with multiple impairments and 40% with co-existing intellectual disability and ASD). In terms of parental background, half of those accessing short break services to prevent the child becoming fully LAC were from a single parent household and seven had a parent with a mental health need. Overall, there no major differences in numbers of parents with mental health needs across single (47%) or two parent (53%) households. Few of those accessing short break services to prevent the child becoming fully LAC were at the highest reported incidence of short break usage (only two children were breaching the 90 day rule and one child using between 81-90 days). The majority (40%, n=8) used between 36-50 days, perhaps a reflection of service availability for those subject to child protection proceedings.

The large majority of short break LAC (92%) were placed in a specialist short break residential facility. Very few availed of foster placements as a short break placement which is in stark contrast to the disabled fully LAC group who were more likely to have short breaks with foster carers than residential settings.

On the whole short break placements were reported to be stable with 87% of short break LAC experiencing no placement changes (see figure 54). A relatively small group (10%) had experienced between one to two placement changes. These short break LAC were mostly aged 12+ years, were twice as likely to be male than female and either had an intellectual disability or co-existing intellectual disability and ASD (reflecting the configuration of the overall short break LAC). Only one child with multiple impairments had experienced instability in short break placement with over 10 changes.

## **Summary**

The population of short break LAC had significant experience of using short break services. More than half had been using short breaks for more than three years, with many of these exceeding five years of short break experience. Whilst the most commonly cited reason for short break usage was a planned break for the carer, for a substantial number it was also regarded as a social opportunity for the child. This was not the case for the disabled fully LAC where short breaks were provided to support carers. Short breaks were rarely used as a crisis response service. However, in 10% of cases they did prevent admission to full-time care. In contrast to the disabled fully LAC sample who used short breaks, the large majority of placements were specialist short break residential facilities, perhaps reflecting the lack of specialist foster care placements available to meet the more complex care needs of these children and young people. For the short break LAC sample, short break provision was a stable service with only 11% experiencing placement changes.



## 5.4 Safeguarding and Risk

In relation to safeguarding, 13% (n=22) of the short break LAC had been involved in a child protection investigation and subject of a child protection case conference prior to becoming looked after through short break usage with 9% (n=15) being on the child protection register (see figure 51). Although these are relatively small numbers overall, they do highlight some child protection concerns amongst this group. A slightly smaller number were involved in a child protection investigation (11%, n=19) and subject to a child protection case conference (8% / n=14) whilst they were short break LAC, with 6% placed on the child protection register (n=11) whilst looked after.

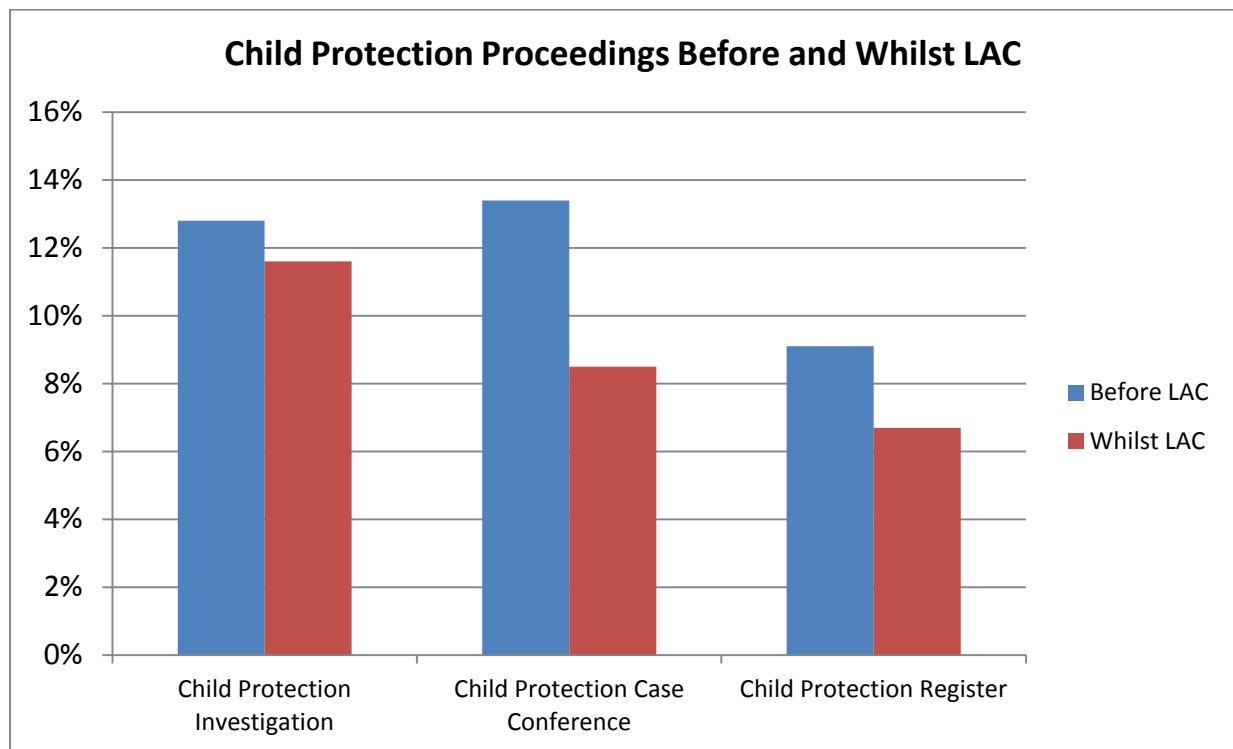


Figure 51. Child protection proceedings for short break sample before and whilst LAC.

Within the short break LAC sample, child protection proceedings were enacted twice as often for males than females. Those involved in child protection proceedings whilst looked after were more commonly in the teenage age ranges (12+ years), however those involved in proceedings prior to being looked after were in the younger age group (5-11 years). The majority of those in contact with child protection proceedings before becoming short break LAC had multiple impairments (46% of those subject to case conference and 53% of those registered), followed by co-

existing intellectual disability and ASD (32% of those subject to case conference and 27% of those registered) However, these two dominant impairment groups were more equally represented for those subject to child protection proceedings whilst looked after (43% of those subject to case conference and 46% of those registered had multiple impairments compared with 43% of those subject to case conference and 46% of those registered with co-existing intellectual disability and ASD).

Relatively low numbers were reported to be presenting with risky behaviours prompting service intervention (see figure 56). Six young people were reported to engaged in risky sexual behaviour and three were reported to be at 'other' risk, which was defined broadly as being vulnerable in the community. Only one young person had received a police caution and none had been convicted. This stands in contrast to the disabled fully LAC sample where risky behaviour was marked (almost a fifth had received a police caution and 11% had been convicted of a crime).

## **Summary**

Safeguarding procedures had been in place for a relatively small number of the short break sample, however, the decrease in child protection proceedings before and after becoming looked after is less marked than in the fully LAC sample. There is limited evidence of risky behaviour amongst the short break group and criminal cautions or convictions was extremely rare. High levels of surveillance of young people with intellectual disabilities or multiple impairments both in residential units and within their home and school life as well as limited opportunities for independence are likely to mediate against public misdemeanor or criminal activity. However, this level of surveillance may also undermine preparation for adult life and opportunities to develop independence skills which may be more needed in negotiating young adult life.

## **5.5 Education**

All of the children and young people in the short break sample had a Statement of Special Educational Need (SEN). The majority attended special school (94%) and

this was a stable school environment with only seven children changing school on one or two occasions. Those who changed school attended special schools or a unit within mainstream schools, with no placement changes amongst those in mainstream school in the short break sample.

## **Summary**

The majority of children and young people were reported to have a Statement of Special Educational Need and to attend a special school. For most, school provided a stable environment with only a small number experiencing minimal school changes. There was a very high level of school placement stability amongst the short break LAC sample, however, in contrast to the disabled fully LAC sample, mainstream school was found to offer the most stable school environment.

### **5.6 Additional Needs and Access to Services**

There were high levels of additional health needs for the short break LAC sample. Figure 52 shows the main types of additional needs which were particularly high in relation to speech and language disorders (60%) and challenging behaviour (57%). Epilepsy (29%), enuresis (29%), ADHD/ADD (21%) and encopresis (18%) were also reported to affect a significant number of short break LAC.

Smaller numbers (not on the graph below as numbers were less than 10% of the sample) of other health related needs were also reported. For example: stomach/digestive problems (9%); asthma (7%); dental problems (6%); eczema (6%); and acquired brain injury (4%). Overall, 7% (n=11) required high level medical intervention(e.g. tube fed).

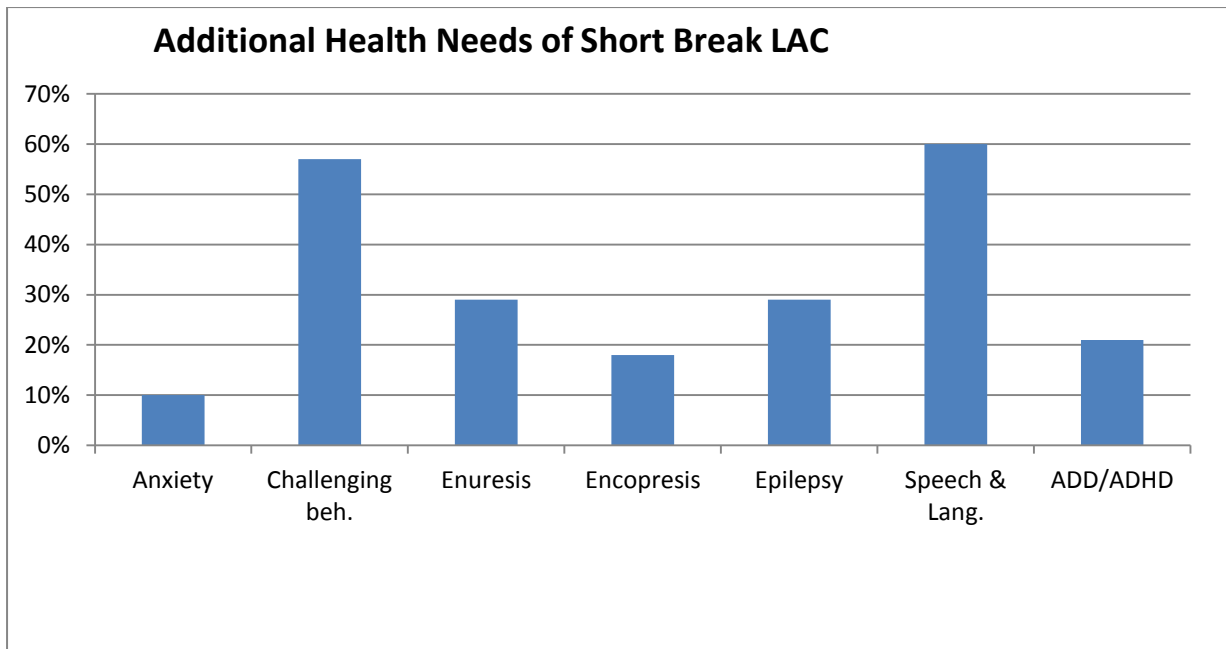


Figure 52. Additional health needs amongst short break LAC.

Figure 53 shows that the additional health needs reported for short break LAC were proportionally higher than those for the disabled fully LAC group in all areas apart from ADD/ADHD and anxiety. Challenging behaviour also featured highly amongst both groups (57% short break LAC; 53% disabled fully LAC). The complexity of the multiple needs of the short break LAC in comparison with the fully disabled LAC are evident with significantly higher numbers of short break LAC with speech and language disorders, enuresis, encopresis and epilepsy.

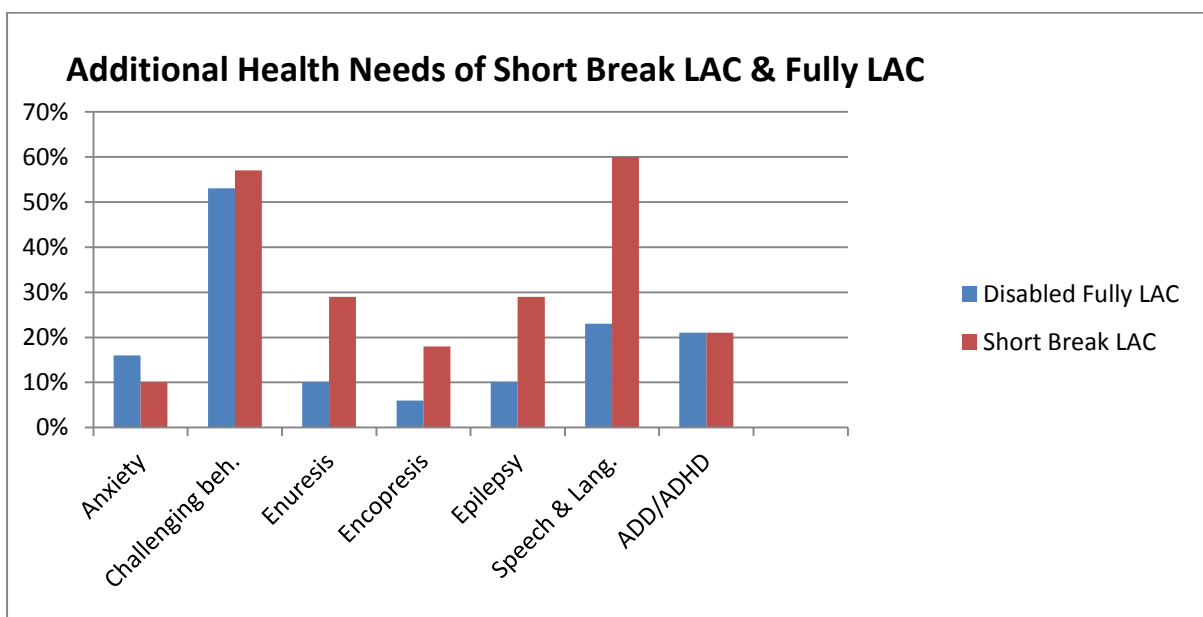


Figure 53. Comparison of additional health needs amongst short break LAC and disabled fully LAC.

Disabled children and young people who are routine users of short breaks were found to have a relatively higher level of additional support than those who are fully LAC, with the exceptions of access to a dentist and health visitor (see figure 54). Substantially higher numbers accessed a community paediatrician (73%, n=120), community nurse (49%, n=80) and a hospital specialist (37%, n=61). Speech and language therapy (58%), physiotherapy (37%) and occupational therapy (53%) are commonly delivered as part of special school activities, and this is likely to account for the high numbers accessing this kind of therapeutic input as a high proportion of this sample attended special schools.

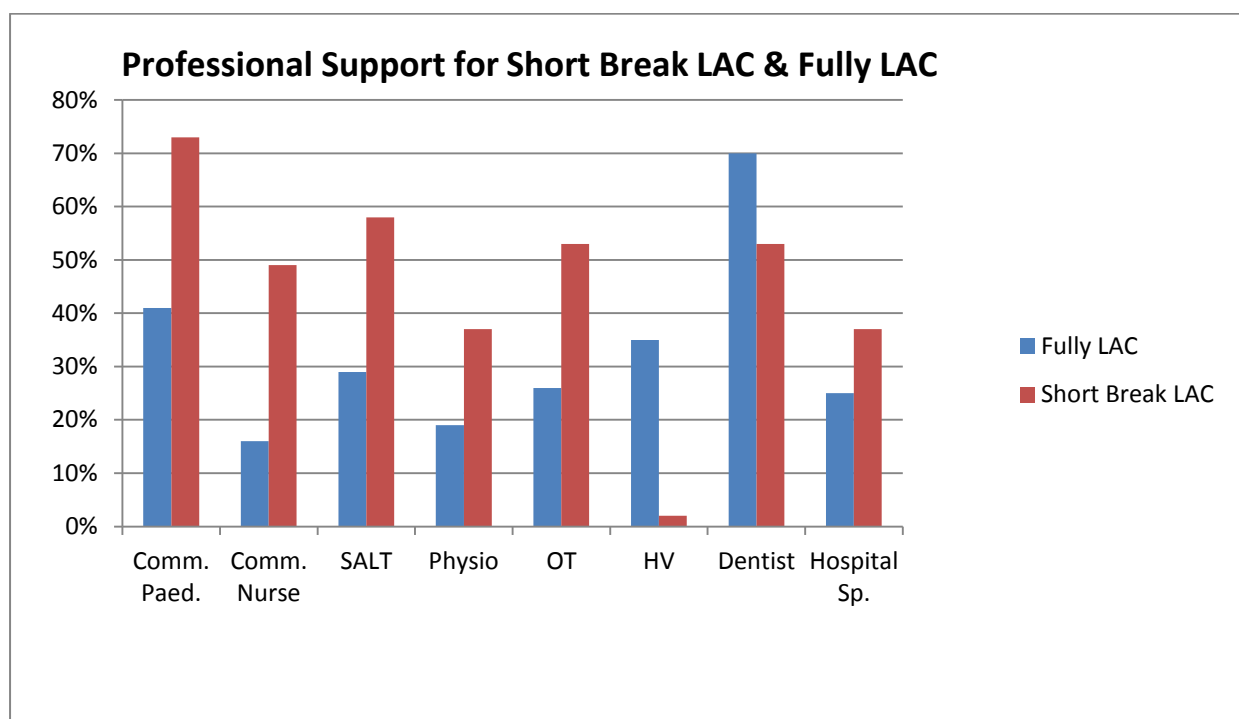


Figure 54. Additional professional support for short break LAC and disabled fully LAC.

Whilst low levels of access to an independent visitor (10%), independent advocate (10%) and Guardian ad Litem (14%) were reported for the fully disabled LAC population, none of the short break LAC sample accessed these services, with the exception of two young people (1%) who had an independent advocate.

Additional short break support (over and above that which is reported as the main short break service) was accessed by 18.3% (n=30) in the form of another short break service which in some instances was accessed through voluntary sector opportunities or arranged through direct payments and 21% (n=34) young people who received domiciliary support, which was also perceived as a short break.

Only 4% of short break LAC (n=6) accessed Tier 3/4 CAMHS and 18% accessed psychology services. In contrast, input from a psychiatrist was reported for 54% (n=88), mostly in relation to intellectual disability, ASD or multiple impairments rather than mental health needs.

Although 45% of short break LAC were aged 12-15 years and a further 36% were aged 16+, only 22% (n=36) had access to a transition co-ordinator. Almost three quarters (72%) of those accessing a transition co-ordinator were 16+, however, more than half of those aged 16+ (56%) and those aged 12-15 years (51%) did not have a transition co-ordinator. In addition, none of the short break LAC sample had access to a 16+ social worker, personal advisor or employment officer. Only two young people had a floating support worker. These findings highlight gaps in transition support for the short break LAC sample, perhaps reflecting barriers in access to leaving care services and expectations that their transitions from children's services and education would occur later than those in the fully disabled LAC sample.

## **5.7 Unmet Need**

Qualitative comments added to the survey by social workers on unmet need for this group fall into three main areas. Firstly, social workers reported on challenges in accessing appropriate support for children and young people with significant or complex impairments, often in addition to other health needs and challenging behaviours. Social workers reported that they were unable to access the numbers of days of short breaks they would recommend for particular children due to limited availability of services, particularly for those with higher level support needs. It was challenging for short break service providers to accommodate children and young people with more complex impairments due to the need for higher staffing ratios, the importance of matching children and young people using a unit at any given time, and the difficulties associated with settling into new environments for some young people. These factors combined may lead to those with the highest need actually receiving a more reduced service. In two cases social workers suggested a particular child or young person needed more than the possible 90 days of short breaks, but that a full-time LAC placement was unavailable.

Secondly, challenges in accessing support out of school for disabled children and young people was identified as a problem both in terms of after-school support and additional support during school holidays. This gap in provision was reported to be placing a strain on families and raising the risk of some children and young people being admitted to care on a longer-term basis. The lack of out-of-school supports could also put pressure on short break providers during the weekend or holiday periods.

Thirdly, social workers reported limited transition support for those in the short break LAC sample. In particular, social workers expressed concerns about the capacity of adult services to meet the needs of those disabled children and young people in the short break sample as they aged out of children's services.

## **Summary**

Relatively high levels of additional health needs were identified for the short break LAC sample, particularly speech and language disorders and challenging behaviours. Across most domains the levels of additional health needs exceeded those evident in the disabled fully LAC group, with ADD/ADHD and anxiety being the exceptions. Likewise, short break LAC accessed a higher level of additional support through a range of professionals, with the exception of dentistry, psychology and health visiting. Very low levels of access to mental health services were reported, however, 54% of the short break LAC sample had input from psychiatry, mainly from learning disability service sector. Almost a fifth of the short break LAC were also accessing additional short break support indicating that their families had access to support from a range of short break services.

Whilst a higher proportion of short break LAC had access to a transition coordinator (22% compared with 4% of disabled fully LAC), this figure remains low as 81% of the short break LAC were aged 12+ years (with more than a third aged 16+). In addition, none of the short break LAC sample had access to a 16+ social worker, personal advisor or employment officer. These findings indicate a lack of transition planning and support for short break LAC and may reflect barriers in access to leaving care services and/or slower transitions for the short break LAC sample. Similarly, there was a gap in independent advocacy and support for short break LAC.

Social workers highlighted the need for more short break provision for those with significant and complex impairments, including the need to extend the 90 day rule. In addition, social workers were concerned about the lack of out of school support for disabled children and their families and transition support for short break LAC.

## **5.8 Conclusion**

The following core themes are highlighted in relation to those disabled children and young people who are looked after due to short break usage:

1. There is considerable variation across HSCTs in relation to the numbers of accessing more than 35 days of short breaks annually which may likely to indicate differing levels of service availability across Trusts .
2. Whilst the most commonly cited reason for short break usage was a planned break for the carer, for a substantial number it was also regarded as a social opportunity for the child (in contrast to the disabled fully LAC sample).
3. In 10% of cases, short breaks were provided to prevent admission to full-time care.
4. It is notable that almost all of the children in the short break sample were identified as having an intellectual disability, with some also being recorded as having ASD, physical disability or a sensory impairment.
5. Very low levels of access to mental health services were reported, however, 54% of the short break LAC sample were accessing psychiatry support from learning disability services. It is possible that mental health need is not well recognised in this group because psychiatric learning disability services are already involved which may result in their exclusion from specialist mental health services.
6. High levels of additional health needs were identified for the short break LAC sample, particularly speech and language disorders and challenging behaviours.



7. Almost a fifth of the short break LAC were also accessing additional short break support indicating that their families had access to support from a range of short break services.
8. Males in their teenage years are more likely to access the higher end (>35 days annually) of short breaks than females.
9. In contrast to the disabled fully LAC sample, more than half of those in the short break sample came from a two parent household.
10. Whilst few parents of short break LAC were disabled, over one fifth had one parent with a mental health need and the majority of these had more extensive short break usage.
11. In contrast to the disabled fully LAC sample, the large majority of placements for short break LAC were in specialist residential facilities, reflecting the lack of specialist foster care placements available to meet the more complex care needs of these children and young people.
12. Child protection proceedings were in place for a relatively small number of the short break sample, however, the decrease in child protection proceedings before and after becoming looked after is less marked than in the disabled fully LAC sample.
13. A significant number did not have access to support with transition, even though a high proportion are in the older age range. Although classified as looked after children, those in the short break sample are not eligible for the range of leaving care services available for the fully LAC population. Social workers expressed concerns about how adult services will provide for the needs of these young people as they age out of children's services. Similarly, there was a gap in independent advocacy and support for short break LAC.
14. Short break placements and educational settings were typically characterised by stability for this group. More than half had been using short breaks for more than three years, with many of these exceeding five years of short break experience. Only 11% experienced placement changes.

15. There is limited evidence of risky behaviour amongst the short break group and criminal cautions or convictions were extremely rare, most likely reflecting high levels of surveillance experienced by those with intellectual disabilities.
16. Social workers highlighted a need for more short break provision for those with significant and complex impairments, including the need to extend the 90 day rule for some disabled children and young people.

## **6.0 Conclusion**

This report presents an analysis of the profile of the population of disabled looked after children and young people in NI across two distinct groups: 323 disabled fully LAC (living away from home on a full time basis) and 164 disabled children and young people looked after due to short break usage (35+ days / more than 28 consecutive days in one year). The total of 323 disabled fully LAC represents 11.2% of the total LAC population. Comparison of this figure with census data confirms that disabled children and young people continue to be over-represented in the LAC population in NI (7% of the general child population in NI being disabled).

Those who are fully LAC will have come into care because they cannot remain in their birth family home, often due to child protection concerns. In contrast, short break LAC are engaged with short breaks for family support reasons as well as a social and developmental opportunities for the child (although there are safeguarding issues for some). Unsurprisingly, then there are a number of notable differences in the findings for the two groups.

Almost all of the short break LAC sample had an intellectual disability, but some also had ASD, a physical/sensory impairment, alongside additional health needs. Almost half of the short break LAC sample had multiple impairments (including combinations of mental health, ASD and physical/sensory impairments) co-existing with intellectual disability. Whilst small numbers were reported to have co-existing mental health needs, a significant proportion of the sample accessed psychiatric learning disability services. This may indicate that the mental health needs of this group and their right to have equal access to specialist CAMHS are not well recognised.

In the fully LAC sample the two dominant impairment types were intellectual disability and mental health, followed by those with multiple impairments. Over one third (39%) were reported to have co-existing impairments. There was some variation in the prevalence of impairment types for LAC across Trusts, particularly ASD and physical/sensory impairments, which suggests a need to review processes for identifying and recording impairment type for LAC to ensure an accurate and consistent picture of the range of impairment related needs regionally.

Those with ASD and/or mental health needs were much more likely to have their impairments identified after becoming LAC. Almost three quarters of those with an assessed mental illness had this identified following their entry to care. Whilst proportionally less than in the fully LAC sample, it is notable that a relatively high number of the parents of children and young people who use short breaks are reported to have mental health needs.

In both the short break and fully LAC groups, males were more highly represented than females, however, this differential was more pronounced in the short break sample where males outnumbered females by 2:1. Gender proportions in both samples are in contrast to the general LAC population where there are only slightly more males than females. In the fully LAC group, the numbers of children and young people increases with age with the highest number being in the 16+ age group. Again this is in contrast to the general LAC population where numbers peak amongst 12-15 year olds and drop in the 16+ age group. The pattern in the general LAC population is mirrored amongst the short break sample where there are fewer young people in the 16+ age group to those in the 12-15 age group. In relation to religion, children in the short break sample mirrored the religious breakdown in the total LAC population and general NI childhood population with a higher representation of Catholics than Protestants. By contrast, in the fully LAC sample there were almost equal numbers of Catholic and Protestant children and young people.

In terms of safeguarding, a high proportion of the fully LAC sample were subject to child protection proceedings prior to becoming looked after, however, whilst they were in care there was a significant reduction in the numbers engaged in child protection proceedings. By comparison, in the short break sample, a relatively small proportion had been subject to child protection proceedings prior to being looked

after, however, there was only a very small reduction in the numbers engaged in child protection whilst looked after.

Those in the fully LAC sample are more likely than those in the short break LAC sample to experience instability both in terms of placement and educational setting. They are also more vulnerable to risk taking behaviour and more likely to have received a police caution or conviction. Proportionally, more of these children and young people have siblings who are also looked after and parents with mental health needs. Those who are fully LAC are most commonly placed in foster care, however, they are less likely to be living in kinship foster care or placed at home than the general LAC population. In comparison with the short break LAC, disabled fully LAC are reported to have less contact with professionals offering a range of support services. They are reported to experience some unmet need and this is particularly notable in relation to support with mental health needs or transition supports. Given the high numbers in the older age range, the very low numbers of fully LAC receiving support from a transition coordinator is concerning.

The reasons given for short break usage amongst those who are fully LAC were often related to breaks for the carer or support for the care placement, with short breaks being more rarely viewed as a social opportunity for the child or young person. In contrast, those in the short break sample are reported to access this service as a planned break for their parent or carer and also a social opportunity for themselves. Few of these children and young people reside in foster placements during their short break with most accessing specialist residential settings. For many, short break placements are stable as is their educational setting. Whilst short break LAC had more access to a transition coordinator compared with the fully LAC sample, concerns regarding unmet need for this group remained in relation to the transition planning and the capacity of adult services to meet their future needs.

In the fully LAC group there are differences in findings for children with differing impairment types. Those with mental health needs are more vulnerable in terms of placement disruption, school changes, risky behaviour and police cautions or convictions. Fully LAC with intellectual disabilities and mental health needs had low levels of access to CAMHS with a high proportion instead being supported through psychiatric learning disability services, rather than specialist mental health services.

## References

Baker, C. (2007) Disabled Children's Experience of Permanency in the Looked after System. *British Journal of Social Work*, 37, 1173-1188.

DHSSPSNI (2010) *Protecting Looked After Children*. Belfast: DHSSPSNI.

DHSSPSNI (2013) *Children's Social Care Statistics for Northern Ireland 2012/2013* Belfast: DHSSPSNI. Available at:

<http://www.dhsspsni.gov.uk/childrensocialcarestatisticsfornorthernireland201213.pdf> (accessed on: 09/04/14).

DHSSPSNI (2015) *Children in care in Northern Ireland 2013-14 Statistical Bulletin*. Belfast: DHSSPSNI.

Dowling, S., Kelly, B. & Winter, K. (2013) *Disabled Children and Young People who are Looked After: A Literature Review*. Belfast: OFMDFM and Queen's University Belfast. Available at: <http://www.ofmdfmi.gov.uk/index/equality-and-strategy/pfg-economics-statistics/equalityresearch.htm> (accessed on: 09/04/14).

Health and Social Care Board (HSCB) (2013) *Delegated Statutory Functions (Including Corporate Parenting Report) Statistical Report for September 2013*. Belfast: HSCB.

Kelly, B., Dowling, S. & Winter, K. (2013) *A Review of the Legislative and Policy Context in relation to Looked After Disabled Children and Young People in Northern Ireland*. Belfast: OFMDFM and Queen's University Belfast. Available at: <http://www.ofmdfmi.gov.uk/index/equality-and-strategy/pfg-economics-statistics/equalityresearch.htm> (accessed 09/04/14).

NISRA (2011) *Census 2011*. Data available at:

[http://www.ninis2.nisra.gov.uk/public/Theme.aspx?themeNumber=136&themeName=Census 2011](http://www.ninis2.nisra.gov.uk/public/Theme.aspx?themeNumber=136&themeName=Census%202011). Accessed on 24/7/15.

Stalker, K. & McArthur, K. (2012) Child Abuse, Child Protection and Disabled Children; A review of recent research. *Child Abuse Review*, 21, 24-40.

## Appendix 1: Survey to Profile Disabled LAC

### PRELIMINARY INFORMATION

Name of Trust	
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**Does this child meet the criteria for the study? Please select the statement which applies to this child/young person.**

- This child is looked after for reasons other than short break usage (fully LAC)
- This child is only looked after because of short break usage (if this option is selected please specify the extent of this child's short break usage in the table below):

No. of days in short break placement in the last year:		
Any placements exceeding 90 days? (please circle)	<b>Yes</b>	<b>No</b>
Any placements exceeding 28 consecutive days? (please circle)	<b>Yes</b>	<b>No</b>

Child/young person's disability (please tick all that apply and specify)				If multiple disabilities, tick one below to indicate main disability type
Disability Type	Please tick	Please specify name of disability/condition if known		
Learning disability		Mild	Moderate	Severe
Physical disability		Wheelchair user? Yes / No		
Sensory impairment				
ASD				
Other				

<b>Is the child/young person assessed as having a mental illness? (please circle)</b>	<b>Yes</b>	<b>No</b>
If yes, please provide further details (if known):		

Child/young person is awaiting /receiving mental health services (please tick all that apply and specify)		
Mental Health Service	Please tick	Please specify service related need
Tier 3 / 4 CAMHS		
Specialist Therapeutic LAC		
Other		

Was the child's disability/mental health need identified before or after they became LAC? (please circle)	Before LAC	After LAC
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Contact details		
Details of child's main field social worker who will complete the profile form	Name	
	Email	
	Phone	
	Name of SW team	
Please indicate other social work support provided for the child/young person (please tick all that apply)	LAC field SW	
	Placement SW (e.g. fostering SW)	
	Children's disability SW	
	16+ SW)	
	Other SW (please specify team)	

Child's SOSCARÉ Number		Child's Health and Social Care number	
Child's gender		Child's date of birth	

### CHILD AND BIRTH FAMILY BACKGROUND

<b>Q1. Please indicate child's birth parent household type:</b>	Two parent	<b>Q2. Do birth parents have a history of being LAC?</b>	Mother	Father
	Single parent			

<b>Q3. Do birth parents have a disability? If yes, please specify type (please tick relevant boxes)</b>							
	None	Learning disability	ASD	Physical disability	Sensory impairment	Don't know	Other (specify)
Mother							
Father							

<b>Q4. Do birth parents have mental health needs? (please circle)</b>	Yes	No
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<b>Q5. LAC status of siblings - please tick the statement which applies:</b>	
Sibling(s) are LAC & reside in same placement to child with disability/mental health need	<input type="checkbox"/>
Sibling(s) are LAC & reside in a different placement to child with disability/mental health need	<input type="checkbox"/>
Sibling(s) are not LAC	<input type="checkbox"/>
No siblings	<input type="checkbox"/>

<b>Q6a. Birth parent's country of birth</b>		<b>Q6b. Child/young person's country of birth</b>
Mother	Father	

<b>Q 7. Please tick all relevant boxes to indicate child's experience of the child protection system before becoming a LAC and whilst in care</b>	Before LAC	Whilst LAC
Has the child been subject to a child protection investigation?	<input type="checkbox"/>	<input type="checkbox"/>
Has the child been subject to a child protection case conference?	<input type="checkbox"/>	<input type="checkbox"/>
Has the child been named on the child protection register?	<input type="checkbox"/>	<input type="checkbox"/>

<b>Q8. Please indicate child/young person's religious background (please select one)</b>	<b>Q9. Please indicate child/young person's ethnicity (please select one)</b>
Roman Catholic	White Northern Irish, White other (please specify)
Protestant	Black Northern Irish, Caribbean, African or other
Hindu	Asian Northern Irish, Indian, Pakistani, Bangladeshi
Muslim	Chinese/Chinese Northern Irish
Sikh	Irish Traveller
Buddhist	Any other ethnic group (please specify)
Jewish	
No religious affiliation	
Other (please specify)	

<b>Q10. Is the child/young person a parent? (Please circle)</b>	Yes	Pregnant	No
<b>Q10a. Number of children?</b>		<b>Q10b. Living with parent? (Please circle)</b>	Yes No

## CHILD/YOUNG PERSON'S ADDITIONAL NEEDS

Q11. Please indicate which, if any, of the following conditions/disorders the child/young person has?					
<i>(please tick all that apply)</i>	<i>tick</i>		<i>tick</i>		<i>tick</i>
Acquired brain injury		Dental problems		Glue ear/ grommets	
ADD/ADHD		Diabetes		High level medical intervention (e.g. tube fed)	
Anxiety		Dyslexia		Kidney/urinary tract problems	
Asthma		Dyspraxia		Migraine/severe headaches	
Cancer		Eating disorder		Obesity	
Challenging behaviours		Eczema		Obsessive Compulsive Disorder	
Chest infection		Encopresis/soiling		Speech/language problems	
Chronic fatigue syndrome or ME		Enuresis		Stomach digestive problems	
Cystic fibrosis		Epilepsy		Other (specify)	

<b>Q12. Does the child require assistance with personal care / a high level of supervision?</b>	Yes		No	
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Q13. Please indicate if any of the following additional risks apply to the child (please tick all that apply)	Risk				Service Intervention		
	High	Medium	Low		Yes	Referred	No
Risky sexual behaviour (e.g. unprotected sex, exploitation)							
Attempted suicide							
Substance misuse							
Other (please specify)							

Q14. Police cautions or convictions	Yes	No	Before LAC	After LAC	Before & After LAC
Has the child received a police caution? If more than one, state total number:					
Has the child been convicted of a crime? If more than once, state total number:					

Q15. Does the child/young person have a Statement of Special Educational Needs? (Please circle)		Yes	No		
Q16. Please indicate type of educational/work setting young person currently attends:	Mainstream school	Q17. Please indicate if there have been significant school changes since child became LAC			
	Unit within mainstream school				
	Special school				
	Residential school				
	FE college			No school changes	
	Training centre			1-2 school changes	
	Supported employment			3-5 school changes	
	In FT/PT employment			6-9 school changes	
	Not in ed/training/employment			10+ school changes	
	Other (please specify)				



## FULLY LAC EXPERIENCE

The next 8 questions should ONLY be completed if child is fully LAC (for reasons other than short break usage.) If the child/young person is looked after only because they use short breaks, please move to Q28.

Q18. For how long has the child/young person been looked after?									
Under 6 months		6-12 months		1-2 years		3-5 years		Over 5 years	

Q19. Please indicate the child/young person's current LAC status			
Voluntarily accommodated		Interim Care Order	
Care Order		Juvenile Justice Order	
Police protection in Trust accommodation		Secure Accommodation Order	
Assessment Order		Other (please specify)	
Emergency Protection Order			

Q20. Please indicate the reason the child/young person became LAC (please select all that apply)			
Neglect		Parent(s) not coping	
Emotional abuse		Family illness/death	
Physical abuse		Child beyond parental control	
Sexual abuse		Other (please specify)	
Witnessing domestic violence			

Q21. Please indicate current LAC placement type			
At home with birth parent		Hospital	
Foster care (non-relative)		Residential school	
Foster care (kinship/relative)		Secure care	
Specialist foster care		Juvenile justice centre	
Children's residential home		Other (please specify)	
Specialist residential -NI/out of jurisdiction (please specify)			

Q22. Please indicate if there have been significant placement changes since the young person became looked after									
No changes		1-2 changes		3-5 changes		6-9 changes		10+ changes	

Q23. If there have been placement changes, please indicate previous LAC placement types (please select all that apply)			
At home with birth parent		Hospital	
Foster care (non-relative)		Residential school	
Foster care (kinship/relative)		Secure care	
Specialist foster care		Juvenile justice centre	
Children's residential home		Other (please specify)	
Specialist residential in NI or out of jurisdiction (please specify)			

Q24. Please indicate who the child has regular contact with and how often?								Q25. Have there been changes in contact since child is LAC?			
	Daily	Weekly	Monthly	Fortnightly	Biannually	Annually	Irregular		Less often	More often	Ceased
Mother											
Father											
Sibling(s)											
Grandparent											
Other (specify)											

<b>Q26. Is contact supervised?</b>	Yes		No		<b>Q27. Is contacted supported?</b>	Yes		No	
If yes please give reason:					If yes please give reason:				

### SHORT BREAK LAC EXPERIENCE

Please go to Q35. if the child does not use breaks. The next 5 questions should be completed if the child is:

- fully LAC and uses short breaks OR
- LAC solely due to short break usage (>35 days or >28 days consecutively in 1 year).

<b>Q28. Please select statement which applies to this child/young person</b>									
Child is fully LAC and uses short breaks									
Child is only LAC because of short break usage									
<b>Q29. How long has the child been LAC due to short break usage (either continuously or periodically)?</b>									
Under 6 months		6-12 months		1-2 years		3-5 years		Over 5 years	

<b>Q30. Please indicate reason for use of short breaks (please select all that apply)</b>				
<b>Q31. Please indicate the current short break type (please select all that apply)</b>		<b>Q32. Please complete one option below to describe regularity of short break usage</b>		
		No. nights per week	No. nights per month	Block usage - specify
Foster placement (kinship/relative)				No particular pattern
Foster placement (non-relative)				
Specialist foster placement				
Mainstream residential children's home				
Hospital				
Specialist residential placement				
Other (please specify)				

<b>Q34. If there have been placement changes, please indicate previous short break types (please select all that apply)</b>				
<b>Q31. Please indicate the current short break type (please select all that apply)</b>		<b>Q32. Please complete one option below to describe regularity of short break usage</b>		
		No. nights per week	No. nights per month	Block usage - specify
Foster placement (kinship/relative)				No particular pattern
Foster placement (non-relative)				
Specialist foster placement				
Mainstream residential children's home				
Hospital				
Specialist residential placement				
Other (please specify)				

### OTHER PROFESSIONAL SUPPORT

<b>Q35. Please select all that apply to indicate key professionals in the child/young person's life in the last 12 months</b>			
Community Paediatrician		Employment Officer	
Community Nurse		Independent Advocate	
Psychologist		Independent Visitor	
Psychiatrist		Personal Advisor (Leaving care)	

Respite Carer (other than short break service already described)		Hospital Specialist (e.g. audiologist, neurologist, heart specialist, ophthalmologist)	
Floating Support Worker		Guardian ad Litem	
Domiciliary Worker		Health Visitor	
Speech Therapist		Dentist	
Physiotherapist		Transition Coordinator	
Occupational Therapist		Other (please specify)	

**Q36. Please complete the table below to indicate this child/young person's unmet needs for interventions/services**

Please state intervention/service needed	Please state reason action not taken (e.g. service unavailable/waiting list/not eligible)

**Thank you - we greatly appreciate the time you have taken to complete this**