5 Year Survey of Need for Mental Health Inpatient Care for Children and Young People in Scotland with Learning Disability and/or Autism

Full Report

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5 Year Survey of Need for Mental Health Inpatient Care for Children and Young People in Scotland with Learning Disability and/or Autism: Full Report

Executive summary and Recommendations

Children and young people with learning disability have disproportionately high rates of mental health issues and behavioural difficulties, physical co-morbidities, adverse life events and poverty. It is estimated that between 4,121 and 12,362 children and young people with learning disability living in Scotland have mental ill-health, between 3,091 and 9,272 of who have persistent mental ill-health. They have been recognised to require improved access to community and inpatient mental health services.

There are no dedicated NHS mental health inpatient units in Scotland for children and young people with learning disability and/or autism spectrum disorder. While some are admitted to the 3 regional adolescent mental health inpatient units or the national unit for under 12s, this is not appropriate or possible for all.

The Scottish Government, NHS Scotland, Mental Welfare Commission and Kindred worked together to assess the need for specialist inpatient mental health beds in Scotland for this group.

Findings

Between 2010 and 2014 at least 45 children and young people with learning disability required specialist inpatient mental health care not available in Scotland. Instead they went to:

Scotland:

    - Adult Learning Disability wards (including secure units) 30%
    - Adult Mental Health units (including intensive care and secure units) 28%
    - Child and Adolescent Mental Health Units 16%
    - Not admitted 8%
    - Pediatric wards 5%
- Specialist units in England: 13%

Impacts

Average costs were upwards of £300,000 per patient per year.

Children and young people remained distressed and under-treated at home or in unsuitable units, sometimes with high use of sedative medication and restraint.

Families were highly stressed, managing severe self-injury, aggression and destructive behaviours in their children.

Some creative individual local solutions were found, but at a cost to the care of other patients.

Better clinical outcomes resulted from admission to specialist units in England, but distance led to dislocation from family and local services.

Recommendations

1. A bespoke national learning disability child and adolescent mental health inpatient unit, with 9 beds, located in Scotland. A more detailed specification is later in this Report.

- This will provide quicker, better planned, safer, more specialist holistic treatment closer to home, not a return to institutionalised care of the past.
- It is anticipated that average cost per admission per year will be less than for current unsatisfactory ad-hoc arrangements
- It will be for children and young people with more severe levels of learning disability, complexity and challenging behavior whose needs cannot be met on the existing Scottish child and adolescent inpatient mental health units
- The number of recommended beds assumes that adolescents with mild learning disability and/or autism spectrum disorder who need secure inpatient mental health care will be accommodated within the proposed Scottish secure/forensic adolescent mental health inpatient unit.

2. A national clinical network to support development of the unit and community services, linking with multiagency partners across Scotland.

3. Improvements in access to the four existing Scottish child and adolescent mental health inpatient units for children and young people with autism spectrum disorder and those with milder degrees of learning disability and less complex needs.

4. Additional training and support for staff at the four existing Scottish child and adolescent mental health inpatient units in order to improve outcomes for children and young people with autism spectrum disorder and those with milder degrees of learning disability who receive treatment in those units.

5. Development of the full range of community child and adolescent mental health services for children and young people with learning disability across Scotland.

6. Health and Social Care Partnerships to review community provision for children and young people with a learning disability and/or autism spectrum disorder in order to maximise appropriate use of a bespoke mental health inpatient unit and work with any new unit to ensure appropriate referral pathways and discharge planning.

7. Health and Social Care Partnerships and NHS Scotland must create clear pathways and commissioning arrangements to existing facilities, including those outwith Scotland.

8. NHS National Specialist Services Division should continue to ensure that pathways to specialist services in England are available for the occasions where an admission to a unit outwith Scotland would be more clinically appropriate.

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ABBREVIATIONS

ALD	Adult Learning Disability
AMH	Adult Mental Health
ASD	Autism spectrum disorder
CAMH	Child and Adolescent Mental Health
CAMHS	Child and Adolescent Mental Health Services
HB	Health Board
IP	Inpatient
IPCU	Intensive Psychiatric Care Unit
LD	Learning disability
MH	Mental health
NCPIPU	National Child Psychiatry Inpatient Unit
NES	NHS Education Scotland
NPF	National Planning Forum
NSD	National Specialist and Screening Services Directorate of NHS National Services Scotland
NSAG	National Services Advisory Group
NSSC	National Specialist Services Committee
YPU	Young People's Unit (adolescent mental health inpatient ward)

Note: 'intellectual disability' has been recently introduced as a diagnostic term to replace 'learning disability'. However, as most Scottish services over the time period of the survey used the term 'learning disability', that term has been retained for the purposes of this report.

1. INTRODUCTION

Children and young people with Learning Disability have disproportionately high rates of mental health and behavioural difficulties, physical co-morbidities, adverse life events and poverty. The need to improve their access to mental health services has been recognised over the last decade in Scotland. This inpatient needs assessment work forms part of the response to that need, alongside the 'LD CAMHS Models and Outcomes Study' which aimed to identify promising models of community service delivery (forthcoming).

There are no specialist mental health inpatient services for children and young people with learning disability in Scotland, many of whom are unable to access child and adolescent mental health inpatient units, of which there are 3 regional units for 12 to 18 year olds and one national unit for under-12s, in Scotland. Concerns have been raised about the impact of this situation on children and young people with learning disability, their families and the services which support them. Some children and young people with autism spectrum disorder but without learning disability have also reportedly had difficulties accessing appropriate mental health inpatient care. As the needs of these groups overlap, they were also included in the survey that underpins this work.

This report summarises and draws conclusions from data collected through survey and research work conducted over the period February to June 2015 with clinicians, families, carers, and NHS NSD in Scotland. It includes financial information and analysis. The work was led by Dr Susie Gibbs. The detail of the data and the methodology of the research are in the Appendices.

In order to give a contextualised picture of this assessment of mental health inpatient needs for children and young people in Scotland, this report begins by giving information on learning disability impact and prevalence in Scotland, mental health facilities for children and young people, problems of access to appropriate mental health facilities for children and young people with a learning disability, and an overview of policy developments.

1.1 Mental health of children and young people with learning disability

A learning disability is a significant, life-long condition with 3 components (Scottish Executive 2000):

1. A reduced ability to understand new or complex information or to learn new skills
2. A reduced ability to cope independently
3. Starts before adulthood with a lasting effect on the individual's development.

Estimates of prevalence of learning disability in the population vary. This population experiences high rates of physical and mental health co-morbidities, adverse life events and poverty (LD CAMHS Framework Document, Appendix A2.2), and a wide range of factors contribute to health inequalities experienced by this vulnerable group, who are at increased risk of exposure to all of the major categories of social determinants of poorer physical and mental health (Public Health England, 2015).

A recent international review (Munir, 2016) concluded that the prevalence of learning disability in children and young people is around

1-3%, with prevalence of co-occurring mental ill-health being around 40%, and persistent mental ill-health around 30%. Based on the National Records of Scotland mid-2014 population estimate (www.nrscotland.gov.uk) that there were 1,030,183 children and young people aged 0-17 in Scotland, there are likely to be between 10,302 and 30,905 children and young people aged under 18 years who have a learning disability. Therefore, it can be estimated that between 4,121 and 12,362 children and young people in Scotland have learning disability and mental ill-health, between 3,091 and 9,272 of whom have persistent mental ill-health.

It has also been estimated that these high rates of mental ill-health in children and young people with learning disability mean that this group accounts for 14% of the total child and adolescent psychiatric morbidity in Britain (Emerson et al, 2007).

1.2 Current access to mental health inpatient care

It is important to be clear that hospital admission for mental health problems can be required by any child or young person, with or without learning disability and/or autism spectrum disorder. In this context, admission is for mental health assessment and treatment, followed by discharge, not for long-term institutional care.

There are 3 regional Young People's Units (YPUs) in Scotland, providing mental health inpatient assessment and treatment for adolescents aged 12 and over. These are in Glasgow, Edinburgh and Dundee and collectively serve the whole of Scotland. Caledonia Ward at the Royal Hospital for Sick Children in Glasgow was the National Child Psychiatry Inpatient Unit (NCPIPU) (predominantly for under 12s) at the time of the survey. This has since moved to become Ward 4 at the Royal Hospital

for Children at Queen Elizabeth Hospital. While these four units will admit some children or young people with learning disability and/or autism spectrum disorder, *specialist* learning disability and autism spectrum disorder children and young people's mental health inpatient units do not exist in Scotland. Children and young people with learning disability and/or autism spectrum disorder have been admitted to NHS and private mental health units in England, most commonly to those run by Northumberland, Tyne and Wear NHS Foundation Trust, and St Andrew's Healthcare in Northampton. An overview of inpatient provision in the UK for children and young people with learning disability is available (Lovell, 2011, currently being updated).

A 'snapshot' of numbers of children and young people aged under 18 with learning disability and/or autism spectrum disorder in mental health or learning disability inpatient beds in Scotland was available from the Scottish Government's Mental Health and Learning Disability Inpatient Bed Census carried out on 29 October 2014 (Scottish Government, 2015). Out of 50 children and young people aged under 18 in hospital on the day of the census, 12 had diagnoses of learning disability and/or autism spectrum disorder. Due to restrictions on data about small numbers of patients, further breakdown of which kinds of wards these children and young people were on is not available for publication. In England, a census of inpatients with learning disability found 165 (6%) were aged under 18 (Health and Social Care Information Centre 2015).

Clinicians working in the field face considerable difficulties in finding appropriate mental health inpatient facilities for children and young people with learning disability when required. Anecdotally, this has been particularly for those with co-morbid autism spectrum disorder and challenging behaviour and for those with more severe levels of learning

disability. Numbers for individual clinicians have been relatively small, but the complexity/severity of the child or young person's difficulties and lack of appropriate services have led to some extremely time-consuming and expensive outcomes. Concern has been raised about negative experiences for patients and their families and also the impact on local services as clinicians attempt to 'cobble together' arrangements for individuals.

A number of children and young people have been admitted, often for long periods, to adult learning disability hospitals in Scotland or to NHS or private LD CAMH inpatient units in England. Regular funding of NHS admissions in England by NHS National Services Scotland and the linking of clinicians in the LD CAMHS Scotland Network has allowed the recognition that these situations are not 'one-off' but have been happening regularly to children and young people with learning disability from across Scotland. The present work resulted from this growing recognition of need, precipitated by a situation in 2014 when changes in NHS England commissioning arrangements further reduced access to specialist beds in England.

1.3 Background to policy development for specialist mental health inpatient provision for children and young people with learning disability

Children with learning disability used to be routinely admitted to institutional care in 'mental handicap' hospitals. Numbers reduced during the 1970s and 1980s and continued during the hospital closure programme to de-institutionalise care for people of all ages with learning disability that began in the early 1990s (Scottish Consortium for Learning Disability, 2014). However, specific plans were not made for children and

young people requiring hospital assessment and treatment of mental health/behavioural problems after hospital closure programmes.

Problems of access to in-patient mental health provision in Scotland for children and young people with more severe levels of learning disability and the most complex difficulties has been recognised for some time. The last published policy document relating to mental health inpatient services for children and young people (Scottish Executive, 2004) specifically excluded those with learning disability from its remit, despite recognition that the specific expertise and environment required to meet their needs was generally unavailable in Scottish mental health inpatient units. A paper was later produced by the LD CAMHS Scotland Network and the National Inpatient Forum giving guidance to staff in young people's mental health inpatient units on the management of young people with learning disability (Appendix A2.1).

There was recognition by the Scottish Government in the mid-2000s of a lack of access to appropriate mental health services in general for children and young people with learning disability. Very different commitment and service responses were noted across the country, with a patchy and often isolated workforce. A Government-funded conference in Perth in 2008 – 'Better Health – Better Care: Delivering Better Mental Health Services for Children with a Learning Disability' brought together clinicians from across Scotland to look at epidemiology, begin mapping services, share clinical experience and network. This led to the development of the LD CAMHS Scotland Network, a multidisciplinary network of now over 190 clinicians from all Health Boards and relevant disciplines. This network collaborated with the Scottish Government Mental Health Division to produce the LD CAMHS Framework Document (Appendix A2.2), which gives guidance on how to implement the CAMHS

Framework (Scottish Executive 2005) to improve the mental health of children and young people with learning disability. This document gives further relevant background information on the needs of this patient group, with reference to UK-wide reports, guidance and standards as well as initial mapping of Scottish services.

An action plan was then developed to support the development of appropriate services. This was overseen by the Government CAMHS Implementation Monitoring and Support Group, in collaboration with the LD CAMHS Network, Health Boards, National In-patient Forum, and NES (NHS Education Scotland). Key points in the action plan included the need to:

1. Gather more information
    a. via service and workforce mapping
    b. on access to mental health services
    c. on which service models work effectively
2. Develop the workforce via training, an LD CAMHS Network website and by further developing Network meetings
3. Develop links/embed in wider multiagency work-streams (regionally/nationally)

Full detail can be found in the document 'Improving Access to Mental Health Services for Children and Young People with Learning Disability in Scotland – June 21, 2011 – Action Plan and Report' at: http://www.gov.scot/Topics/Health/Services/Mental-Health/Strategy/Child-Adolescent-Services

Through this work there was recognition of the need to improve access for children and young people with learning disability to mental health provision across all the 'tiers' of CAMHS service, i.e. universal services, uni-professional targeted services, multidisciplinary specialist community teams, intensive community treatment, and inpatient services. The initial focus was on community services and a commitment was made in the Scottish Government Mental Health Strategy 2012-2015: *'We will work with clinicians in Scotland to identify good models of Learning Disability (LD) Child and Adolescent Mental Health Services (CAMHS) service delivery in use in different areas of Scotland or other parts of the UK which could become, or lead to, prototypes for future testing and evaluation'.*

http://www.gov.scot/Topics/Health/Services/Mental-Health/Strategy/Child-Adolescent-Services/C10

As a result, the Scottish Government Mental Health Division funded Glasgow University, in collaboration with the LD CAMHS Scotland Network, to carry out the 'LD CAMHS Models and Outcomes Study' in order to deliver on this commitment. An initial paper reviewed research on the experiences of service users and providers (Jacobs et al, 2015). Reports from the Models and Outcomes study, which focused on community LD CAMHS are being finalised. They will complement this report, which focuses on specialist mental health inpatient services.

As this needs assessment goes to press, a report commissioned by the English Department of Health has been published by the Council for Disabled Children – 'These are our children' (Lenehan, 2017). Lenehan's report is highly relevant to the children and young people described in this needs assessment, setting inpatient provision in the context of wider multiagency services and strategy.

1.4 Focus of this work

The focus of this work is on the need for inpatient mental health services for children and young people with learning disability (who also often have autism spectrum disorder) in Scotland. However, there is also recognition that some children who have autism spectrum disorder but no Learning Disability have difficulty accessing inpatient services. As there appears be an overlap, information on this group was also sought.

1.5 Potential impact of this work

Along with the LD CAMHS Models and Outcomes Study, this study will provide an important evidence-base for developing appropriate services across community and inpatient settings. As well as information from clinicians and NHS managers, it was equally important to establish the views of parents in order to inform proposals for changing services. Families have expressed many concerns about the current provision, but the short and long-term impact on them and their children is not fully understood.

The themes uncovered during this work also link to national concerns about people with learning disability having long admissions to out-of-area health and social care placements; these concerns are heightened by reports of poor or abusive care (DOH, 2013). The findings from this work can helpfully inform recommendation 51 of 'The Keys to Life: Improving quality of life for people with learning disabilities' (Scottish Government, 2013), which is establishing data on out of area placements and making recommendations on how people with learning disability can be supported to live nearer their family in Scotland.

2. AIMS AND OBJECTIVES

The primary aim of the survey was to ascertain the need for specialist mental health inpatient provision for children and young people under age 18 with learning disability and/or autism spectrum disorder in Scotland. To do this, the survey aimed to gather comprehensive information over a 5 year period (2010-2014 inclusive) on service usage and parent and clinician experience and opinion. This included:

a) Demographic and clinical characteristics of children and young people with learning disability and/or autism spectrum disorder in Scotland who have either had a mental health admission in the 5 year period, or who have required one but have not been able to access it.

b) The nature of inpatient or alternative arrangements that have been made for these patients.

c) The outcomes and impacts of the various arrangements that have been made on children, young people, their families and local services.

d) The financial cost of the inpatient admissions or alternative arrangements.

The survey results were intended to inform recommendations for future mental health inpatient provision for this group of children and young people. This report summarises the analysis and findings from the survey, and makes recommendations.

3. METHOD

Information was sought on patients meeting the following inclusion criteria:

1. Aged under 18 years
2. Diagnosis of learning disability and/or autism spectrum disorder
3. During years 2010 – 2014 (inclusive) had one or more of the following:

    (a) An admission to a hospital facility of any kind for mental health/behavioural reasons.

    (b) An admission to a non-hospital facility of any kind for mental health/behavioural reasons, where ideally a mental health inpatient admission was required.

    (c) Remained at home/usual place of residence, where ideally a mental health inpatient admission was required.

Questionnaires were distributed to clinicians across Scotland and followed up with interviews (mostly by telephone) to fill in any gaps and gather qualitative information and opinion. Clinicians were asked to send on questionnaires to families of the children and young people affected. Families who responded were also offered interviews regarding their experiences by an independent family support service. Further details on methodology, including the questionnaire and interview crib sheets, are in the appendices (section A3).

4. RESULTS AND DISCUSSION

The results and discussion sections are combined in this report, to aid the flow for the reader in following the complex quantitative and qualitative data and issues. Response rates are presented and explored first, including possible reasons for variation between Health Boards. Demographic and clinical information is presented next. Then the report weaves a route through the need for a mental health inpatient admission, pathways into the admission, where the patient was actually admitted to (if at all), issues during an admission and pathways out of hospital. The impact of the current situation on children, young people, families and services is reported and discussed. The numbers and profiles are given of patients requiring specialist mental health inpatient care not presently available in Scotland. Finally, other findings from the study, such as information on community LD CAMH services, are noted.

More detail on the quantitative results are included in the appendices (section A4), which contain much rich qualitative data, illustrating the experiences of children and young people, their families and professionals. Graphs and tables contained in the appendices also present more detail on the quantitative results reported in the main part of the report.

4.1 Responses from clinicians

153 questionnaires were returned by 43 clinicians from 13 out of the 14 territorial Health Boards in Scotland, relating to 84 individual patients who were admitted to hospital on 1 or more occasions. This represented 106 overall periods of inpatient care, 32 transfers within admissions, 8 situations where patients requiring hospital admission stayed at home/usual place of residence and 7 where they went to a non-hospital

placement. Steady numbers of admissions were reported on from 2012-2014, but less for 2010-2011. Interviews with 37 of the 43 clinicians from a range of professional backgrounds and from all Health Boards that submitted questionnaires took place between March and May 2015.

The high number of responses to this survey from senior clinicians from a variety of child and adult services across Scotland (see appendices, section A4.1.2 (i) for detail) pointed to the research addressing an important issue for their patients. Clinicians reported lack of access to inpatient services for children and young people with learning disability (and for some with autism spectrum disorder but no learning disability) as being a longstanding issue, well before the study period. Excepting for the limited number of LD CAMHS specialist psychiatrists, numbers affected on individual clinician's caseload were small. However, the impact of the lack of inpatient care on children and young people, their families and local services was considered highly significant. The vast majority of those submitting questionnaires also gave considerable time to telephone interviews which added depth and insight into the situations outlined in the questionnaires. They were keen to see services develop to better meet the need of this patient group and their families and contributed valuable opinions and ideas as to how this could be done.

It was clear that the considerable difficulties experienced by many of the children and families described by clinicians had made a big impression on clinicians themselves. For example, one Consultant CAMHS Psychiatrist commented that these are the kind of patients and situations that Psychiatrists wake up in the night thinking about, even years later. Others said that their patient's situation was the most difficult and stressful they had ever had to manage.

4.2 Possible under-reporting

4.2.1 Practical difficulties in identifying historical admissions

Despite the apparent high number of responses received, participating clinicians were concerned that the study would not uncover the full extent of need. Under-developed IT recording systems and a lack of management and strategic oversight of services for this patient group were common issues. Clinicians mostly had to identify patients for inclusion from memory and manually 'trawling' through diaries. Where there are no learning disability CAMHS or autism spectrum disorder teams or teams are small, movement of 1 or 2 clinicians away from services severely affected ability to identify cases. Even having 1 key clinician on leave at the time of the survey may have meant that important cases were not highlighted. It is therefore not surprising that greater numbers were included from the last 3 years of the time period covered by the survey compared with the first 2 years.

4.2.2 Children and young people with autism but without learning disability

Only a small minority of clinicians submitted questionnaires for all of their patients with autism spectrum disorder but no learning disability meeting study criteria. Most only reported on these where they considered that more specialist care was required (usually due to forensic concerns/need for security). This impression was backed up by additional statistical data provided by 2 of the Scottish CAMH inpatient units on the diagnoses of children and young people admitted over the study period. For example, the National Child Psychiatry Inpatient Unit had a total of 37 patients with diagnoses of learning disability and/or autism spectrum disorder over the 5 year period, and Skye House (West of Scotland YPU)

36, many more than picked up by the study. Less than 5 of these in each case had learning disability diagnoses and this is more consistent with study figures.

4.2.3 Difficulties in identifying mental health issues and need for admission

Clinicians get used to having an exceedingly high threshold for admitting patients when there is no suitable unit and try to avoid admission by trying to manage in the community. Most clinicians have not themselves been to or experienced the outcomes of specialist LD CAMH units so may not be aware of when a patient would benefit from admission. Where there are no specialist LD CAMH community services, mental health elements to behavioural presentations may not be recognized at all. Children and young people can therefore move up increasing levels of restrictive and secure care and school settings with their mental health needs unaddressed.

In this study Health Boards without an LD CAMH service tended to report relatively more admissions for those with autism spectrum disorder but no learning disability, who often did not require specialist inpatient services. They were less likely to report admissions/need for admission for those with learning disability. A lack of community LD CAMH expertise may mean they were not working with and identifying the need amongst those with learning disability, particularly of more severe levels.

4.2.4 Other evidence of under-reporting

A number of clinicians identified patients for the survey but were not able to gather information and submit forms in the timescale required. Forms were received too late for inclusion in the analysis for 7 admissions relating to 4 individual patients. These were all looked after and

accommodated children, with mild or moderate learning disability, aged 14-15, one of whom also had autism spectrum disorder. They all had additional major mental illness, severe behavioural problems, significant background issues of deprivation and/or neglect and had been charged with serious crimes. 3 had been admitted to adult IPCUs (Intensive Psychiatric Care Units) or adult low secure wards. All ideally required low or medium security on LD CAMH or 'mainstream' secure adolescent wards and required 2:1 or 3:1 nursing care. Only 1 received such care in a hospital in England. They were all in hospital for lengthy periods, up to 6 years, and 3 remained in hospital, including in adult forensic wards at the end of the study period. This indicates that there may be significant cases missed from the study and this needs to be taken into account when estimating the level of need for specialist beds and the interface with the proposed forensic CAMH unit.

Information on admissions to pediatric wards for mental health/behavioural reasons was submitted from very few Health Boards; therefore this number is also likely to be an underestimate.

4.3 Responses from families and carers

17 questionnaires were received from families/carers, describing 18 admissions/ parts of admission for 10 children and young people. Despite relatively small numbers, demographic and diagnostic characteristics broadly matched those of the patients described by clinician questionnaires and the children and young people were admitted to a similar range of units and usually had long waits for admission. Themes from parent/carer interviews were strikingly similar to those from clinician interviews and these experiences were incorporated into the relevant qualitative results sections. Important additional

perspectives were gained and are given in section A4.17 of the appendices.

Overall, staff understanding of children and young people's needs was reported as being variable, and with clear room for improvement. Some good outcomes were described, but also significant difficulties and negative impact on children and young people's emotional well-being. Distance from home was a major issue for families who had to travel significant distances to visit their child (up to 8 hours).

Recruitment from families was more limited compared to that from clinicians. Recruitment relied on clinicians passing on questionnaires to families and this may have been thought to be inappropriate in some cases. For example, where they had lost contact with the family and were not sure of their circumstances, or where the children and young people were looked after by the Local Authority. It was clear from the information provided by those who did complete and return questionnaires that many parents remained in the midst of circumstances relating to their child's mental health. A number had been deeply affected by their child's difficulties and their journey through services. Therefore participating in the study may have been too difficult emotionally or time-wise for a number of other families.

Good service is what is expected and by virtue of things working well people move on. Generally speaking, people give feedback because they are unhappy or particularly pleased with some aspect of a service. Not surprisingly therefore, approximately 90% of those who selected themselves to be interviewed wished to do so to report on their "*negative and difficult experiences*". However, when talking about mental health services the importance of emotion must be acknowledged as a particular factor in people's understanding and perception of their

experiences. When considering parental experience of their child's health the impact of this factor is further amplified. Parental understanding of their role as protector, care-giver, provider and problem-solver is hugely compromised by what is happening to their child and by the need for the involvement of professionals and agencies (Beresford B, Rabiee N & Sloper P, 2007).

The emotional impact on families of caring for a child with disability should not be underestimated. Added to that, the onset and diagnosis of mental ill health can be, as one parent reported it, *"both devastating and frightening, we were thrown into the unknown and remain there even now".* All the parents interviewed were in varying states of 'rawness'. They reported the experiences they had as *"traumatic"*, some were able to describe particular aspects of the process quite clearly but others were hazier in their descriptions and timelines. Most parents described a strong sense of *"isolation and separation, including from other parents of kids with autism".* All of this was likely to have impacted on their experience of services and their reporting of it.

In addition to the evidence gained directly from the survey questionnaires and interviews, Kindred has provided advocacy support to four families over the past two years with children and young people with a diagnosis of autism spectrum disorder who have had long term experiences of inpatient care. They have also supported a further six families of children and young people with very challenging behaviour. The perspective gained over time of the impact on families who may have benefitted from a specialist inpatient facility in Scotland is included in the appendices (section A5).

4.4 Views of children and young people

Whilst incorporating the experiences and views of families and carers, it is important to acknowledge that this survey was not able to seek such information directly from children and young people themselves. In any development and design of the recommended unit, views and experiences of children and young people should be sought, supported by the use of appropriate communication techniques. For example, links with LD CAMH units in England could be used to seek views from children and young people who are inpatients there, with help from independent advocacy organisations.

4.5 Variation between Health Boards

Differences in overall submission rates to the study from different Health Boards (see section A4.1.2 (i) of appendices) were likely to be due to a range of factors, including participation rates of individual clinicians, focus or otherwise of local services on this issue, and presence or absence of specialist LD CAMH services. It also depended on whether clinicians chose to submit data on patients with autism spectrum disorder but no learning disability who did not require specialist autism spectrum disorder services. This was highly variable. The information in this section is based on submission rates relative to the population size of the Health Boards. Numbers submitted from each Health Board were not sufficient to report statistically significant analysis; however, some interesting trends emerged.

Health Boards with the most established LD CAMH community services generally had:

- Lowest overall submission rates to the study - which may be due in part to a focus on those more complex children and young people requiring specialist inpatient units not currently available.
- A higher total number of admissions for children and young people with learning disability to units within their Health Board, particularly for those with moderate and severe learning disability – may be due to their ability to support their patients within local adult LD, adult mental health or YPU wards.

There were 2 notable exceptions:

- In one Health Board with an LD CAMH service, there were fewer admissions for those with learning disability, but the psychiatrist supported a number of patients with moderate learning disability at home or in local residential special schools who should have been in hospital.
- The Health Board with the highest rate of admissions of those with learning disability was one with no LD CAMH psychiatrist, but which had a large residential special school in its area from which a number of children and young people were admitted to the adult LD unit.

The Health Board of residence (i.e. origin) of patients requiring admission to hospital also appeared to vary in relation to the community LD CAMH services in that Health Board:

- Where there was no specialist community LD CAMH service, rates of reported admissions tended to be lowest - this may indicate hidden need, with community services not identifying and treating mental health problems in this group.
- Where services were partially developed, admission rates were highest - perhaps indicating that more problems were identified, but

services were inadequate to treat children and young people with more severe/complex problems in the community.

- Where community services were most well developed, admission rates were in between - this may mean that mental health problems were being identified and that some admissions were prevented due to more comprehensive and, in one Health Board, intensive work being done in the community.

4.6 Demographics, diagnoses, presenting issues and admission characteristics

More detail can be found on these results in sections A4.2 to A4.4 of the appendices.

4.6.1 Ethnic group

>95% white British.

4.6.2 Gender

63% male. As the severity level of the learning disability increased, males were more likely to be over-represented: 55% were male where there was no learning disability, up to 80% male where there was severe/profound learning disability. This is consistent with higher rates of learning disability diagnosis in males in general, and increased % of males with increasingly severe levels of learning disability. This contrasts with admissions for children and young people under age 18 in general, as illustrated by 32 out of 50 patients in the 2014 census on people in mental health and learning disability inpatient beds being female (Scottish Government 2015).

4.6.3 Age

Range 8-17 years; mean 14.9, mode 16. Those with moderate, severe and profound learning disability were more likely to have admission at a younger age. The relatively younger age of admission for those with these more severe levels of learning disability may be due to the increased severity and complexity of their co-morbid conditions.

4.6.4 Looked after and accommodated children

30% of submissions were for looked after and accommodated children, with highest rates for those with moderate learning disability. High rates of submissions for looked after and accommodated children were likely to be due in part to a significant proportion being accommodated with family agreement in residential schools and care settings (particularly those with moderate learning disability and challenging behaviour). In addition, children with learning disability are known to be exposed to high rates of abuse (Taylor et al, 2014), and some children and young people may have therefore been looked after and accommodated for child protection reasons.

4.6.5 Level of learning disability and rates of autism spectrum disorder

The patients described in clinicians' questionnaires had a range of levels of learning disability. Due to inclusion criteria, all those without learning disability had autism spectrum disorder. 30% of patients had no learning disability, 30% had mild learning disability, 30% had moderate learning disability, and 10% had severe/profound learning disability. 75% had autism spectrum disorder, including 100% of those with no learning disability, 52% of those with mild learning disability, 73% of those with

moderate learning disability and 90% of those with severe/profound learning disability.

4.6.6 Diagnoses

Multiple co-morbidities were common. Additional psychiatric diagnoses included:

- Affective disorder (24%)
- Anxiety and trauma related disorder (23%)
- Psychosis (21%)
- ADHD (15%)
- Other developmental disorders (6%)
- Other additional psychiatric diagnoses (13%)

50% had additional physical health diagnoses:

- 15% had multiple physical health diagnoses
- The number of additional physical health diagnoses increased with the severity of learning disability

The high rate of autism spectrum disorder in patients with learning disability, increasing with severity of learning disability and high rates of comorbid mental illness and physical health diagnoses, reflects clinical experience and extensive research evidence for this population.

4.6.7 Presenting behaviours

- 65% had self-injury (100% where severe/profound learning disability)
- 67% had aggression (100% where severe/profound learning disability)
- 51% had destructiveness (80% where severe/profound learning disability)

- 28% had sexualized behaviour (42% where mild learning disability)

4.6.8 Police involvement

41% had police involvement at some stage (52% where mild learning disability)

4.6.9 Admission rates over time

Steady admission numbers were reported from 2012 – 2014, but less for 2010 and 2011. This is likely to be due in part to issues described above in identifying patients for inclusion in the study. In addition, it is possible that there was: improved identification of mental health difficulties and the need for inpatient care over time; less capacity in some local children and young people and adult services to pull together local alternatives to hospital admission; an actual increase in numbers of children and young people with complex mental health and behavioural needs requiring admission.

4.6.10 Reasons for admission

Most common across all levels of learning disability were:

- Mental health assessment and stabilisation (58-67%)
- Risk management (excluding suicidality/deliberate self harm) 50% of those with no learning disability, 70-80% of those with all levels of learning disability.

Suicidality/deliberate self harm: 37% of those with no learning disability, very low rates in all levels of learning disability.

Medication management: 16% of those with no or mild learning disability, 29% for moderate learning disability and 35% for severe/profound learning disability.

Home/care placement breakdown was a common reason for admission only for those with moderate learning disability (23%).

4.6.11 Mental Health Act

53% of patients were noted to have been detained under the Mental Health Act for all or part of an admission.

4.6.12 Staff: patient ratio

Limited information given, but >15% needed more than 2 nurses per patient.

4.7 Where children and young people were admitted to

4.7.1 Admissions to hospital settings

The questionnaires returned by clinicians described episodes of care in a range of Scottish settings: 56 in adult mental health wards, 30 in young people's (12-18 years old) mental health inpatient units (YPUs), 25 in adult learning disability (adult LD) wards, 7 in pediatric wards, and 5 in the National Child Psychiatry Inpatient Unit (NCPIPU). 17 patients were admitted to wards in England during the study period: 9 to LD CAMH inpatient units (including secure LD CAMH inpatient units) and 8 to other units (including secure adolescent and ASD specific).

More detail on the profile of patients admitted to different types of ward is given in section A4.6.2 of the appendices. Patients with increasingly severe levels of learning disability were more likely to be admitted to adult LD wards, but only 2/3 of those even with severe/profound learning disability were admitted to a learning disability specific ward, with ½ of these being an age-appropriate facility.

The most common age for those admitted to adult MH, adult LD, YPU and LD CAMHS (including secure) wards was 16-17 years. Those remaining at home or admitted to non-hospital placements tended to be younger teenagers.

Rates of autism spectrum disorder varied according to the type of ward admitted to. Very high rates in those admitted to adult mental health units reflects that a significant number of patients in the survey with no learning disability (and therefore by definition due to inclusion criteria with autism spectrum disorder) were admitted to these wards. There were higher rates of autism spectrum disorder in those on adult LD wards compared with those on YPUs. This may have been due to the greater severity of learning disability in those admitted to adult LD wards, with high rates of comorbid learning disability and autism spectrum disorder in this group. YPUs seemed to be able to generally manage those with Mild LD and more straightforward mental illness presentations. The added complexity of autism spectrum disorder with learning disability may have made these units less likely to cope with/accept admissions.

4.7.2 Admissions to age-appropriate facilities

The percentages of children and young people in the survey admitted to age-appropriate mental health wards (including transfers within admission) were 27% for those with autism spectrum disorder but not learning disability, 36% for those with mild learning disability, 33% for those with moderate learning disability and 43% for those with severe/profound learning disability.

In the 2014 Mental Health and Learning Disability Inpatient Bed Census (Scottish Government 2015), 38 out of 50 patients aged less than 18

years were in a children or young people's unit (76%). Methodological differences do not allow direct comparison with admissions of the general population of children and young people in Scotland to age appropriate mental health inpatient wards, however these percentages do appear to indicate likely poorer access to age appropriate care for children and young people with learning disability and/or autism spectrum disorder compared to their peers. It should be cautioned that reporting of admissions for those without learning disability but with autism spectrum disorder in this survey was biased towards those admitted to adult wards due to many submissions coming from one Health Board who reported difficulty accessing beds in their regional YPU during the study period.

4.7.3 Admissions to non-hospital settings or remained at home

In addition to these admissions to hospital settings, there were 15 patients who required admission but remained at home or were admitted to non-hospital placements. These patients tended to be younger, have moderate learning disability, usually had major mental illness and all had highly challenging behaviour. The main reasons for not being admitted were lack of a suitable age-appropriate specialist ward at a manageable distance, and cross-border issues related to the Mental Health Act.

4.8 Pathways

This section covers routes into admissions (including waits), routes through admissions (including transfers), lengths of stay, separate periods of admission for the same patient, and routes out of admissions. There was a wide variety of complex pathways for patients ideally requiring specialist LD CAMH, adolescent mental health secure or ASD-specific secure inpatient provision, which only a minority actually received in specialist units in England. Section A4.14 of the appendices gives detailed information on all aspects of patient pathways, including examples of pathways followed by children and young people requiring inpatient care currently unavailable in Scotland (section A4.14.4).

4.8.1 Waits for an admission

Patients often spent significant time making no or limited progress at home, or in residential care, or on one or more inappropriate wards (or some combination of all of these).

Finding a bed in hospital was usually difficult. Clinicians described extremely ‘high thresholds’ for admission, meaning they did not arrange admission for these children and young people until they were much more unwell than peers without learning disability and/or autism (or than adults with learning disability), due to lack of suitable facilities. Admissions were usually undertaken only in absolute crisis, when the risk of staying in the community exceeded the risk of an inappropriate ward. There was a lack of community mental health services to support the child and their family, with ‘cobbled-together’ arrangements and gaps being filled by other services. Despite this, once admission could no longer be avoided, children and young people often waited considerable periods of time even for an inappropriate bed, with 27% waiting more

than 4 weeks. The majority were not admitted directly to appropriate wards, having to wait again for transfer (if that happened) to a specialist bed.

4.8.2 Length of admission

Admissions were lengthy (44% over 6 months), particularly for those with learning disability. Examples were given where patients needing specialist admissions were kept only for brief periods on non-specialist wards and then discharged home or to social care placements with inadequate mental health assessment/treatment. Whilst these admissions may have been reported in the survey, the length of them would have been less than that really required. Conversely, there were patients in hospital for much longer than ideally required because treatment took much longer in non-specialist units and because of ‘delayed discharges’ where there was a lack of suitable social care/education provision to discharge to. These factors make estimation of the likely average required length of stay on a specialist unit difficult. One of the English LD CAMH NHS inpatient units aims for a 3 month length of stay for those with severe learning disability. However, this varies considerably, those with forensic needs and those with highly complex or treatment-resistant mental illness usually requiring significantly longer. A reasonable overall estimated average length of stay would be between 6 and 12 months, with significant individual variation.

4.8.3 Transfers and multiple admissions

27% of patients had at least 1 transfer during their admission, most commonly those with mild learning disability. 16% had more than one separate admission. Numbers of transfers during an admission are likely

to be an underestimate of the true picture. In some cases, information on questionnaires was unclear about timing of transfers so they were not counted. There were also a number of patients with learning disability known to have moved on to adult LD inpatient units after the age of 18. Only transfers before age 18 were counted in the data.

4.8.4 Discharge destination

The discharge destination at the end of the last admission in the study period varied according to the presence or absence of learning disability, and the level of severity. The discharge destination was home for 75% of those without learning disability, but 55% for those with more severe levels of learning disability. 18% (14 patients) remained in hospital, some due to lack of appropriate social care or education resources to move on to. This was particularly distressing for children and young people and their families, and impacted on the service provision available for other patients.

4.9 Impact and outcomes of the current situation on children and young people and families

There was evidence of willingness and efforts of practitioners in attempting to meet children's needs at a local level, in order to reduce the impact of long-distance separation from families. This involved creative responses and examples of cross-disciplinary working. However, the difficulties faced in Scotland by children and young people with learning disability (often also with autism spectrum disorder) who required mental health admission were considerable, as was the impact on their families and services who attempted to meet their needs. These were explored in detail with clinicians and families and fully documented in the appendices (sections A4.6 to A4.13). Time and resources were

wasted on admissions to inappropriate units, which could in some cases contribute to further deterioration.

4.9.1 Impacts of waiting for a bed

Children and young people endured long periods of inadequately treated illness and distress at home, potentially leading to poorer long-term prognosis. It was highly stressful for families supporting children and young people displaying severe self-injury, aggression and destructive behaviours at home. Families, exhausted from caring responsibilities, had to make difficult decisions. They were fearful of admission, especially when no appropriate unit was available and/or they had previous negative experiences. It was difficult to hand over care, especially to staff inexperienced in working with children and young people and/or those with learning disability

Risks were unacceptably high in the community from aggression, self-injury, and destructiveness, use of high levels of psychotropic medication without the ability to safely monitor and from families having to use unsafe physical restraint.

There were particular difficulties for vulnerable patients, including those with severe learning disability and more complex needs, and looked-after children and young people in out-of-area placements.

4.9.2 Outcomes from admissions to wards in Scotland

Some good outcomes from admissions to all types of ward were reported, despite the lack of suitable facilities and expertise for children and young people with learning disability. Examples were given of acute risks being managed, behaviour stabilised, medication adjusted, care needs identified and discharge or transfer to more specialist units

supported. However, in general, children and young people with more than mild learning disability admitted to wards in Scotland faced significant difficulties, including lengthy admissions, sometimes in highly restrictive environments, with multiple transfers and transitions for those most in need of consistency. Lack of specialist age/developmentally-appropriate multidisciplinary care and environment could contribute to unnecessarily high use of medication and restraint.

Children and young people on local adult LD and mental health wards had better family contact and continuity with services, but the lack of staff expertise, age-appropriate physical environment, education and activities led in some cases to an escalation in challenging behaviour, with high use of medication and restraint. There could be a lack of progress over months or years. Children and young people exposed to adult patients were anxious or socially and sexually vulnerable. Some adult LD wards took in children and young people with highly challenging behaviour with successful outcomes, due to flexibility in adapting physical environment and staffing, but at significant cost to services to adult patients. Other children and young people were reported to have been discharged too quickly and inadequately treated due to concern about the adult setting.

Children and young people with autism spectrum disorder but no learning disability generally did well in the regional mental health YPUs, except for those children and young people requiring inpatient mental health care with a degree of security, including forensic. Although staff expertise of autism spectrum disorder reportedly appeared to be improving over recent years, it remained variable and parents had particular concerns in this area. However, when these children and young people were admitted to adult mental health wards, they (like those with learning disability) were disproportionately affected compared

with typically developing peers. This was due to the child or young person's poorer communication and social skills, developmental level and need for an adapted environment and activities.

The YPUs usually managed children and young people with mild learning disability and typical mental illness presentations well. The success of admissions to YPUs for those with moderate learning disability and greater complexity varied according to staff experience and support from local LD CAMH professionals. Support was generally unavailable for patients from outside the Health Board in which the YPU was situated, leading potentially to unequal access and outcomes.

Young people with severe learning disability and/or highly aggressive or destructive behaviours were rarely accepted for admission to the YPUs. Staffs on the National Child Psychiatry Inpatient Unit were considered more experienced in working with children with greater neurodevelopmental complexity. However, even on the National Child Psychiatry Inpatient Unit, some under 12s with severe/profound learning disability were only manageable as day patients and ultimately required LD CAMH inpatient admissions in England.

Families were often deeply upset by the experience of their child being in hospital, describing a lack of emotional support to deal with diagnoses and the need for improved communication. They felt that a focus on just one aspect of a young person's difficulties created problems in meeting their needs and that better access to therapy, education and activities was required. Negative experiences impacted on future relationships and engagement of young people and families with adult services.

4.9.3 Outcomes when a child or young person was not admitted to hospital when required

Extremely high levels of input from community clinicians and multiagency partners were given for some individual children and young people who required hospital but were not able to access it. Despite this high level of input, children and young people endured unnecessarily prolonged periods of illness and distress and families were stressed and exhausted caring for them.

There were high risks to children and young people and families from self-injury, aggression and destructiveness, as well as from an inability of community services to adequately monitor mental state and medication. Support agencies and schools sometimes withdrew support due to an inability to manage the severity of behaviours. In the absence of appropriate mental health inpatient care, some children and young people's challenging behaviour escalated and they were moved through increasing levels of security in expensive social care or educational residential placements which could themselves be out of area and without access to specialist mental healthcare.

4.9.4 Outcomes from admissions to specialist units in England

Patients who were admitted to specialist LD CAMH and ASD specific wards in England generally received comprehensive, age-appropriate, multidisciplinary assessment and treatment in an appropriate physical environment with developmentally appropriate activities, education and peer-group. There were significant improvements in mental health, sleep and well-being for children and young people and their families. This demonstrated what was possible to achieve for some children and young people with highly complex problems, with recommendations and

support plans continuing to helpfully inform local services several years after discharge.

Most difficulties described with these admissions related to distance from home, causing additional distress to children, young people and their families. Dislocation from family and local services complicated discharge planning. Accessing beds was complicated and involved prolonged negotiations with families, local and national services, long waits for beds, and complex cross-border Mental Health Act issues

4.10 Impact and outcomes of current situation on services, clinicians and their other patients:

4.10.1 Summary of financial costs

Children and young people admitted to specialist LD CAMH and ASD CAMH NHS units in England are funded via the NHS National Services Scotland risk share scheme on behalf of Scottish Health Boards. Costs were variable with a peak of costs at the end of the study period where total NSD spend on Forensic LD CAMH, LD CAMH and ASD CAMH specialist care cost £1.06 million in 2014/15.

Admissions to specialist private hospitals are funded directly by the patient's Health Board of residence, with costs varying from £330,000 to £624,000 per patient per annum. Where children and young people were nursed in Scottish mental health inpatient units (including adult LD, adult mental health and YPU wards), additional staffing costs to Health Boards on top of usual care were up to £300,000 - £500,000 per patient per annum. Other additional costs to Health Boards were less easy to quantify but these included assessments (£2000 per patient), travel and subsistence allowances for families, and costly adaptations and repairs to existing wards.

Considerable time and resources were used in ‘containing’ situations, with patients being maintained in unsuitable units pending an appropriate bed. Costs to local councils for some patients awaiting suitable hospital care were similarly high, between £260,000 and £360,000 per patient per year.

4.10.2 Costs of patients admitted to specialist LD CAMH/ASD specific wards in NHS England

4.10.2 (i) Financial risk sharing scheme

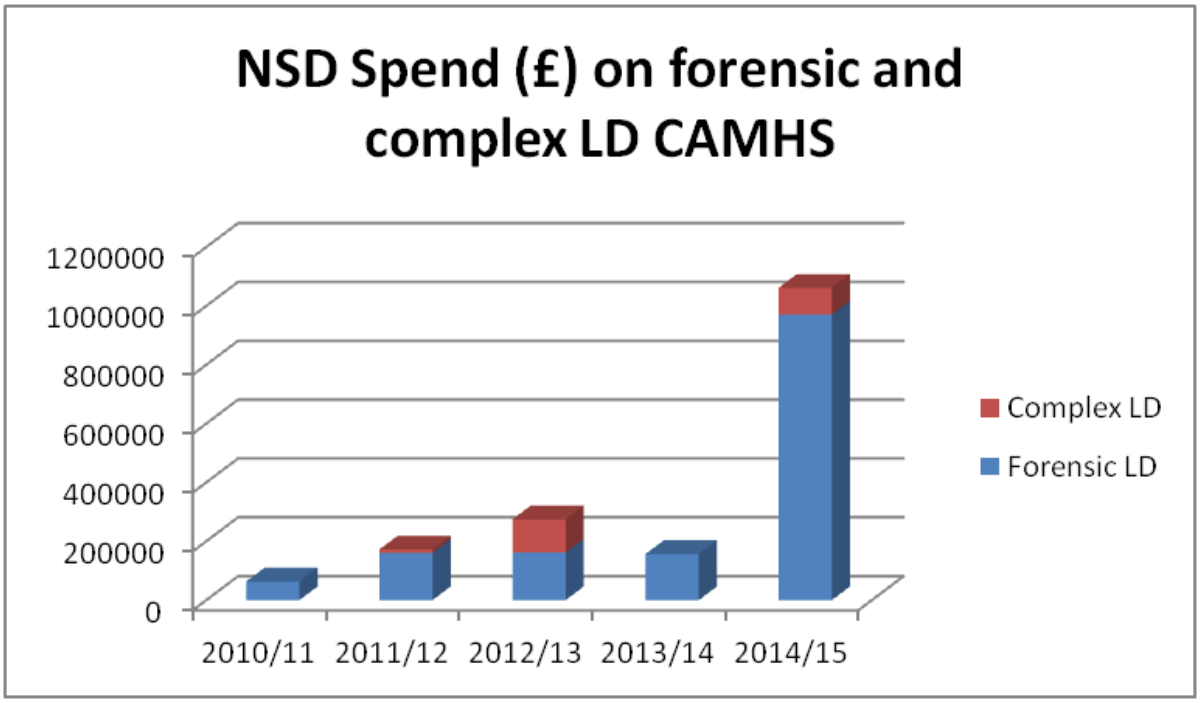
The access of patients who were admitted to specialist LD CAMH and ASD specific wards in NHS England is covered under a financial risk sharing scheme administered for and on behalf of the 14 territorial NHS Scotland Health Boards by NSD (National Specialist and Screening Services Directorate of NHS National Services Scotland). This risk share scheme was established in 1999 following the Management Executive letter setting out the policy on replacement of Extra Contractual Referrals issued on 25 January 1999 (MEL1999/4).

NHS Board Chief Executives and Scottish Government colleagues approved the former National Services Advisory Group (NSAG, now National Specialist Services Committee, NSSC) recommendation for funding to be top-sliced off Health Board allocations and transferred to NSD to cover equitable Scottish access to specialised services in England where equivalent services were not available in Scotland. The analysis of national expenditure and referral patterns has enabled NSD to identify opportunities to encourage service development in NHS Scotland and reduce the need for cross-border care in other acute areas of health care.

The establishment of new commissioning arrangements for specialist CAMHS services within NHS England from 1 April 2013 led to changes in the arrangements that had been in place for Scottish patients to access specialist services in England. This made it more difficult for patients from Scotland to access beds due to priority being given to NHS England patients. This restriction in access to NHS England beds was not reflected in NSD spends. However, there is likely to have been financial impact on Health Boards, who would have had to pay for private LD CAMHS hospital admission instead, or (along with Councils) for alternative arrangements whilst awaiting an NHS bed.

4.10.2 (ii) NSD spending on LD CAMH and ASD CAMH inpatient care

The cost attached to the provision of specialist LD CAMH and ASD CAMH inpatient care in NHS units in England has risen sharply over the last 5 years from a figure of £ 63,269 in 2010/11, to a sum £1.06 million in 2014/15. Patient numbers are less than 5 for both of these financial years and therefore cannot be reported. Northumberland, Tyne and Wear NHS Foundation Trust are the main provider of care. It should be pointed out that costs do not necessarily reflect demand. For example, there can be limited access to beds, and costs incurred over the last 5 years will have been contained by these restrictions. Further factors are discussed in section 5.9.4 of this report.



It would be prudent to estimate a figure of circa £1 million per annum for the provision of specialist LD CAMH and ASD CAMH inpatient care in England based upon case mix and complexity of care delivered over the past two years. However, costs to NSD are directly proportional to access to service provision in NHS facilities in England. Costs can also vary significantly because of the level of care package required. Some patients require much more nursing support than others, and with relatively long lengths of stay, it is possible for the care of individual patients to prove very costly. As each patient will have had a package of care tailored to their individual needs, the range of costs will have varied considerably. However the costs for the non-forensic care tend to be limited by the fact that Northumberland, Tyne and Wear NHS Foundation Trust look to complete their assessment and seek a discharge plan for their patients within a 13 week window, limiting costs for complex LD CAMHS patients to around £120,000 per in-patient episode. It is recognised that limited access for complex LD CAMHS patients to NSD-funded NHS England LD CAMHS inpatient units for a variety of reasons

has meant that costs for those requiring inpatient mental health care has been mostly borne by Health Boards and Local Authorities.

It should be noted that pre-admission assessments generally cost an additional £2000 per patient, and an individual patient may require more than one assessment. This cost is usually borne by NSD via the risk sharing scheme for patients assessed by NHS England units but paid for directly by Health Boards for private hospitals.

4.10.3 Direct costs to Health Boards

Information received by the survey on direct costs to Health Boards was limited and incomplete. Therefore it was difficult to estimate an overall cost that includes all the various elements involved. However, the following costs were identified:

Cost of private hospitals in England: Where NHS England LD CAMH/ASD beds were unavailable or unsuitable for the children and young people in this survey, a small number were admitted to private hospitals in England. These admissions were paid for directly by the home Health Board and were most commonly to St Andrews Healthcare in Northampton. Costs varied from £330,000 to £624,000 per patient per year. Some admissions were very lengthy, e.g. for 2 ½ years.

Cost of adult LD hospitals in Scotland: Costs were variable when children and young people were admitted to adult LD wards, basic costs being approximately £3,300 per week per patient (£170,000 per annum). However, to nurse the children and young people safely in that environment additional cost were common, e.g.

- £8,000 – £10,000 for additional nursing staff for 2:1 or greater levels of care (£400,000 – £520,000 per annum)

- £6,700 per week (£345,000 per annum) for one admission where a part of an adult ward had to be used for one young person with high staff ratios.

Admissions could be lengthy, e.g. 3 years at £455,000 per annum for one patient, 18 months at £520,000 per annum for another.

Cost of admissions to adult mental health wards, including IPCU: Costs were quoted as between £1,000 and £6,000 a week (£52,000 - £312,000 per annum), presumably due to variable levels of support required.

Cost of admissions to YPUs: Costs for nursing children and young people 1:1 or 2:1 on YPUs were described of up to £312,000 per annum.

Cost of care on pediatric wards: Admissions to these wards tended to be shorter, but there was still significant cost of between £4,000 and £8,000 a week for additional nursing staff to support individual children and young people.

Cost of other admissions: The Lothian LD CAMH Intensive team uses existing staff to support admissions to a dedicated individual unit when their patients require admission. On top of the existing cost of intensive team nurses, additional nursing care, including bank staff, can cost £200,000 per year.

Travel and subsistence costs: The Health Board of residence is responsible for refunding travel and subsistence costs for families visiting their child in hospital. Limited information was received on this but an example was given of approximately £3,000 for 1 child or young person for 6 months.

Costs of adaptations to wards: It was not possible to ascertain the costs to Health Boards associated with adaptations and repairs during admissions to existing wards. These were most commonly made when adolescents with severely destructive, self-injurious or aggressive behaviours were admitted to adult LD wards. Costs could be significant over prolonged periods, e.g. building of a 'bespoke' robust, ASD-specific unit within an adult LD ward to accommodate one teenager. Daily repairs, including by out-of-hours joiners, were commonly required. Similar costs were associated with a smaller number of patients admitted to one of the YPUs, but for shorter lengths of time.

4.10.4 Costs to local authorities

The survey received very limited information about costs to local authorities associated with admissions (or lack of availability of admissions) for this patient group. However, there were indications that costs of looking after these children outside hospital while awaiting hospital care were of a similar cost to inpatient care. For example:

- £360,000 per annum for a residential special school
- Estimated £130,000 for additional support locally for 6 months for a young person while awaiting a bed in an LD CAMH NHS unit in England.

Some local councils also contributed to the cost of admissions, mostly to local adult LD wards, for example, by funding education and social care professionals to work with a young person in hospital. This could be to maintain education and community access, to keep up contact with known care staff, or to develop relationships with care staff prior to discharge. One council indicated that they paid £400 per week for education to be provided to a young person on an adult LD ward.

4.10.5 Other impacts on local services and on clinicians

Each local admission for those with more severe learning disability and complex needs/severe challenging behavior was a time-consuming and stressful ‘special arrangement’ for clinicians. Admissions to specialist units in England involved lengthy negotiations around funding and arrangements. Whilst arranging/waiting for a bed, or as an alternative to admission, community clinicians had to manage unacceptably high levels of risk in the community with very limited services. This was anxiety-provoking, with clinicians feeling isolated and unsupported. Relationships between services were strained due to a lack of management responsibility and ‘ownership’ of these children and young people.

Community-based LD CAMH psychiatrists had to retain responsibility for inpatients over long periods. Inpatient teams and facilities in non-specialist wards had to be ‘cobbled together’ for individual patients, building up working relationships from scratch each time. Inpatient nurses were anxious due to lack of experience with this particular patient group, and some nurses sustained some serious injuries. Adult patients with learning disability lost access to inpatient care. Many additional unpaid hours were worked, impacting on clinicians’ personal lives and care of other community patients. There was a concern that recruitment to such stressful community services will be affected. More detail on these impacts can be found in appendices section 4.18.

4.11 Numbers and profiles of patients requiring specialist inpatient care not presently available in Scotland

A total of 54 patients were identified by their clinicians over the 5 year period as having required inpatient care not presently available in Scotland. 45 of these required LD CAMH specialist inpatient provision

and 9 required non-learning disability specific inpatient provisions (see also section A4.19 of appendices).

4.11.1 Profile of patients requiring specialist LD CAMH inpatient provision

Compared with patients able to access ‘mainstream’ YPUs, the 45 requiring specialist LD CAMH inpatient facilities had greater degrees of learning disability, with all of those with severe/profound learning disability requiring such provision. They were more likely to be male (70%). 21 patients were aged 16-17, 15 aged 14-15 and 9 aged 13 or under. The main reasons for requiring hospital admission were risk management and mental health assessment/stabilisation. Children and young people had very high levels of distress and severe challenging behaviours, requiring high staff ratios, 40% needing 1:1 and 31% needing 2:1 care.

These 45 children and young people had 76 periods of inpatient care, mostly due to transfers between units during 1 admission, a minority having more than 1 admission. 44 periods of care were in Scottish adult LD or adult mental health wards (including secure and intensive psychiatric care units), 12 in Scottish CAMH wards, 4 in Scottish pediatric wards, 6 were not admitted to hospital at all, and 10 were in specialist LD CAMH wards in England.

Of the 45 children and young people identified by this survey as requiring LD CAMHS specialist provision:

- 29 required an LD CAMHS specialist unit without additional security or individualised provision
- 9 (mostly with mild learning disability) required a secure LD CAMH inpatient facility

- 7 (with moderate/severe learning disability) required a robust, individualised LD CAMHS inpatient environment, giving the option of nursing children and young people away from others when required.

Those requiring robust, individualised environments were amongst those with the most complex and challenging difficulties. Some could not access inpatient care at all, or had required highly expensive bespoke provision to be built locally, with huge impact on local services.

4.11.2 Autism spectrum disorder (non- learning disability) specific provision

9 children and young people in this survey required autism spectrum disorder (non-learning disability) specific provision that is not available in Scotland. The majority of these had autism spectrum disorder and no learning disability or mild learning disability and required secure/forensic inpatient care. There was insufficient evidence of need for a specialist unit for children and young people with autism spectrum disorder without learning disability. However, information on these children and young people highlights the need for the proposed secure forensic CAMH inpatient unit to have high levels of autism spectrum disorder and learning disability knowledge and skills and an appropriate physical environment to meet the needs of this group.

There is also likely to be a very small ongoing number of children and young people with autism spectrum disorder but no learning disability who will require specialist inpatient care not covered by the remits of the proposed secure forensic CAMH or LD CAMH inpatient units, for example, those requiring a higher level of autism spectrum disorder expertise or a higher level of security than can be provided. The

information gathered by this study indicates this is likely to be for an average of less than one young person from Scotland each year. It is important that clear commissioning arrangements are in place so that such admissions can be easily arranged elsewhere in the UK if required.

4.12 Other study findings

4.12.1 Community LD CAMH services

Results confirmed previous reports (LD CAMHS Framework Document, Appendix A2.2) of inadequate community mental health services for children and young people with learning disability. Where present, community expertise could be so fragile that having one key clinician on leave could result in an absence of LD CAMHS expertise. This meant that services struggled to safely manage the children and young people at home whilst awaiting admission. Section A4.16 of appendices provides further detail.

Intensive community LD CAMHS services, along with earlier, more robust specialist social care, education and health provisions could have helped manage some children and young people more safely in the community before and after admission. Given the inclusion criteria for this survey and from information provided by clinicians, it is likely that the vast majority of patients identified in the survey would have required hospital admission even if intensive community treatment services had been available locally. Indeed, thresholds were so high that numbers are likely to underestimate true need. However, such provisions could also have allowed for shorter admissions and a sooner return home or to a community placement nearer home.

Intensive community treatment services capable of working in children and young people's homes, school and respite provisions are crucial to

provide the full range of appropriately stepped care for children and young people with learning disability and mental health/behavioural difficulties. Their development nationally, alongside the development of an LD CAMH inpatient unit, would prevent unnecessary admissions to such a unit. Along with adequate availability of specialist educational and social care resources, these would be essential in ensuring appropriate admissions and aiding timely discharge out of the unit.

The ‘LD CAMHS Models and Outcomes Study’ (Glasgow University) is specifically investigating intensive models across the UK and results will be available soon. Clinicians in this study also noted that, while these services could be very valuable, intensive support in patients’ homes is not always practical or appropriate, due to family issues or physical layout of their house. Home may not be a safe environment for workers as well as family. Families may not want strangers in their house overnight, particularly where there are siblings. Intensive treatment services can only work in the context of appropriate social care support and respite.

4.12.2 Robust individualized settings

The need for robust individualised settings was a key theme throughout the results of the survey, in inpatient and community settings, including social care and education. The relatively small number of children and young people that required this were amongst those with the most complex and challenging difficulties who were most difficult to place in inpatient care. Some were unable to access inpatient care at all and admissions that did take place had a huge impact on local services and other patient care. For a minority, there was no hospital (NHS or private) in the UK that could provide the physical environment required and major

adaptations and building work had to be carried out in a local adult environment to accommodate them.

Very physically robust physical environments are required to withstand highly destructive behavior for these children and young people to be safely and effectively treated in hospital. Importantly, these environments need to also take into account the sensory processing difficulties common in children and young people with autism spectrum disorder and aim to reduce arousal/anxiety levels. Some children and young people need to be nursed separately from other patients for variable periods of time. They therefore require an individual part of a unit with their own living, sleeping and bathroom areas, with access to safe outdoor space, activities, education and a full multidisciplinary team. Both patient and staff safety need to be considered in the design of the building for children and young people with very severe self-injurious and aggressive behaviours.

5. WHAT THIS WORK INDICATES

5.1 Service size of a Scottish LD CAMH inpatient unit

The minimum recommended bed numbers for a Scottish LD CAMH inpatient unit based on results of this survey and other sources are 12 beds in total. These should consist of:

- 6 LD CAMH inpatient beds without additional security or individualised provision
- 3 secure LD CAMH inpatient beds
- 3 robust, individualised LD CAMH inpatient environments (bedroom and living space separate from other patients).

It should be noted that the 3 secure LD CAMH inpatient beds may be provided within a Secure/Forensic CAMH unit in Scotland, assuming appropriate environment and staff expertise. This would leave a 9 bed unit required for those with more severe levels of learning disability and complex needs.

The following sections show how these figures have been calculated and cross-referenced with other relevant sources of information.

5.1.1 Estimated bed requirements from survey evidence

45 children and young people were identified by this survey as requiring LD CAMH specialist inpatient provision. Of these:

- 29 required an LD CAMH specialist inpatient unit without additional security or individualised provision
- 9 (mostly with mild learning disability) required a secure LD CAMH inpatient facility

- 7 (with moderate/severe learning disability) required a robust, individualized LD CAMH inpatient environment, giving the option of nursing children and young people away from others when required.

If the lower reporting rates for the first 2 years covered by the survey are taken into account, 25% should be added on top of the numbers identified in the study, taking figures to 56 requiring LD CAMH specialist inpatient provision, of whom:

- 36 required an LD CAMH specialist inpatient unit without additional security or individualized provision
- 11 required a secure LD CAMH inpatient facility
- 9 required a robust, individualized LD CAMH inpatient environment

Based on these figures and aiming for an average length of admission of 6 months for the main part of the unit and 1 year for the secure/individualised parts, the following would be required:

- 4 LD CAMH beds without additional security or individualised provision
- 2 secure LD CAMH beds
- 2 robust, individualized LD CAMH environment beds

The above is based only on identified need from the survey (likely to be less than actual need for reasons given above) and a 100% bed occupancy rate. Taking these into account, the suggested minimum bed numbers for a Scottish LD CAMH inpatient unit would be:

- 6 LD CAMH beds without additional security or individualized provision

- 3 secure LD CAMH beds (these could be provided in the secure/forensic CAMH inpatient unit, given appropriate environment and staff expertise)
- 3 robust, individualised LD CAMH environments (bed and living space separate from other patients)

Some work has been done cross-referencing the secure/forensic CAMH inpatient needs assessment results with those from this study. This confirmed the overlapping populations of those children and young people with mild learning disability who have mental health and forensic issues. This highlights the need for the detailed planning of an LD CAMH inpatient unit to be carried out in close collaboration with the secure/forensic CAMHS inpatient developments, further described below.

Recommended bed numbers in this report are calculated on ideal rather than the current actual length of admissions for this patient group. In the survey, 50% of all admissions were longer than one year, often due to a lack of specialist community social care services to enable discharge. These bed numbers would therefore become quickly ‘blocked’ without additional measures being taken to provide such community provision alongside the development of the inpatient unit. Recommended bed numbers for a Scottish LD CAMH unit are therefore an absolute minimum requirement as a starting point for a unit and will need to be reviewed regularly according to bed use and development of community services.

5.1.2 Other evidence and recommendations regarding bed number requirements

These figures can be compared and cross-referenced with other evidence and recommendations:

- At the end of this 5 year survey, 14 children and young people remained in hospital. Some of these were by that time under the care of adult LD services and some may have been medically ready for discharge but awaiting suitable social care support in the community.
- The Mental Health and Learning Disability Inpatient Bed Census, 2014 (http://www.gov.scot/Publications/2015/06/7555) identified 12 children and young people in Scottish beds with diagnoses of learning disability and/or autism spectrum disorder. It is not possible to distinguish which of these would require specialist beds not currently available. The figure does not include Scottish children and young people with these diagnoses who were inpatients outside of Scotland.
- The Royal College of Psychiatrists recommends the following: 'A total population of 1 million requires about 3–4 beds for young people with severe intellectual disabilities, 2–3 beds for those with mild intellectual disabilities and 1 bed for those who require low secure provision. The last is for those who require security because of the intensity of their disturbance or because of the risk they present to others and is distinct from medium secure beds'. (Royal College of Psychiatry, 2016). Taking 5,347,600 as the population of Scotland (http://news.scotland.gov.uk/News/Scotland-s-Changing-Population-1c1d.aspx), this would equate to more than 18 beds for those with severe learning disability, 13 for those with mild learning disability and 5 for low secure beds.
- The increased spend year on year across the study period on specialist NHS beds in England via the NHS Scotland risk share

scheme is also striking and this may additionally have been influenced by the following:

- A reduction in overall adult LD beds may mean that less children and young people have been able to be accommodated in local adult LD wards within their home Health Boards, resulting in more referrals out of Scotland to age-appropriate wards
- Clinicians may have a greater recognition of the need for age-appropriate inpatient care, also resulting in more referrals out of Scotland
- Government and Mental Welfare Commission guidance discourages admission of children and young people to adult beds

5.2 Age range catered for

The unit would be for children and young people under the age of 18 years, although there should be some flexibility about the age range, see below. Younger children would need to be nursed separately from older children, with space being used flexibly according to the patient mix at the time. Close liaison with the National Child Psychiatry Inpatient Unit would be required to decide the best unit for individual younger children referred. Ongoing consultation and support would be required from the National Child Psychiatry Inpatient Unit for those admitted to the LD CAMHS inpatient unit and vice versa.

Decisions about the most appropriate unit for older teenagers would also need a flexible approach, in close liaison with the young person, their family and adult LD services in the home Health Board. Adult LD services are more closely linked in with local adult social care services

once young people leave school. In some cases, a young person needing admission shortly before their 18th birthday, particularly if they have already left school, may be best served by their local adult LD inpatient facility. This can aid discharge planning and allow care providers to work with the young person on their local ward before discharge. In others, young people may remain at school until aged 19 and an LD CAMHS inpatient unit may better meet their needs, even if they are already aged 18.

5.3 Estimated average length of stay

A reasonable overall estimated average length of stay would be between 6 and 12 months, with significant individual variation. This estimated average length of stay is significantly longer than the average lengths of stay in the 3 regional YPUs and it will be strongly affected by care pathways, particularly discharge arrangements.

5.4 Service specification for a specialist LD CAMH inpatient unit

While it is beyond the scope of this needs assessment to develop a formal service specification for a Scottish specialist LD CAMH inpatient unit, this report contains much information to usefully inform development of the design of the physical environment, staff skill-mix, referral criteria, care pathways and interfaces with other inpatient and community services. The NHS England service specification for Tier 4 CAMHS inpatient LD services may also be used to inform a service specification for a unit in Scotland (NHS Commissioning Board, 2013).

5.4.1 Physical environment

A developmentally appropriate physical environment is crucial, with education and recreation facilities and an ability to nurse some children

and young people in individualised robust settings as described above in section 4.12.2.

Patients requiring access to an LD CAMH inpatient unit will have a range of ages, gender and level of learning disability. Consideration would also be required during the design of a unit as to how the physical space is best subdivided to allow children and young people to have suitable peer groups or individual space as appropriate. For example, a possible configuration may be:

- 2 x 3 bedded subunits for those who do not need secure or robust provision (could be allocated by age, personality/interests of children and young people, level of learning disability, mental health/behavioural presentation or gender, depending on patient need at any one time)
- 1 x 3 bedded secure subunit (note this may not be required if the needs of these patients are met by the secure/forensic CAMH unit)
- 3 x 1 bedded robust, individualised subunits

Whilst the individualized one-bedded subunits would be designed for those with severe destructive and aggressive behavior, they may also be used flexibly if required, for example for very young or vulnerable children who need to be nursed separately from other patients.

5.4.2 Staff skills

It is clear that additional skills are required in working with children and young people with learning disability due to the level, complexity and subtlety of diagnostic and treatment issues. Professionals need to understand learning disability, autism spectrum disorder and mental health issues and how they interact, in the context of childhood development and family systems. They need experience in working with

children and young people with learning disability, their families and the multiagency services that endeavour to support them, They also need expertise in the physical issues associated with learning disability e.g. epilepsy, motor function, gastrointestinal disorders, which can all present with or complicate mental health and behavioural issues.

The following disciplines/services would be required as core members of a specialist inpatient service:

- Psychiatry
- Nursing
- Clinical Psychology
- Occupational Therapy
- Speech and Language Therapy
- Physiotherapy
- Dietetics
- Neurodisability Pediatrics
- Pharmacy
- Education
- Social Work
- Advocacy
- Family support

5.4.3 Patient characteristics

From this survey, it would be anticipated that children and young people requiring the beds would be likely to have the following characteristics:

- Gender: 70% male, 30% female
- Age: 47% 16-17 years; 33% 14-15 years; 13% 12-13 years; 9% 11 or under years
- Level of learning disability: mild 27%; moderate 51%; severe/profound 22%
- Those requiring secure LD CAMHS beds would have mild or moderate learning disability and tend to be in the older age range
- Those requiring a robust individualised environment would have moderate or severe learning disability

The main reasons for children and young people being admitted to a specialist LD CAMH inpatient unit are anticipated as being for assessment and treatment of mental health issues where it is not possible for this to be carried out safely or effectively outside a hospital setting or in an existing Scottish CAMH inpatient unit.

High staff ratios would be required: 40% needing 1:1 care, 32% 2:1 care

Children and young people with mild learning disability could generally be expected to be managed on existing CAMH inpatient units, unless there is additional complexity or need for security. Where there is a need for security, they may be able to be managed on the proposed Scottish secure forensic adolescent mental health inpatient unit, given sufficient learning disability expertise and experience. However, where there is additional complexity and co-morbidity, an LD CAMH specialist unit would sometimes be more appropriate.

Some children and young people with moderate learning disability can access existing CAMH inpatient units, particularly where there is LD CAMH support or expertise amongst staff and a more typical mental illness presentation, without additional co-morbidity.

5.4.4 Co-location with other units

There is an identified overlap in the needs of the LD CAMH inpatient population and the Forensic CAMH inpatient population. Some of the former have forensic issues or need for additional security over and above that provided by YPUs or the National Child Psychiatry Inpatient Unit. Many of the latter have mild learning disability, autism spectrum disorder and other neurodevelopmental co-morbidities. There is a separate piece of work ongoing to develop a detailed proposal for a forensic mental health inpatient unit for young people; co-location of the two units would be helpful. For the LD CAMH inpatient unit, co-location on a site with existing adult LD wards is also essential.

5.4.5 Other service specification information

The NHS England service specification for Tier 4 CAMHS inpatient Learning Disability Service (NHS Commissioning Board, 2013) can be used to inform the development of a Scottish service. Clinicians participating in the survey were not made aware by the 5 year survey team of this service specification. It is striking therefore that there is a high correlation between the NHS England service specification and the identified unmet needs of Scottish children and young people from this survey.

It is important to be clear that an inpatient mental health service for children and young people with learning disability is in no way intended to equate to the long term institutional hospital care of the past. Hospital

admission would be for assessment and treatment of mental health and associated behavioural difficulties, as is the case for their peers without learning disability.

Given the complex physical co-morbidities of this patient group and their greater risks associated with psychopharmacology, an inpatient unit would need ready access to pediatric neurology and other acute pediatric specialties. A service-level agreement would be required for input, including arrangements for out-of-hours support. Out-of-hours psychiatry support will be required. Both of these factors would need to be taken into account when considering the location of a Scottish unit.

Clear arrangements need to be made for specialist education to be available to children and young people from all local authority areas admitted to a unit.

The crucial role of families and carers was clear from this survey. An inpatient unit must be designed to work closely with children and young people’s families and existing carers to harness their expertise and personal knowledge of their child’s personality, interests, strengths and needs. On-site accommodation and family support services would allow relationships to be maintained and for families and care staff to engage with and understand results of assessments. They can be further skilled up to implement support plans and manage their children’s needs at home or in a local care setting.

5.5 Parallel developments required in services outwith an inpatient facility

The development of a LD CAMH inpatient unit, in the context of a time of integration of health and social care budgets and re-organisation at Health Board/Local Authority level gives an opportunity for collaborative planning of effective multiagency pathways and support within the GIRFEC (Getting It Right For Every Child) framework (http://www.gov.scot/Topics/People/Young-People/gettingitright)

The complex inter-relationships between inpatient treatment, community treatment, education and social care provision were evident from this study, with deficits in one leading to difficulties in others. These 9 or 12 beds would quickly become inadequate and/or stop operating effectively as an inpatient treatment facility without parallel development of community LD CAMHS, particularly intensive community services and also specialist robust education and social care provision for the most complex children and young people.

Innovative models need to be considered to avoid delayed discharges, such as a social care/education facility located near the unit. This could provide expert input to inpatients and an interim placement for complex patients discharged from hospital where local services need more time and support to develop long term provision nearer to home. Such a facility would require health and social care to work in partnership.

5.6 Care pathways and interface of a Scottish LD CAMH inpatient unit with other services

The need for improved access to appropriate community mental health services for children and young people with learning disability was highlighted throughout this survey, including early intervention, outpatient and intensive community treatment services. An inpatient unit needs to be firmly linked into these services, with clear admission criteria/guidance and pathways for safe discharge. Local, regional and national services need to develop clear care pathways so that children and young people with learning disability can access the full range of health and social care services required. Work to develop an inpatient unit needs to also include the development of such pathways, which can be informed by the LD CAMHS Framework document (Appendix A2.2) and the 'Do once and share' care pathway (Pote & Goodban, 2007). An LD CAMH inpatient unit would need to be located on a hospital site with existing LD inpatient units, to provide staff back up and support, because it is clear from this survey that the patients with the most severe and complex needs have required nursing care from trained learning disability nurses.

5.6.1 Existing inpatient units

This study indicated that existing regional YPUs and the national under 12's inpatient provision of the National Child Psychiatry Inpatient Unit vary in their experience, knowledge and confidence in working with children and young people with learning disability. This is also dependent on physical environments and support available from specialist community services. Children and young people with even moderate learning disability can do well in 'mainstream' provision, with sufficient expertise in staff and where the child or young person has good verbal

skills and a more typical mental illness presentation. For example, Skye House in Glasgow has a number of learning disability-trained staff working as part of the staff team.

It would be important for the presence of a national specialist LD CAMH inpatient unit not to ‘de-skill’ staff in existing units, but rather to play a role in training and support to encourage access to these units where appropriate. Clinicians from the existing units could be ‘seconded’ to a specialist unit and vice versa to learn and share expertise. Links with the National Child Psychiatry Inpatient Unit would be crucial in supporting expertise in dealing with younger children with complex neuropsychiatric presentation.

5.6.2 Forensic CAMHS

The need for a forensic/secure adolescent mental health inpatient unit in Scotland has been recognized and work is underway on proposals. The present study identifies the need for forensic/secure mental health inpatient care for a number of young people with learning disability and/or autism spectrum disorder. There is a clear overlap in the populations identified by this needs assessment and that carried out for the forensic mental health inpatient unit. The majority of children and young people with forensic issues and mild learning disability or autism spectrum disorder without learning disability were considered to be within the remit of a mainstream adolescent forensic mental health inpatient unit. The frequent neurodevelopmental co-morbidities between these groups were recognised. However, for them to access such a unit there would need to be sufficient expertise in learning disability, autism spectrum disorder and other neurodevelopmental conditions amongst the multidisciplinary staff group and an appropriate physical environment.

People with moderate/severe/profound learning disability with a need for security are generally not subject to formal court proceedings or considered the remit of forensic services but rather viewed as having 'challenging behaviour'. However, there are some common/overlapping needs between these groups of children and young people, for example, the need for some to be nursed in the type of robust, individualised setting described above.

Co-location of an LD CAMH inpatient with the proposed Scottish forensic CAMH inpatient unit would make sense to allow development of expertise, provide support and nursing back-up. This would also allow a range of expertise and flexible use of resources. Learning disability-trained staff are generally very experienced in managing those with autism spectrum disorder and other neurodevelopmental disorder and can support and could share these skills with staff working in forensic CAMHS. CAMH-trained staff working in a forensic CAMH inpatient setting may be more experienced in working with patients with mental illness and could provide support to a LD CAMH unit in working with some patients with learning disability and co-morbid mental illness. Both staff groups have experience of managing severely challenging, including aggressive and destructive, behaviours and could provide support and back up to each other where required.

Whilst patients with more severe levels of learning disability would need to be mostly kept separate from peers with forensic issues, both units could share the use of a number of facilities, for example, safe outdoor space, education and gym facilities. If a number of robust individualised environments were built, these could be used by children and young people with staff from either unit according to need.

5.6.3 Referral criteria

Clear referral criteria for a LD CAMH inpatient unit need to be developed in collaboration with community services nationally and in relation to other CAMH inpatient units. However, flexibility needs to be maintained so that the needs and circumstances of individual children and young people and their families can be fully taken into account. For example, the evidence from this study indicates that referral criteria should include the following general rules and associated exceptions:

- Most children and young people with mild learning disability requiring inpatient mental health care should be admitted to existing CAMH inpatient units; although a small number of those with more complex co-morbidities may need to access the LD CAMH inpatient unit.
- Most children and young people with moderate learning disability would need to be admitted to the LD CAMH inpatient unit, although this will vary according to the environment and staff skills within individual YPUs and the type of issues that the individual child or young person presents with.
- All of those with severe/profound learning disability require a specialist LD CAMH inpatient unit for assessment/treatment purposes. However, very brief crisis admissions for these and other children and young people may still be more appropriately supported by community clinicians on local wards.
- The vast majority of those with autism spectrum disorder (without learning disability) should be admitted to existing CAMH inpatient units where inpatient mental health care is required, except for

those requiring security provided by the proposed forensic CAMH unit.

- A very small number of children and young people with autism spectrum disorder (without learning disability) may rarely require admission to specialist ASD inpatient care outside Scotland. This requires ongoing monitoring, enabling review of the situation for these children and young people.
- The needs of younger children should be considered on a case-by-case basis, in collaboration with the National Child Psychiatry Inpatient Unit. Generally, the National Child Psychiatry Inpatient Unit can effectively manage children with more severe levels of learning disability and complexity than the YPUs. However, in some cases a learning disability-specific setting is required. If younger children are admitted to the LD CAMH unit, support and consultation from the National Child Psychiatry Inpatient Unit will be invaluable and vice versa.

5.6.4 Outreach/support function to community LD CAMHS

Community clinicians participating in the survey were keen that any unit had an outreach and consultancy service. They were particularly enthusiastic as to the potential value of this where mainstream CAMHS see all children and young people, including those with learning disability and/or autism spectrum disorder, especially in remote/rural areas. Whilst providing a generic service, they recognised the need for specialist expertise in understanding and managing the complex needs of this group. These clinicians would welcome help from an inpatient unit in discussing complex cases and their management in the community, whether or not admission of an individual child or young person was

ultimately required. They would also find a crisis support service for intensive/urgent advice helpful, although the logistics of this would need to be considered.

The outreach/consultancy function provided by the National Child Psychiatry Inpatient Unit was given as an example of good practice and a similar function recommended. Types of outreach supports suggested included telephone and video-linked consultations and team members to travel to local areas to carry out assessments and offer advice. These should all be multidisciplinary, including perspectives from nursing, clinical psychology, psychiatry (including prescribing advice), occupational therapy, speech and language therapy and neurodisability pediatrics. Advice from social work and education professionals from a unit could also be offered, where requested by local council or Health and Social Care Partnership colleagues.

Such an outreach/consultancy remit would enable the unit's team to often gain an understanding of individual patients' and families' situation well in advance of admission. Additionally, they would build up a knowledge of and relationship with local multiagency services. This would allow the local situation, services and geography to be more fully considered during assessment and treatment. The feasibility of recommended support plans following discharge could be more effectively taken into account. Where local services are limited, the unit would need to offer a more active role in training and giving outreach support to those implementing plans after discharge.

5.6.5 Other health services

Other local community child health and pediatric services would be an integral part of the network of an individual child's care and there would be appropriate liaison with these services across Scotland.

A unit would also need to have strong links with local/regional specialist pediatric services in the area in which it was located. The pediatrician and other medical staff from the unit team would need to be able to access specialist opinion, most commonly from pediatricians specialising in neurology, gastroenterology, ear, nose and throat and respiratory medicine.

The survey shows that a significant proportion of children and young people are older teenagers, with some moving on to adult learning disability services after discharge from hospital. Good working links with these services need to be made in the planning and development stages of the unit to enable smooth transition pathways.

5.6.6 Other agencies

Consistent with the findings of the 'These are our children' report (Lenehan, 2017), the complex inter-relationship between health, social care and education services in the care and support of these children and young people is evident from the survey. Deficits in one part of the system can lead to difficulties for others. For example, a lack of local mental health/behavioural services can lead to an escalation of difficulties resulting in home placement breakdown and an out of area residential school placement at high cost to the local council. These placements themselves may not have access to mental health services and in some cases have broken down leading to hospital admission. Or a lack of suitably specialist robust education or respite facilities may

mean that children and young people may be stuck in hospital for many months or even years after their treatment there is completed. Only a small minority of admissions in the survey may have been prevented altogether by these types of education/care services, but their availability may have reduced the length of hospital stays and /or given intensive LD CAMH community treatment services an environment in which to work. Families also need suitable reliable respite and support in order to be able to implement the demanding strategies required to care for their children and young people at home.

Clinicians in the survey would find it helpful if a unit held a ‘pool of information’ available about services and placements as they can find it difficult and time consuming to keep up to date themselves. This could be utilised both to support discharge planning and to prevent admission where appropriate.

5.6.6 (i) New models of proactive multiagency working

The integration of health and social care budgets and organisation at Health Board/Local Authority and national level could be used as an opportunity to explore and understand these interactions. Planned earlier interventions from various agencies to manage and prevent escalation of difficulties in high risk groups should benefit children and young people, their families and lessen the number of high cost and out of area hospital and care placements. Multiagency economic analysis and outcome studies of early intervention/intensive community services are required to evidence the need for service development and reorganisation to better meet the needs of these children. Given the complexity and networks of services, collaborative multiagency planning and reorganisation at a strategic level is required to drive improvement.

A Scottish LD CAMH inpatient unit would need to understand and be linked in to relevant social care and educational services at local and national levels. These can be as diverse in their structure and degree of specialism as are mental health services for children and young people with LD. Links would need to be established in the planning stages of the unit to enable understanding of the unit's role and for effective relationships and pathways to be developed. Collaborative working within the 'GIRFEC' framework (http://www.gov.scot/Topics/People/Young-People/gettingitright) and creative use of multiagency resources, e.g. via self-directed support, could be used to develop individualised support packages.

5.6.6 (ii) Supporting timely and effective discharge

Clinicians in the survey recognised the difficulty for some local authorities in developing the individualised specialist support required to discharge complex children and young people from hospital. Discussions during interviews led to a suggestion for an innovative development aimed at enabling timely discharge from hospital for children and young people and encouraging patient flow through the unit. This would involve the commissioning of a small residential care facility, with access to suitable education, in the community near to the hospital inpatient unit. Councils unable to offer a permanent local care package when a children and young people is medically fit for discharge would be able to purchase an interim placement at the care facility pending their local package being arranged.

The interim care facility could make shared use of education and other facilities with the inpatient unit. Care staff could be involved in providing outreach support and activity to the inpatients, using their skills to aid

rehabilitation and inclusion for all inpatients. Thus the children and young people using the interim facility would be familiar with the staff and vice versa prior to transfer there. The inpatient multidisciplinary team would give outreach support to the interim unit, thus maintaining continuity of mental health care. For very complex children and young people and/or those with very challenging behavior, the care facility would be able to trial and demonstrate how to provide a robust and effective community care package. Social care and education staff could play a leading role in developing person-centred plans for future provision back in the family home or residential care provision. Local services can lack confidence in taking on very complex young people who have spent time in inpatient care. The interim unit's staff could have a specific remit to advise and train up the local care teams who will be supporting the children and young people on return to their local area, whether directly from the inpatient unit or via the interim care facility. This would enable sharing of multiagency expertise and a bridging of what can sometimes seem a large gulf between inpatient mental health and community social care provision.

5.6.7 Cross-border issues

Clear agreements and protocols will be required for cross-border arrangements for both Scottish children and young people and those from other UK jurisdictions. Issues were described around patients who are originally from England, but in care placements in Scotland. There appear to be increasing numbers of English (and possibly Welsh/Northern Irish) patients in Scottish secure care units, including some patients with learning disability and/or autism spectrum disorder. This also appears to be a trend in remote and rural areas where risk is managed by geographical isolation and high supervision rather than a

secure unit per se. If a Scottish specialist LD CAMH inpatient unit is developed and such patients are detained into it, there will need to be good links and clear pathways to transfer where appropriate to beds in their home area.

With increasing pressures on LD CAMHS beds elsewhere in the UK, there will need to be protocols to deal with requests for admission of patients from outside Scotland to a Scottish unit.

Cross border issues are a particular concern for access to inpatient care for patients of any age who are on remand and not yet sentenced. They cannot be moved over the border to England for legal reasons therefore there is currently no access at all to age-appropriate inpatient mental health beds for CAMHS patients (including those with learning disability) who are on remand.

5.7 The LD CAMHS Scotland Network

A new LD CAMH inpatient unit must be designed to fit in with the existing networks of services, as well as later playing a role in supporting future community service development. A number of participating clinicians suggested using a clinical network approach to support the planning and development of an inpatient unit, ensuring that it is embedded within clear pathways of care in community services across Scotland, for example, learning from the successful role of the Forensic Network (http://www.forensicnetwork.scot.nhs.uk/). The North of Scotland Tier 4 CAMHS (obligate) Network was also recommended as a model, formed to support the development of the new regional North of Scotland Young People's Unit in Dundee. Now the unit is open, the North of Scotland Tier 4 CAMHS Network continues to link regional community services, with inpatient care.

The LD CAMHS Scotland Network is a multidisciplinary, clinician-led network of now more than 200 clinicians, formed in 2008. It aims to improve access of Scottish children and young people to mental health services, by encouraging peer support, sharing of information and expertise, and supporting local and national service development. A committee has representation from all Health Boards and relevant disciplines. An e mail database allows information to be shared and for representative views to be gathered on national consultations. Annual meetings are held to share clinical and service development expertise. Discipline-specific groups within the network offer peer support and supervision.

The LD CAMHS Scotland Network, with funding for a network manager, administration support and lead clinician time, could be built on to:

- Support the development of an LD CAMH inpatient unit, its role, remit and service specification.
- Embed the new unit within pathways well connected to community health, social care and education provision across Scotland.
- Take forward training and workforce planning in conjunction with NES, to ensure sufficient trained staff for the unit and community services.

Once the unit is functioning, the Network could be based there to support links with local services and encourage patient flow. The Network would also:

- Play a strategic role in national and local community LD CAMHS organisation and development.
- Share the outcomes of the LD CAMHS Models and Outcomes Study and support Health Boards seeking to develop the identified promising service models.

- Advise Scottish Government on issues relevant to LD CAMHS.
- Link into other relevant work-streams, e.g. regional CAMHS Networks, CAMHS Lead Clinicians, GIRFEC, Adult LD and Autism Strategy, Education.
- Support the measurement of access to mental health services of children and young people with learning disability, e.g. via the Balanced Scorecard Key Performance Indicator.
- Work with NES to develop a training plan for the specialist LD CAMHS workforce and for wider CAMHS and multiagency partners.
- Support training rotations and secondments for LD CAMHS clinicians in the unit and community.
- Encourage and support clinical and service-related research.
- Review, develop and support annual multidisciplinary network meetings and committee.
- Support discipline-specific groups for peer support and supervision.
- Maintain the Network membership database and e mail system.
- Develop and maintain the network website to enable it to be a forum for sharing of information, e.g. on clinical pathways, service models, with links to other relevant forums.

5.8 Potential benefits of a specialist Scottish LD CAMH inpatient unit

5.8.1 Summary of study participants' views

The vast majority of clinicians interviewed thought that specialist LD CAMH inpatient provision was required in Scotland. Quite a number felt very strongly about this, commenting that they had seen the same issues arising across Scotland for years. They found it unjustifiable that a patient group with more severe and complex needs than children and young people without learning disability should have less access to inpatient care. Given that the numbers of children and young people requiring such provision would be unlikely to justify more than one unit for Scotland, there was acknowledgement that distance would still be a factor for some. However, in general for those with the most complex needs, a specialist LD CAMH inpatient unit was felt to be worth travelling to compared with trying to support them in local adult LD or regional YPU provision.

Parents interviewed had been asked to consider whether they would prefer their child to be admitted to a local but less specialist unit or to a specialist LD CAMH unit at a greater distance. They certainly found the distance an added stress factor in separation from their child. However, the nature of the setting was generally regarded as more important (and a source of stress) than location. One parent stated this explicitly, *"the specialist needs override the challenges of travel and separation."* Another parent was very clear that a unit in central Scotland was necessary to "*stop the outrageous practice of sending young people miles away to England and placing them in adult units".*

5.8.2 Benefits to children and young people with learning disability requiring mental health admission

Participating clinicians gave numerous reasons why their patients included in the survey would have benefitted from a specialist LD CAMH inpatient unit in Scotland. These are detailed in section A4.20 of the appendices and include quicker, better planned, safer, more specialist holistic assessment and treatment closer to home, preventing long periods of untreated illness/distress at home or in inappropriate units and escalation of difficulties. Access straight to an appropriate unit would prevent the multiple transitions currently experienced by a patient group who are particularly sensitive to change. An age and developmentally appropriate environment, activities and education would aid recovery and rehabilitation. More contact with family and local services would facilitate effective discharge planning.

5.8.3 Benefits to community LD CAMHS and other patients

There was a clear consensus from CAMH, adult LD and LD CAMH clinicians across Scotland that it would be important for an inpatient unit not to be developed in isolation from community services. Support for local services by a unit, particularly via a consultation role (whilst respecting local knowledge) was suggested by many. This would be particularly valued by those from remote and rural areas and smaller Health Boards who cannot realistically sustain comprehensive specialist LD CAMH community services.

At present these relatively few children and young people who require inpatient care absorb a huge proportion of mental health and other services time with constant crisis management. In addressing their needs, community services would be freed up from having to manage

severely unwell children and young people in the community, from making time-consuming referrals to England or from cobbling together less than ideal local ad-hoc solutions. They would be able to direct this time to more proactive outpatient work and earlier interventions.

Recruitment to community mental health services for children and young people with learning disability is likely to be improved if they can become more proactive and less focused on stressful and time-consuming situations where clinicians attempt to find hospital beds or manage children and young people in inappropriate settings.

A specialist LD CAMH inpatient unit could become a centre of expertise that could resource and trains developing community LD CAMH services, as well as provide consultation around complex cases and inpatient care for those who require it. Thus community LD CAMH services across Scotland could become more experienced and resilient, allowing more complex children and young people to be treated in their local communities.

5.8.4 Financial benefits

At its highest point during the 5 year survey, total spending on this patient group via the NHS Scotland risk sharing scheme alone was approximately £1 million in 2014/15. The average cost per patient with non-forensic but complex LD /ASD for admissions paid for by NHS Scotland was £112,000 per admission.

As illustrated by the graph in section 4.10.2 (ii), spending by NHS Scotland shows an upward trend. This trend is likely to be exaggerated by the relatively short time that the beds have been commissioned for. It may also reflect growing awareness amongst practitioners of the

specialist inpatient units and of the mental health needs of children and young people with learning disability in general.

Costs do not necessarily reflect demand. Costs incurred over the 5 year period will have been contained by limited access to NHS England LD CAMHS beds. For example, in 2015/16 (after the study period), NHS Scotland costs were down on the 2014/15 figure. This was influenced by a number of children and young people being discharged at the end of 2014/15 and no beds being available for others referred for admission. If beds had been available in 2015/16, costs would have been significantly higher. Significant fluctuations in cost are highly likely to occur when a small number of expensive admissions are being considered.

Due to limited bed availability in NHS England units, Health Boards paid for some children and young people to be admitted to private LD CAMH hospitals at a cost of £330,000 to £624,000 per annum. Costs may have been higher than to NHS units partly due to more of these admissions being in a secure setting. Costs of nursing children and young people in adult LD wards in Scotland were up to £520,000 per patient per annum, with some requiring considerable extra (but unknown) costs for building adaptations and repair. Shorter admissions (often of those with less severe levels of complexity and challenging behavior) to adult mental health and YPU wards could still cost up to the equivalent of £312,000 per patient per annum.

Long waits for inpatient provision in England also were costly to Health Boards and Local Authorities. For example, costs of supporting admissions to adult LD wards which were effectively ‘holding places’ pending treatment in LD CAMHS units in England included £56,524 for 16 weeks, £288,462 for 13 months and £91,449 for 26 weeks. A total of £232,000 in extra nursing costs was required for a patient in an YPU

while awaiting an appropriate bed in England. Another patient required additional multiagency support costing £130,000 over a 6 month period whilst awaiting an LD CAMHS inpatient bed. Faster access to appropriate LD CAMH beds in Scotland would therefore save the cost of such ‘holding arrangements’ as well as the cost of admissions themselves being potentially reduced.

These figures are similar to those found by a recent report (Lenehan, 2017), which quotes a cost of approximately £1 million per child over a 3 year period for those with learning disability and/or autism and complex needs requiring inpatient mental health care or residential schooling

It would be anticipated that a Scottish unit, well linked in to Scottish community services would facilitate quicker discharge planning. Local social service departments can benefit from detailed holistic assessments of care needs as well as mental health treatment that admissions provide. However, discharge will often depend on the availability of social care and education packages to move on to. Such packages often need to be ‘bespoke’ and are themselves very expensive. The overall cost to the ‘public purse’ of quicker discharges of some patients may therefore remain relatively constant, but with considerable benefit to children and young people and their families of being closer to home in a non-hospital setting sooner. For others, early treatment by specialist LD CAMH community and inpatient teams can improve or prevent further escalation of mental health and behavioural issues, with subsequent savings across agencies. Appropriate specialist care could also allow better planning of adult supports and placements, and avoid lengthy admissions to adult LD wards in crisis in early adulthood.

5.9 Cautions about a specialist Scottish LD CAMH inpatient unit

5.9.1 Travel

The main concern relating to a Scottish LD CAMHS unit was significant travelling times from parts of Scotland. It was recognised by study participants that it could be very difficult for children and young people with learning disability and/or autism spectrum disorder to be far from familiar places and people. If there was a national Scottish LD CAMH inpatient unit, travelling time from all parts of Scotland would still need to be considered, as would the financial implications for families. It was noted that the same challenge exists for mental health as for specialist residential care and education placements in how to maintain pre-existing relationships, raising questions about whether a specialist unit at a distance is better than non-specialist units more locally. However, experience described across settings suggested that where a specialist unit understands the communication and other needs of the child or young person and has an appropriate physical environment, the child or young person can settle quite well. Families and local professionals would need support to travel and on-site accommodation would help considerably.

5.9.2 A specialist unit would not replace all use of admissions to non-specialist wards

Clinicians were concerned that regardless of a Scottish Specialist LD CAMHS unit, there will always be a need for very short local crisis admissions and while these do not happen very often when they do circumstances are quite extreme. Services available to support such situations are currently extremely rare. Local ad-hoc solutions can be successful but are very dependent on what and who happens to be

available at the time. Clear pathways and protocols are required locally and consideration given as to the role a national unit could play in advising and supporting such situations.

5.9.3 Any specialist unit must be a mental health treatment facility not a long term residential care unit

It is important to be clear that the hospital admissions required by children and young people in this study were needed for assessment and therapeutic interventions for children and young people with learning disability and/or autism spectrum disorder who have additional severe and complex mental health and behavioural difficulties. This should be clearly distinguished from the long-term institutionalised hospital care of the past. Long-stay hospital beds for children and young people with learning disability were closed for good reasons, including the belief that these children and young people were particularly vulnerable to inappropriate admissions arising from a lack of home-based supports. Putting children and young people in a specialist hospital was at times a cheap solution for community and family breakdown. There remains a risk that lack of community services could drive admissions to and delay discharges from a mental health inpatient unit.

5.9.4 Development of a specialist unit should not detract from development of community LD CAMH services

Concerns were raised by participating clinicians that a focus on developing inpatient provision may detract from the urgent need to build up community mental health services for children and young people with learning disability. It is crucial that any development of a specialist LD CAMH inpatient unit facilitates rather than sets back development of the

wide range of high quality community health, social care and education services required by these children and young people and their families.

5.10 Role of families

The crucial role that the vast majority of families play in caring for, supporting and advocating for their children is evident throughout this report. It is important that the development and ongoing work of any specialist LD CAMH inpatient unit fully involves children and young people, their families and carers. The needs of families and their relationships with their children must be considered carefully at all stages.

6. FULL RECOMMENDATIONS

1. **A bespoke national learning disability child and adolescent mental health inpatient unit, with 9 beds, located in Scotland,** for children and young people with more severe levels of learning disability, complexity and challenging behaviour.
   - A minimum number of 9 beds is initially required, to include 3 robust, individualised environments
   - It will be for children and young people with more severe levels of learning disability, complexity and challenging behavior whose needs cannot be met in the existing Scottish child and adolescent inpatient mental health units
   - The recommended bed numbers assumes that adolescents with mild learning disability and/or autism spectrum disorder who need secure inpatient mental health care will be accommodated within the proposed Scottish secure/forensic adolescent mental health inpatient unit.
   - Accommodation should be available on-site for families and carers
   - Advocacy for children and young people should be provided
   - Family support services should be provided
   - The service specification should be informed by information gathered by this study, and the NHS England LD CAMHS inpatient service specification

   Options appraisal of the location should take into account:
   - Access to specialist pediatric support, including pediatric neurology
   - Need for co-location with adult learning disability wards for nursing support and back-up

- Consideration of co-location with any Scottish secure forensic adolescent mental health inpatient unit to share expertise and make joint use of facilities such as safe outdoor space, sporting, educational and therapeutic spaces
- The site should have capacity for expansion, given that recommendations for bed numbers are minimum estimates of need and the possibility that development of community LD CAMH services may uncover further hidden need.

There should be broad stakeholder involvement in the planning and development of a unit, its referral criteria, and pathways in and out and service specification. Stakeholders should include:

- Children, young people, families and carers
- CAMHS, LD CAMHS, adult LD, child health/pediatrics
- Local authority social care and education partners
- Third sector organisations

The unit should develop and support local community LD CAMH services with:

- Clear pathways in and out of the unit
- Telemedicine links for consultation advice on complex outpatients and for inpatient review/planning meetings
- An ability for staff to travel to assess and advise on the management of complex children and young people who may or may not ultimately require admission

Referral criteria, role and remit should be clearly set out in relation to the regional YPUs, National Children's Psychiatry Inpatient Unit, Adult LD wards and any young person's Secure forensic mental health inpatient unit.

Close links with the regional YPUs and the National Child Psychiatry Inpatient Unit should be maintained, with sharing of expertise and joint working to best meet the needs of all children and young people.

Consideration should be given to the development of a specialist interim social care/education facility located near to the inpatient unit:

- For children and young people no longer requiring hospital care, but whose local authorities need time and support to commission bespoke local care packages
- This facility and the inpatient unit could share staff and skills to benefit of the children and young people
- Revenue costs should be borne by the home health and social care partnerships of the temporary residents
- Discharge planning must be part of the entry criteria.

2. **A national clinical network to support development of the unit and community services, linking with multiagency partners across Scotland.**

   The current LD CAMHS Scotland Network should be developed into a more formal funded network.

   The Network will:

   - Support the development of a unit, its role, remit and service specification
   - Work with NES to take forward training and workforce planning, to ensure ongoing sufficient trained staff for the unit and community services
   - Be based in the unit once open, to support links with local services across Scotland, encourage patient flow and have an ongoing role in community service development

- Develop links with multiagency partners nationally to encourage collaborative strategic service planning.

3. Improvements in access to the four existing Scottish child and adolescent mental health inpatient units for children and young people with autism spectrum disorder and those with milder degrees of learning disability and less complex needs.

- Children and young people with autism spectrum disorder (without learning disability) and children and young people with mild learning disability should be treated on existing child and young person's mental health inpatient units, unless there is a need for security
- Staff need additional training and support in working with these children and young people
- Some children and young people with moderate learning disability may be treated on existing units, but may require additional support.

4. Additional training and support for staff at the four existing Scottish child and adolescent mental health inpatient units in order to improve outcomes for children and young people with autism spectrum disorder and those with milder degrees of learning disability who receive treatment in those units.

5. Development of the full range of community child and adolescent mental health services for children and young people with learning disability across Scotland.

Development must include early intervention, multidisciplinary outpatient teams and intensive community assessment/treatment services.

6. Health and Social Care Partnerships to review community provision for children and young people with a learning disability and/or autism spectrum disorder in order to maximise appropriate use of a bespoke mental health inpatient unit and work with any new unit to ensure appropriate referral pathways and discharge planning.

7. Health and Social Care Partnerships and NHS Scotland must create clear pathways and commissioning arrangements to existing facilities, including those outwith Scotland.

8. NHS National Specialist Services Division should continue to ensure that pathways to specialist services in England are available for the occasions where an admission to a unit outwith Scotland would be more clinically appropriate.

There needs to be clear guidance and commissioning agreements made for easier access to NHS England beds:

- Pending the development of a LD CAMH inpatient unit
- For the very small number of children and young people likely to still require specialist care in England in the future.

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APPENDICES

A1: Contributors and supporting costs

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74. Susan Tait, Nursing Officer, Mental Welfare Commission for Scotland

75. Dr Tanya Thiagarajah, Consultant Psychiatrist, Adult Intellectual Disability, NHS Forth Valley

76. Ms Cecilia Thompson, Interim CAMHS Manager, NHS Grampian

77. Ms Joan Tilley, CAMHS Manager, NHS Western Isles

78. Dr Kate Towlson, Consultant Child and Adolescent Psychiatrist, NHS Greater Glasgow & Clyde

79. Mr Marcus Vosoughi, Senior Information Analyst, NHS Fife

80. Anita Ward, Senior Assistant Accountant, NHS Dumfries & Galloway

81. Dr Morag Watson, Clinical Psychologist, NHS Highland

82. Dr Chris Wiles, Clinical Psychologist, NHS Grampian

83. Dr Elizabeth G Willox, Consultant Psychiatrist, Adult Intellectual Disability (Forensic), NHS Grampian

84. Mr Philip Wilson, CAMHS Manager, NHS Highland

85. Dr Mike Winter, Medical Director PCF SBU, NHS National Services Scotland

86. Dr Joanna Young, Consultant Child and Adolescent Psychiatrist, NHS Ayrshire and Arran

A2.1: Discussion paper re issues to consider when young people with learning disabilities are admitted to adolescent inpatient units

This paper was produced after a meeting where representatives from the 3 inpatient units and clinicians working with young people with learning disabilities were invited to share thoughts on managing support needs. Not all of the suggestions will be necessary for every young person with a learning disability but all are relevant for consideration when planning the admission of a young person with a learning disability. All of the suggestions would be in addition to the usual good practice which occurs when a young person is admitted to one of the units.

Consultation prior to admission

We felt it would be useful (where possible, depending on urgency) for the clinicians seeking an admission to request a consultation with the proposed unit in the first instance. Where the admission is urgent, detailed telephone consultation is required. It is helpful to clarify whether the unit can meet the young person's needs prior to involving the young person in the process. An important issue to clarify would be around the unit's physical environment, how they would identify possible presentation of significant behavioural challenge, possible triggers, escalation cycle and possible de-escalation strategies. It is also important to assess whether the unit is equipped to meet the young person's medical needs e.g. able to respond to potential medical emergencies or have access to appropriate specialist support. It is also helpful to get a sense from community teams about premorbid functioning to have a sense of what is mental illness and what is disability and what normal functioning may look like.

Pre admission

If clinically indicated it may be necessary / beneficial to assess the young person in their own environment for example visiting them at home with the referring clinician.

It is helpful to seek advice from family / carers re the level of preparation a young person would need prior to admission and the most helpful form e.g. a social story, a video of the unit, a tour.

We felt it might be helpful to develop social stories for the units around coming into hospital at different communicative levels.

It is helpful to get a sense from families / carers of young people's communication systems. If speech is limited it is helpful to get information from parents / carers re communicative vocalisations or sounds. This would include their capacity and awareness of hunger / thirst / physiological discomfort e.g. full bladder and bowels / pain and how this might be communicated. Also to get a sense of a young person's ability to seek help. A personal passport may have a role here perhaps produced by the community team.

It is helpful to get a sense of a young person's capacity to make informed choices both in terms of admission and the need for use of the Mental Health Act and/or the Adults with Incapacity (Scotland) Act but also for much smaller things such as meal choices.

It is helpful to get a good understanding before admission of the person's needs in terms of environment. Young people with Learning Disability, particularly if they also have Autism may find busy, noisy, visually stimulating environments difficult. For example, some young people may find it difficult being in a room with more than one or 2 other people,

particularly when they are talking. School staff as well as family/carers can be a good source of information about their needs in this respect. Apparently unexplained sudden outbursts of agitation may occur due to being over-aroused/over-anxious by the environment.

These individuals may benefit from a small group of identified keyworkers whom they could possibly meet prior to admission.

Admission

We felt it might be helpful to develop social stories around going into hospital – what to expect in terms of your own room / bathroom, meal times etc. We also thought social stories around visiting, investigations, therapeutic interventions including medication and who will help me would be useful. Due to initiation difficulties it might be helpful to have a social story re asking for help / communicating pain / discomfort.

There would also be a need to individualise additional social stories around areas of mental health difficulty e.g. anxiety or other symptoms.

Ongoing care

A speech and language assessment can often be useful on admission to get a sense on receptive and expressive communication and the number of information carrying words a young person can understand. This can inform care planning and may change over time as a young person's mental health improves. This knowledge can also help staff to make therapeutic interventions accessible to a patient and assess their capacity. SLT can support the provision of accessible information e.g. about medication and mental health disorders.

It can also be helpful to request a consultation from Clinical Psychology to allow a staff team to get a sense of a young person's cognitive profile

and possible strengths and weaknesses. Young people with learning disabilities can sometimes present patchy cognitive profiles that can make their presentation and overall level of functioning appear inconsistent and difficult for people to make sense of. Both the speech and language and psychological assessment may be available from the community team at admission if the young person is well known to the service.

Young people with learning disabilities generally benefit from visual supports such as a visual timetable with clear now / next indicated to help the young person to understand the activities of the day. Maximal use of routine is helpful to reduce anxiety.

It is important family contact / the opportunity to phone home / carers is on the timetable to help the young person not to feel abandoned. Time concepts are often difficult and they can struggle to hold people in mind. Also there may be a greater need to keep to a set schedule of appointments to avoid where possible something unexpected happening.

It is likely to be helpful for a staff member to go over the timetable and help prepare a young person for the next day and then at intervals throughout the day e.g. morning, afternoon and evening.

It is important to monitor physical health needs as young people with learning disabilities can struggle to initiate, for example in communicating they are in pain / discomfort or experiencing drug side-effects. They are also more likely to have co-morbid medical and mental health disorders.

Young people with Learning Disabilities can be particularly sensitive to medication side effects. It is generally best to start with lower than normal doses of medication and increase slowly, with careful monitoring, to reduce the incidence of side effects and increase the likelihood of a

successful response. Physical co-morbidities are common and liaison with Pediatricians and Pharmacists is often required to ensure safe prescribing.

It is important to consider the sensory environment in that a young person maybe seeking or avoiding sensation in terms of sight, auditory, olfactory, gustatory, touch, movement. If these are viewed to be an issue seeks occupational therapy support.

Young people with learning disabilities need access to developmentally appropriate activities in leisure time to reduce their anxiety and improve coping. They may want to watch television programmes suitable for younger children because they are unable to make sense of age appropriate programmes. They need to space to watch / play with toys which is separate from other young people to reduce ridicule. Toys will likely need to be brought from home as they are likely to be unable to engage with ward games.

They are likely to require greater staff support and supervision during unstructured times as they may struggle to occupy themselves and won't understand the communication of their peers and general conversations.

Young people with learning disabilities may struggle to make an informed choice and may well repeat the last option presented. It is best to present two choices simultaneously to promote understanding.

It is worth considering the usefulness of an advocate if the young person does not already have one.

It may be helpful for staff to have additional training in challenging behaviour looking at definitions, understanding the function of challenging behaviour, recording systems and such like.

Discharge Planning

The adults with incapacity act can be helpful if a young person (over the age of 16) is deemed to be incapable of acting on decisions; making decisions; communicating decisions; understanding decisions; or retaining the memory of decisions. It allows you to consider whether a young person can make safe decisions about their lives or if they need to be made by others in their best interests.

When a young person is ready for discharge it is helpful to consult back to the system about what has worked well to promote their management in the community.

We felt a social story around “I’m feeling better and I’m going to leave hospital soon” might be helpful. Also a social story about how to get help in the community.

Consideration should be given to a communication passport for the community particularly if the young person is not returning home.

Occupational therapy where appropriate can be very useful in supporting meaningful integration.

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A2.2

The Mental Health of Children and Young People: A Framework for Promotion, Prevention and Care.

Effectively implementing the Framework to improve the mental health of children and young people with learning disabilities

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On behalf of the LD CAMHS Scotland Network

June 2011

The Mental Health of Children and Young People: A Framework for Promotion, Prevention and Care.

Effectively implementing the Framework to improve the mental health of children and young people with learning disabilities

Introduction

Children and young people with learning disabilities have high mental health needs, which often go unrecognised, and unmet (Emerson & Hatton, 2007). This document addresses concerns about the general paucity and inequity of mental health provision for children and young people with learning disabilities across Scotland. "The Mental Health of Children and Young People: A Framework for Promotion, Prevention and Care" (Scottish Executive, 2005i) (hereafter referred to as 'the Framework') has led to considerable work being done to drive improvements in Scottish Child and Adolescent Mental Health Service (CAMHS) delivery. Children and young people with learning disabilities are mentioned in the Framework but specific focus is required to meet their mental health needs.

"Mainstream health services should develop the resources and expertise necessary to respond to young people with learning disabilities, their families and networks and should not exclude people because they have a learning disability" (Foundation for People with Learning Disabilities, 2002). This document aims to highlight the mental health needs of children and young people with learning disabilities and to give guidance on how service planners and providers can fully implement the Framework to meet the needs of this vulnerable group. The underlying principles of the Framework apply to all children, including those with learning disabilities. This document should be read in conjunction with the Framework and does not repeat information contained in it. It follows the main themes of the Framework, commenting only on areas where additional consideration is needed to ensure that the mental health needs of children and young people with learning disabilities are properly addressed. While acknowledging the importance of all agencies at all levels in improving mental health of children and young people with learning disabilities, this paper is aimed at health boards and local CAMHS. Its emphasis is on how CAMHS can improve its provision and contribution to existing networks around children and young people with learning disabilities.

Background

One in 40 children under the age of 18 years has a learning disability (Box 1). The number of children with severe and complex disabilities is increasing, with many young children with profound and multiple disabilities now surviving through childhood and into adulthood (Scottish Executive, 2006). Rates of mental health problems in children and young people with learning disabilities are much higher than their non-learning-disabled peers, with over 1 in 3 having impairing mental health disorders that are diagnosable and for which help can be offered. Increased prevalence is particularly marked for autism spectrum disorder, hyperkinesis, "challenging behaviours" (Appendix i) and anxiety disorders (Emerson and Hatton, 2007). The proportion rises to 1 in 2 for children with moderate to profound learning disability. Without intervention, such problems will lead inevitably to further disability, significantly impaired quality of life, and underachievement (Bernard and Turk, 2009). The higher rates of emotional disorder in children with learning disability are significantly linked to the higher rates of adverse life circumstances for this group, with 53% living in childhood poverty compared to 30% for the population in general (Emerson & Hatton, 2007). In Scotland, there are therefore at least 12 000 children and young people with learning disabilities currently in need of access to appropriate mental health services (Appendix ii). Children with learning disabilities account for 14% of all British children with a diagnosable psychiatric disorder.(Emerson & Hatton, 2007; Emerson, 2003).

Box 1: Definition of learning disabilities
Learning disability is a significant, life-long condition that has three components: • a reduced ability to understand new or complex information or to learn new skills; • a reduced ability to cope independently; and • it starts before adulthood (before the age of 18) and has a lasting effect on the individual's development. Taken from 'The same as you?' (Scottish Executive, 2000(i))

In addition to the universal risk factors for developing childhood mental health problems, children and young people with learning disabilities are exposed to additional risk factors (Box 2). Families struggle to cope with their children's complex physical and behavioural problems, especially where support and respite services are inadequate. The incidence of parental stress and mental illness is higher than in parents of children with typically developing children (Fidler et al., 2000) and these can be exacerbated by associated factors such as loss of sleep. These all impact on parents' ability to carry out recommended intervention strategies, so further increase the risk of mental health problems in their children (Emerson, 2003). Unresolved grief and loss reactions relating to the child's disabilities can also have profound effects on families. These are often prolonged and can re-emerge, particularly at times of transition.

Box 2: Some additional factors that explain the high incidence of mental health problems in children and young people with learning disabilities	
• Increased rates of communication difficulties • Limited coping strategies due to level of cognitive functioning • Limited social skills • Higher rates of specific disorders such as autism • higher rates of physical health problems (e.g. epilepsy) which are often severe, multiple and complex	• Very frequent severe sleep disorders • Increased risk of abuse • Lack of early recognition of mental health problems and lack of access to appropriate mental health services leading to more severe and entrenched presentations • Increased risk of being 'looked after and accommodated' • More likely to be living in childhood poverty or to experience multiple adverse life events

Scottish service provision

In the past policy and practice led to many parents of children with learning disabilities being advised that their children be indefinitely admitted to hospitals, often from an early age. With the closure of such institutions and the welcome shift to community care, Scottish mental health services have struggled to develop timely services to meet the needs of these complex and vulnerable children and young people. Possible reasons for this include a lack of recognition for the need for such services and a lack of specific transfer of health funding to the community. Where services are absent or poorly developed, there is a danger that the mental health needs of this population remain hidden. A number of barriers preventing children and young people with learning disabilities from accessing good mental health services can be identified (Box 3). Services are very variable and complex across the country, with mental health input, where present, coming from a variety of sources across the Tiers. These may include CAMHS, life-span learning disability services, child health/paediatrics, educational psychology, social services and non-statutory organisations. These arrangements usually developed according to local historic arrangements or the interests and drive of local clinicians and managers, rather than in an evidence-based, policy-driven or planned manner. Appendix iii shows the current patchwork of services known to be available across Scotland at the time of this report.

In the past 10 years, specialist learning disability CAMHS ('LD-CAMHS') teams have been set up in a small number of Scottish Health Boards. However, even the most developed Scottish LD-CAMHS teams lack the resources that are available in other parts of the UK and fall well short of recommended staffing levels (Appendix iv). There are no specialist day and in-patient units in Scotland available to adolescents with moderate to profound learning disabilities and severe mental illness. There is almost no intensive community treatment capacity. These young people can rarely access CAMHS in-patient units and clinicians have to resort to ad-hoc local arrangements. These may be dependent on the good-will of services and colleagues, who may lack the required expertise and resources. In some cases this has necessitated admission of children and young people to adult learning disability hospitals and pediatric wards, which is considered clinically inappropriate and unacceptable by current mental health guidelines. Other children are sent to private or NHS LD-CAMHS in-patient units in England, a long way from their families, support systems and local professionals. This is not only highly distressing to both the child and his or her family, but makes any form of integrated care with local health services and multiagency partners extremely challenging. Children with learning disability and mental health problems whose behaviour challenges local services may be placed in residential schools which can be in areas where the CAMHS infrastructure is not able to extend to this group.

Box 3: Barriers for children and young people with learning disabilities to accessing appropriate mental health services include:

- Often excluded from Specialist CAMHS and children generally no longer seen within Learning Disability services
- Exclusion from other existing Tier 2 services, e.g. school counselling services
- Lack of identification of the specific needs of children and young people with learning disabilities in health promotion and prevention work, including lack of developmentally appropriate and accessible information. This can result in their exclusion from such work
- Difficulties accessing traditional clinic-based CAMHS models when children have physical disability and/ or severe challenging behaviour
- A lack of awareness across health, education and social care of learning disability, associated mental health problems and their impact.
- 'Diagnostic overshadowing', where presenting problems are ascribed to a child's learning disability alone, rather than looking at other, potentially treatable physical or mental health causes.
- A lack of clarity of language and definitions (of learning disability) between professionals and agencies resulting in confusion.
- Service rigidity and lack of co-ordinated service planning, for example individual services establishing referral criteria that result in families being 'bounced' between services.
- CAMHS practitioners lacking a working knowledge of the services involved and required for children and young people with learning disabilities may further exacerbate poor communication and co-ordination between services.

A clinical network for LD-CAMHS has been developed in Scotland, with representation from Psychology, Psychiatry, Nursing, Pediatricians and Allied Health Professionals. It aims to develop as a focus for specialist knowledge and evidence-based practice; to liaise with UK-wide networks; and to support service development in Scottish CAMHS (Appendix v). Other relevant networks for those working with this group include the Forensic Mental Health Services MCN (www.forensicnetwork.scot.nhs.uk). Children with dementia are also a group whose needs overlap with the population of children with learning disability (Childhood Dementias, Stirling 2008).

Policy Context

Children and young people with learning disabilities are identified in the Framework as a group at high risk for developing impairing mental health problems (Emerson & Hatton, 2007). The need for further elaboration as to how those needs should best be met is recognised in the writing of this report. However, other reports, for example the Child Health Support Group In-Patient Strategy (Scottish Executive, 2004), specifically exclude children and young people with learning disabilities from their remit with the understanding that further work was required to look at these specific needs. This work is still outstanding. This was despite recognition that the specific expertise and environment required to meet the needs of children and young people with learning disabilities is generally unavailable in generic Scottish psychiatric in-patient units. Consequently this group of children and young people are at risk of falling into gaps between services as they are seen as outside the core remit of both CAMHS and Learning Disability Services.

In addition to the policy context outlined in the Framework, a number of strategic policies and initiatives relating to people with learning disabilities are relevant including, 'The same as you?' (Scottish Executive, 2000i), which was the first major review of learning disability services in Scotland for 20 years, where the need to maintain a focus on positive mental health is emphasised. The Needs Assessment Reports for Learning Disability (NHS Health Scotland, 2004) and Autistic Spectrum Disorders (Public Health Institute of Scotland, 2001) developed recommendations outlining the work required to reduce health inequalities as well as developing comprehensive services, including mental health provision for young people with ASD and their families. "This is what we want" (Foundation for People with Learning Disabilities, 2006) outlines guidelines developed through consultation with children and young with learning disabilities and their families as to what they want from CAMHS.

In England and Wales, following the development of their National Service Framework (DOH, 2004), the drive to develop appropriate mental health services for children and young people with learning disabilities was facilitated by the Public Service Agreement (PSA) Targets for 2005 which identified access to mental health services for children with learning disabilities as a key indicator for a "Comprehensive CAMHS" (see Box 8 in final section of this document). Such access was also one of the 3 performance indicators for CAMHS in England and Wales. Subsequently a 'Mental Health Care Pathway for Children and Young People with Learning Disabilities' (Pote & Goodban, 2007) was developed, with the aim of guiding future clinical and IT developments in the NHS and co-ordinating these with similar developments in Education and Social Care.

Person-centred multi-agency liaison and planning, as outlined in 'Getting it Right for Every Child' (Scottish Executive, 2005ii) is essential for children and young people with learning disabilities who may have complex physical/mental health needs as well as social care/educational needs. The proposed Integrated Assessment, Planning and Recording Framework could be of particular value for these children and families, who often find re-telling their stories to multiple agencies very difficult.

Some recent concerns have been raised (The Scottish Parliament, 2009) about an impact of 'Hall 4' (Scottish Executive, 2005iii) which has led to fewer routine universal health checks. This could have a particular impact on children with learning disabilities. Developmental delays which may be signposts to later learning disability are often not identifiable in the very early months of life. A lack of universal screening may lead to further delay in the diagnosis of learning disability, thereby losing valuable opportunities for early intervention and support to families.

Basic Principles

Whilst the basic principles of the Framework apply equally to children with learning disabilities, some warrant particular comment in this report:

Physical activity: Children with learning disabilities may have difficulty accessing community facilities such as sports and leisure centres, with deleterious consequences for their physical and mental health. Perceived stigma, sensory sensitivities, exclusion due to a misunderstanding of learning disabilities and behaviours, and lack of physical support required all contribute to reducing access to a range of community facilities.

Terminology: Terminology used to describe learning disabilities varies widely between and within agencies, thus complicating further existing terminology differences regarding mental health. This increases the risk of children with learning disabilities 'falling through gaps' in services, particularly mental health services. For example, education colleagues often use the term 'learning difficulties', with a moderate learning *difficulty* equating to the health term mild learning *disability.* In health terminology 'learning difficulties' refer to specific disorders such as dyslexia.

Transition: Children and young people with learning disabilities are particularly vulnerable during times of transition. They are often sensitive to change in routines and may not be able to communicate their anxieties and needs to those in new services which they enter. Concurrent multiple transitions are common, for example, a young person with difficulties may experience moving from pediatrics to adult health services at the same time as leaving school, moving from children's to adult's social care services and moving to adult mental health services. Maintaining good mental and physical health at this crucial time in growing up can greatly affect future life chances and a disabled young person's ability to participate fully in society (DoH, 2006). Losing young people in the transition to adult health services is likely to increase the risk of avoidable and treatable complications of their conditions (DoH, 2006). CAMHS can provide consultation and support to those in community child health, education and social work who manage the multiple transitions for children with severe and complex needs and advise on the emotional impact of transition on individuals. They can also assist in understanding the impact of other specific issues, for example the're-grieving' of the child's disabilities often experienced by their family at times of transition.

Participation and involvement: The meaningful participation and involvement of children and young people with learning disabilities poses particular challenges to services, due to cognitive impairment and frequent communication difficulties.

Evidence-based services: Service provision and interventions need to be evidence-based. There is considerable evidence for the effectiveness of a variety of interventions for child and adolescent and mental health problems (Roth and Fonagy, 2004; Fonagy, Target et al., 2002). This evidence should be used to inform the development of services for children and adolescents with learning disabilities, who can benefit from many of these approaches. However, there remains a need for specific research into the effectiveness of interventions in this group, whose mental health problems can differ in their pattern and presentation. Specific outcome measures appropriate for children with learning disability and their families are currently being piloted by CAMHS Outcome Research Consortium. Future studies evaluating the clinical effectiveness of CAMHS should include effectiveness for children and young people with learning disabilities.

Consent: Ability to assess the capacity for consent is particularly required by professionals working with children and young people with learning disabilities. Knowledge of the Adults with Incapacity Act (Scottish Executive, 2000ii) is also essential in working with those approaching, or following their 16th birthday.

Early Years - Universal

The need to shift resources towards early intervention is outlined in The Early Years Framework (Scottish Government & COSLA, 2009). The skills of CAMHS practitioners can make a valuable contribution in aiding the development of competencies within universal services working with children with learning disabilities (Box 4) for example, via Primary Mental Health Worker roles. It should be noted that at pre-school age, children are more likely to have a diagnosis of 'global developmental delay', rather than a learning disability.

Box 4: In early years, CAMHS can link with universal services to provide:

- Training and consultation to universal services staff in order to build capacity in understanding the psychological and mental health needs of children with developmental delay, the identification of psychological distress and helpful approaches
- Specific training to staff regarding the presentation and management of mental health problems in young children with developmental delay
- Advice and consultation to Community Child Health services who play a vital role in the early identification and management of children with developmental delay and emerging emotional and behavioural problems
- Advice to professionals regarding the psychological and emotional needs of parents of children with development delays, particularly in the period immediately following diagnosis
- Advice regarding the additional complexities of attachment and infant mental health in this group, including children with autism
- A sharing of knowledge and skills in understanding the impact of disability on families and family relationships, and its potential effects on collaborative working with parents and carers
- Joint work with Health Visitors and other Tier 1 professionals
- Joint assessment clinics with other professionals, e.g. Pediatricians
- Participation in integrated assessment protocols and multi-agency meetings
- Consultation clinics for parents for brief interventions
- Parenting interventions which have an evidence base for children with developmental delay. May be provided by CAMHS or by universal services with consultation and advice from CAMHS

School Years - Universal

Educational needs of children with learning disabilities are now addressed under the Additional Support for Learning Act (Scottish Parliament, 2004). Special Education Needs schools often provide a vital facilitating role for children with complex needs, supporting access to child health, mental health and social services as well as providing important support and advice to families. They are a locus for liaison with further education and adult learning disability health and social services at transition from school. With increasing inclusion of children with learning disabilities into mainstream education, it is important that all schools have knowledge of and links into the appropriate services so that appropriate care is accessed and needs met. The role of CAMHS link worker/Primary Mental Health worker needs to include the mental health needs of children and young people with learning disabilities in mainstream and special education.

If mental health needs are unaddressed, then children with learning disabilities and severe challenging behaviour are at high risk of exclusion from school. Families may be required to provide full time care at home, increasing family stress and leading to a downward spiral - increased family stress further increasing the child's distress and challenging behaviour. A significant group of children with the most severe and complex mental health needs attend residential schools, often outside their local authority and health board area. Such schools often lack easy access to co-ordinated LD-CAMHS services. In such circumstances, mental health problems may remain unaddressed, becoming more entrenched and posing great difficulties in transition back into local adult learning disability services.

Box 5: During school years, CAMHS can link with universal services to provide:

- Training and consultation to universal services staff in order to build capacity in understanding the psychological and mental health needs of children and young people with learning disabilities, the identification of psychological distress and helpful approaches
- Specific training to staff regarding the presentation and management of mental health problems in children and young people with learning disabilities
- Participation in integrated assessment protocols and multi-agency meetings
- Support in adapting interventions to make them appropriate for children with learning disabilities, e.g. emotional literacy, anti-bullying, sex education
- Support for parents and schools in dealing with issues of puberty and adolescence, taking into account the child's learning disability
- Consultation and training to ensure that counselling and other therapeutic Tier 2 services are accessible to children and young people with learning disabilities
- Provide relevant advice to Education Services so they can identify appropriate school environments and placements to meet the social, emotional, developmental and mental health needs of individuals.
- Support in understanding and responding to the emotional impact of teaching and learning
- Support in understanding and responding to the emotional impact on children and families of transitions to primary school, secondary school and to adult services
- Information about local support services, particularly where the child is in mainstream school

Note: During school years, CAMHS can continue to advise staff from universal services on parenting, attachment issues, the effect on the family of ongoing grief and loss and other issues described in the early years section. Continued close liaison with Community Child Health and Hospital Paediatrics (e.g. Pediatric Neurology) is vital in order to properly assess and manage mental health problems in this group.

Community-Based Activity

Many young people with learning disabilities are supported by independent sector clubs specific to their needs. These, alongside befriending and respite/short break care services accessed via the local authority social work department, have a role in supporting development in adolescence by enabling: access to mainstream culture and leisure opportunities; development of social skills; and provision of a supportive space to explore difficulties or worries. The respite provided to families and siblings by such services also reduces stress levels and promotes positive mental health and family relationships. This can be crucial for families of children with severe challenging behaviour and with severe complex physical disabilities. Without such support families are often also unable to put into place therapeutic strategies developed with the support of LD CAMHS and others.

Box 6: CAMHS can link with community-based organisations to provide:

- Training and consultation to community-based organisations in order to build their staffs' capacity in understanding the psychological and mental health needs of children with learning disabilities, the identification of psychological distress and helpful approaches
- Specific training to staff regarding the presentation and management of mental health problems in children and young people with learning disabilities
- Support and consultation to these systems in relation to specific mental health or challenging behaviour conditions in individuals to allow them to fully benefit and prevent their exclusion from services
- Provision of training on the impact learning disability on other areas, including child protection
- Support for community-based initiatives for addressing issues such as emotional literacy, peer support and counselling, to ensure that the specific needs of children and young people with learning disabilities are taken into account, thus preventing their exclusion from services

Additional and Specific Supports

Children with learning and/or physical disability are recognised by the Framework as being at greater risk of developing mental health problems. They are also likely to be overrepresented in other 'at risk groups' described in the Framework, such as those who are or have been looked after or accommodated; have experienced or are at risk of neglect or abuse; have a chronic or enduring illness; and have communication difficulties (Foundation for People with Learning Disabilities, 2002). Those working with the specific needs of these groups therefore need to be able to identify whether a child or young person has a learning disability and recognise potential mental health problems in such individuals. CAMHS practitioners with specialist knowledge and experience of working with children and young people with learning disabilities need to be available for training, consultation and support to these other specialist services to avoid exclusion and encourage collaborative working.

Specialist mental health services for children and young people with learning disabilities

Generic CAMHS practitioners have many of the competencies required to meet the mental health needs of children and young people with mild learning disabilities. Professional development (for example peer mentoring from practitioners experienced in working with this group) can improve confidence and help practitioners to appropriately adapt their assessments and interventions. Those working with children and young people with moderate and severe learning disability or very complex difficulties need more specific training and experience, with ongoing continuing professional development. In addition to understanding the presentation and treatment of mental health problems in children and young people with learning disabilities, CAMHS practitioners should have experience of the specific issues faced by their families.

The need for children and young people with learning disabilities and mental health difficulties to be able to access mainstream CAMHS services is acknowledged in the Framework. In addition, it recommends planning for the development of specialist CAMHS whose members have training in relation to both children's and young people's mental health and learning disability. Professionals contributing to such specialist 'LD-CAMHS' generally include Nurses (often from a Learning Disability Nurse background), Clinical Psychologists and Psychiatrists. Some services also benefit from Allied Health Professionals, in particular Occupational Therapists and Speech and Language Therapists. However, this is currently rare in the Scottish context.

These specialist multidisciplinary services, by seeing children and young people with learning disability in sufficient numbers and focusing on their needs, are able to attain and maintain specialist expertise and competencies with this population. In addition to direct work, usually with those with the most severe and complex difficulties, they can also resource CAMHS to work with partner agencies in meeting the mental health needs of children and young people with learning disabilities across the Tiers. For example, generic Primary Mental Health Workers should be supported to develop specialist skills, knowledge and practice in working with this group. The needs of children and young people with learning disabilities should be part of all generic mental health training programmes and LD-CAMHS practitioners should be involved in its planning and delivery.

The exact model of how LD-CAMHS services are provided across the Tiers will differ according to local needs and historical developments. What is not acceptable is for generic CAMHS to exclude children with learning disability in the absence of any other form of specialist mental health service provision. From the mapping exercise (Appendix iii), a common emerging model in Scotland for specialist mental health services for children and adolescents with learning disabilities is that of a specialist LD-CAMHS multidisciplinary team, situated within CAMHS and working predominantly at Tier 3. Other models include children and young people with learning disabilities and mental health problems being seen within generic CAMHS or by mental health practitioners based within child health services. In the absence of a dedicated LD-CAMHS service, it is particularly important that staff in generic CAMHS are provided with ongoing training and additional resources to allow them to meet the needs of all children, irrespective of the child's level of functioning.

The 'Mental health care pathway for children and young people with learning disabilities' (Pote & Goodban , 2007) is an important resource for developing local services to ensure that all aspects of mental health provision are considered, whatever the local service model is. The complexity of the children and young people's needs and multiagency services around them require clear, defined and agreed pathways between all Tiers. QINMAC-LD standards (Dugmore & Hurcombe, 2007) allow services to evaluate their provision against national standards. The support of local adult or lifespan Learning Disability services in developing LD-CAMHS services is important, particularly where CAMHS do not have experience of working with children with learning disabilities.

The higher incidence of co-morbidity adds to the complexity and intensity of clinical cases for those working with children and young people with learning disabilities. This, along with routine complex multiagency working and the need to be able to see children at home, school or in other accessible community settings needs to be recognised and reflected in smaller caseloads (Greco et al, 2005). The young person and their family may need to be seen over a longer period of time before change can be expected, which will have implications for throughput of cases. The life-long nature of learning disability and associated conditions such as autism contribute to high rates of re-referral.

There are currently major gaps and variation in knowledge, experience and service provision across Scotland in specialist CAMHS for children and young people with learning disabilities. In particular there is a complete lack of psychiatric inpatient provision for those with the severest disabilities and mental health problems. Emergency and out of hours mental health arrangements for this group are often unclear, and there is a dearth of intensive outreach services. As services strive to develop and improve mental health services for children and young people with learning disabilities, the workforce shortages acknowledged in CAMHS as a whole will be seen to be particularly acute for specialist practitioners skilled in working with this group. CAMHS workforce planners locally and nationally urgently need to take this shortage into consideration. Capacity and skill mix required to meet the additional needs of these children and young people needs to be included in CAMHS workforce planning and workforce figures and capacity calculations need to be adjusted accordingly for this population.

Summary and steps forward

Children and young people with learning disabilities have the same rights as any other child, including timely attention to their mental health needs. It would be a breach of human rights to discriminate on the grounds of IQ, and therefore children and young people with learning disabilities must have the same access to mental health services as those without learning disabilities and to specialist support from learning disability professionals where required. The current piece-meal and ad-hoc service provision of mental health service provision for children with learning disabilities is unacceptable and a specific focus is required from strategic planners across Scotland. Boards will need to take account of the short and long term risks in not addressing the mental health needs of this vulnerable group by providing well co-ordinated and resourced services. (Box 7)

Box 7: Risks of not addressing the mental health needs of children and young people with learning disabilities

Risks to the child or young person

- **Impact on psychological well-being, which may lead to deterioration in mental health**
- **Failure to achieve developmental potential** where behaviour is managed or 'contained' rather than addressed therapeutically
- **Physical injury** caused by severe recurrent self-harm, or arising from carers being unable to cope with or safely manage children's behaviour
- **Long term treatment costs and more restrictive environments** due to increasing degrees of challenging behaviour
- **Inappropriate use of medication** with the risk of significant side effects which may be irreversible and chronically disabling
- **Exclusion from local educational provision** due to unmet mental health needs and/or challenging behaviours
- **Exclusion from social and community activities**, further reducing important opportunities for development
- **Increased risk of all forms of child abuse** may result where families lack the capacity to provide appropriate care, or where there is breakdown and social isolation

Risks to the family and other individuals

- **Deterioration in mental health of parents**, impacting on their relationship with their child, their ability to manage behaviour difficulties and to engage with services and implement advice
- **Families providing full time care at home for children with significant mental health problems and/or challenging behaviour** due to lack of access to education and other services
- **Impact on psychological well-being of siblings**
- **Impact on siblings' educational, social and other developmental opportunities** due to impact on family of unresolved problems relating to the child with learning disabilities
- **Family breakdown**
- **Risk of serious injury to others:** family members, carers, school staff, or other children due to serious challenging behavior

Risks to services

- **Poor clinical governance**: Children's mental health needs not met; ineffective interventions; lack of specialist assessments and evidence-based interventions, including prescription of sedative, rather than symptom-specific, medication to manage challenging behaviour; ineffective professional systems; and increased professional stress and morbidity
- **Impact on children's services:** increased sibling stress and mental health problems
- **Impact on adult services:** increased parental stress and mental health problems; problems inadequately treated in childhood impact on adult learning disability services by becoming more entrenched and difficult and costly to treat
- **Breakdown of school placement:** schools less able to respond appropriately and contain health problems and challenging behaviour
- **Costly out of area or specialist placements:** resulting from breakdown of school placements and/or the inability of families to care for the child at home and/or breakdown of respite (these factors are interactive). Out of area placement reduces integration with families and local areas and disrupts the transition to adult services. Expensive out-of-area residential schools or social care settings may still lack the expertise, internally or locally, to appropriately identify and address mental health needs
- **High cost ad hoc packages of care:** due to lack of planned integrated mental health services for children and young people with learning disabilities, including intensive community intervention teams and inpatient services
- **Financial overspend:** Unmet need is not quantified due to the lack of service pathways so costs may be unpredictable and not planned for in both the short and long term.

- **'Bad press':** serious incidents and /or litigation from families may result from no, poor or inappropriate services that are part of Health Boards' corporate responsibilities.

This document as a whole aims to increase knowledge and awareness of the mental health problems faced by this group and the need to improve and increase service provision. This final section offers guidance for Scottish Health Boards and their CAMH Services attempting to implement the Framework to fully meet the mental health needs of children and young people with learning disabilities. The advice is given with 'GIRFEC' principles (Scottish Executive, 2005ii) in mind.

Public Service Agreement (PSA) targets (Foundation for People with Learning Disabilities, 2005) are offered as a basis for thinking about planning mental health services for children and adolescents with learning disabilities (Box 8)

Box 8: PSA target: The availability of a full range of CAMHS for children and adolescents who also have a learning disability.

Services should be provided by staff that have the necessary training and competencies to deal with children who [have] learning disabilities. Children and young people with learning disabilities should receive equal access to CAMHS, including:

- **Mental health promotion and early intervention** (including attention to attachment and parenting issues)
- **Training and support to front line professionals**, in particular in the recognition of normal development and developmental delay
- **Adequately resourced Tiers 2 and 3 learning disability specialist CAMHS** with staff with the necessary competencies to address mental health difficulties in children and young people with learning disabilities or pervasive developmental disorders
- **Access to Tier 4 services** providing in-patient, day-patient and outreach units for children and adolescents with learning disabilities and severe and complex neuro-psychiatric symptomatology.

Steps in the development of comprehensive LD-CAMHS services

There is a need to acknowledge the magnitude of the unmet mental health needs of children and young people with learning disabilities in Scotland and the challenge faced by local services in developing comprehensive CAMH services for this group. With this in mind, 'steps' are provided as guidance for Health Boards as they embark on a pathway towards ensuring the provision of equitable and effective mental health services that include children and young people with learning disabilities. The initial steps can be taken by all and should be achievable within realistic timescales and existing resources. They also form a good basis for the development of comprehensive services described in the later steps. Some Health Boards will have already had some components of the pathway in place.

1. **Identify key managers, clinicians and multiagency partners responsible for planning and developing mental health services for this group of children.** Depending on local service structures and responsibilities, these are likely to include the following:
   - Managers and clinical leads from CAMHS, Child Health and Learning Disability services.
   - Education and Social Work colleagues

   Input from user and carer organisations and local care provider, voluntary sector and advocacy organisations is invaluable.

2. **Define the local demographics**
   - Extrapolate from population figures (see introduction)
   - Adapt figures according to factors such as social deprivation or high densities of children in local residential schools.
   - Use information already held within health, education and social services, such as Special Needs Systems.

3. **Identify the local mental health services currently available and accessible** to this group at each tier of service. Mental health input, especially at Tier 2 will be being provided by various professionals within Child Health, lifespan Learning Disability Services, Education, Social Work and the Voluntary/Independent Sectors. Mapping existing provision and how it links with CAMHS, then developing these links (e.g. with consultation models) can improve the effectiveness of existing services.

4. **Identify the gaps in service provision** across the Tiers for this group, using the Framework and this document as a guide.

5. **Multiagency/ strategic planning.**
   - Evaluate funding for services and evidence for their cost-effectiveness across multiple agencies. There needs to be recognition of the impact of services or lack of services in one agency on the work of another. For example, improvements in LD-CAMHS services may not only improve the well-being of children and families but as a consequence also lead to cost savings in education, social care or in later adult learning disability services.
   - Address terminology, together with local agencies and practitioners by engaging *"in discussion about their differences, with a view to developing shared accounts of the young person's needs"* (PHIS 2003). This applies particularly to terminology around learning disability in addition to that around mental health and disorder.
   - Clarify who is responsible for mental health services to children in out of area and residential school placements.

6. **Identify workforce needs**
   - Acknowledge the specialist skills, experience and capacity required to meet the needs of this part of the population (Appendix iv)
   - Identify the skills available in the existing workforce across the tiers. For example, behaviour and sleep interventions by Community Child Health staff, Specialist CAMHS, older adolescent and transition work in Learning Disability Services.
   - CAMHS Skills for Health (Care Services Improvement Partnership, 2007) can be used to define the competencies required to work with children and young people with learning disability.
   - QINMAC-LD Standards (Dugmore & Hurcombe, 2007) make recommendations regarding staff competencies and resources (standard 3.4 – Appendix vi) and workforce planning (standard 8.1- Appendix vii)

7. **Build capacity in the workforce**
    - Improve the skills of staff across the tiers in working with children with learning disabilities and associated mental health problems by incorporating their needs into CPD programmes.
    - The developing Scottish LD-CAMHS Network can provide professional support for practitioners
    - CAMHS can make links with local Learning Disability Services who may be able to provide training, service development advice and clinical consultation. Consideration could be given to liaison work between CAMHS and LD services, secondments or identifying LD 'champions' in CAMHS.

8. **Develop care pathways for this group**
    - The care pathway developed by the 'Do Once and Share' Project (Pote and Goodban, 2007) is recommended as an invaluable resource to local services.
    - Benchmarking against this model of interagency working will help local services to identify what improvements need to be made.
    - Establish a transition pathway with education, adult health, social care, and learning disability services to provide continuity of clinical care, inform person-centred planning and provide continuing education/vocational training. Health Action Plans can be used to ensure individuals' continued access to services they need to stay healthy and do not 'fall between' services.

9. **Fill the gaps and develop services**
    - The 'QINMAC-LD' standards (Dugmore & Hurcombe, 2007), are recommended as standards for the provision of Tier 2 and 3 mental health services for children and young people with learning disabilities. Services may wish to consider joining the 'QINMAC-LD' network to take part in peer-review of services.
    - See appendix iv and appendix vi for further detail
    - Tier 2 services themselves often need building up and strengthening to ensure the capacity to provide developmental assessments and interventions for difficulties with (for example), behaviour, communication and sleep. Tier 3 support, consultation and training should be made available to Tier 2 services.
    - Tier 3 mental health services, usually in the form of specialist multidisciplinary teams should be available to all children and young people with learning disabilities.
    - Tier 4 intensive community treatment and in-patient facilities, particularly for children and adolescents with moderate to severe learning disability and serious mental health problems need to be available across all Health Boards.

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Appendices

Appendix i

Definition of Challenging behaviour: *"Behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to and use of ordinary community facilities. (Emerson et al, 1988)*

Appendix ii

Estimated numbers of children under 16 with learning disability and mental health problems in Scotland, using figures taken from the 2007 Census (General Register Office for Scotland, 2008).

Total population of Scotland	5,144,200
Children 16 and under was 18%	925,956
Children with Learning disability estimated at 3.5%	32,408
Children with learning likely to have a diagnosable psychiatric disorder 35-40%	Between 11,342 and 12,963

Appendix iii

LD-CAMHS Scotland- **mapping of current service provision** (as of April 2010)

The following table gives the results of an initial mapping of LD-CAMHS provision across Scotland. It is based on the knowledge of services by members of the Scottish LD-CAMHS network, the Scottish Senior LD Nurse network and the Scottish CAMHS Lead Clinicians. While the Framework document as a whole looks at mental health services across all Tiers for children with learning disabilities, this mapping focuses on Tier 3 and 4 services, with some comments about Tier 2 services in some areas. Consideration should be given as to whether a more comprehensive national mapping needs to be carried out across all Tiers, as part of a wider needs assessment.

Appendix iii **LD-CAMHS Mapping based on information supplied to the LD CAMHS Scotland Network as of April 2011**

Area	Population (GRO 2008 estimates - 2009 data from ISD Scotland CAMHS Workforce Project 2009)	*Recommend-ed workforce (ref Appendix iv) For T2-T3 LD-CAMHS; mild- severe levels of LD.*	Dedicated LD-CAMHS Workforce (including vacancies)	Service structure/ development: describes how needs are met across tiers, where service sits, who holds the focus for LD-CAMH needs. TIERS	LD SPECIFIC	GENERIC INTEGRATION	Reps on Scotland LD—CAMHS Network Committee
Ayrshire and Arran	367,510	*18-22*			Rainbow House- resource for children with developmental delay. Plans for ASD and LD, complex needs pathways. 2 transition nurses attached to Adult LD services for YP with complex needs, link with CAMHS.	Have forum for discussion with CAMHS for children seen in Community Paediatric Service. Regular joint management meetings of CAMHS and Children's services.	Alan James Clinical Psychology alan.james@aapct.scot.nhs.uk
Borders	112,430	*5.5-6.5*	0.2 CAMHS consultant psychiatrist 1.0 clinical psychologist 0.5 OT 0.3 SALT 1.0 LD- nurse (currently vacant)		Dedicated LD-CAMHS team for moderate to severe LD and challenging behaviour	Moving towards a fully integrated service with generic CAMHS. CAMHS see young people regardless of disability	Ellen Baird SLT Ellen.Baird@borders.scot.nhs.uk

Dumfries and Galloway	148,580	*7.5-9*	0.1 Consultant Clinical Psychologist		NHS staff in short stay respite unit.	CAMHS psychiatrists see children with LD.	Bruce Kidd Cons Clinical Psychologist wkidd@nhs.net
Fife	361,815	*18-22*	Tier 2: 2 wte child LD nurses Tier 3: 1 wte consultant clinical psychologist, 1.5 wte clinical psychologist, 2x 0.5 doctoral trainee psychologists, 1.5 child development nurses (1 Community LD charge nurse & 0.5 CAMHS nurse)	Tier 2 Tier 3	Dedicated Child Learning Disability nurses provide the service for LD and Primary Mental Health Care needs. Psychological and Mental Health services provided by Clinical Psychologists and Doctoral Trainees, Child Development Nurses. Plan for 0.6 Consultant Psychiatry post. LD Transition Nurse post.	Service sits within Child Health. Combines a stepped care pathway, team around the child/ adapted CPA model. CAMHS see mild LD.	Tracey Watson Nurse tracywatson2@nhs.net
Forth Valley	290,047	*14.5-17.5*	0.5 staff grade psychiatrist 0.5 clinical psychologist 0.2 Consultant Psychiatrist				Dorothy Laing Psychiatry (Associate Specialist) dorothylaing@nhs.net
Grampian	539,630	*27-32*	1 consultant psychiatrist- for Aberdeenshire (cover for Orkney and Shetland)			Within CAMHS. Clinical Genetics and CAMHS have joint clinics for assessment and management where child with LD is	Dee Rasalam Psychiatry adrasalam@nhs.net

			2 specialist nurses 1 clinical psychologist --- 2 consultant psychiatrists- Moray			referred to CAMHS/ child with complex LD referred to CG. CAMHS see LD children	
Glasgow **Clyde**	1,194,675	*60-72*	1 consultant psychiatrist 5 clinical psychologists (4.1 wte: 0.7 consultant wte + 3.4 wte) 4 nurses (1wte nurse specialist + 3wte nurse therapists) 1 SLT (1 wte) 1 OT (1 wte) 2 support workers (2 wte)	Tier 2 Tier 3 & 4	LD-CAMHS links with special needs school 'Joint Support Meetings' (children and family social work/ SHS/ education/ educational psychology/ LD-CAMHS) to facilitate joint working/ offer consultation re cases. Dedicated multidisciplinary LD-CAMHS team for moderate to severe LD. Tier 3 / Tier 4 provision. Greater Glasgow area with consultation to Clyde. 5-18 years --- Glasgow LD-CAMHS provide consultation/ support to CAMHS teams taking on LD cases.	Tier 2 mental health / psychological services for C&YP with LD unable to meet demand. Within CAMHS services structures where mild LD is seen with support from LD-CAMHS. National Child IPU admits LD. West of Scotland adolescent IPU admits mild LD, some moderate with support from LD-CAMHS team.	Lorna Fitzsimmons Nurse Lorna.Fitzsimmons@ggc.scot.nhs.uk

Highland	309,900	*15.5-18.5*	1 consultant clinical psychologist 1.5 principal clinical psychologist		Developing: joint clinic between Child and Adolescent Psychiatry and Clinical Psychology for young people with complex mental health needs. CAMHS does not see those with LD routinely but discussions are ongoing about this.	For NHS Highland (generally not Argyll and Bute) and do not cover the Western Isles. Two multi-agency Children and Families Affected by Disabilities Teams do some work on Mental health Issues. Do not completely cover the region. Multi-agency centre for Children and Families affected by ASD.	Morag Watson Clinical Psychologist Morag.Watson@nhs.net
Lanark - shire	561,174	*28-33.5*	1 Clinical psychologist 2 Specialist Nurses 1.2 consultant psychiatrists	Tier 2 Tier 3	Mapping Tier 2 provision across Lanarkshire – significant gaps identified (e.g. no post diagnostic input for autism, OT exclude children with autism form input from their service) Dedicated LD-CAMHS team located within CAMH services. For children with moderate to profound LD. No specialist Tier 4 service available	CAMHS teams expected to provide services to those with mild LD.	Susie Gibbs Psychiatry Susie.Gibbs@lanarkshire.scot.nhs.uk

				Tier 4			
Lothian	817,722	*41-49*	0.8 consultant psychiatrist 1 consultant psychologist 0.5 clinical psychologist linked with Action For Children respite service Clinical Associate Psychologist for Early Intervention	Tier 2 Tier 3	Care pathway jointly with Tier 2 using 'Do Once and Share' guidance. Joint assessment and consultation in CCHDCs. Psychological input provided in conjunction with Tier 2 services. Training/ liaison/ ongoing evaluation of outcomes for families. Early years' service: work alongside Paediatric and AHP services to identify infants and children at risk of developing behaviour problems because of their LD/ASD/additional health problems. For moderate / severe LD 0-16years. LD Lifespan Services: CLDN have up to 30% of caseload for children- consultation with consultant clinical psychologist in LD-CAMHS. Link to Action For Children residential respite service: 4 beds able to offer assessment for children with severe challenging behaviour.	Within CAMHS. CAMHS see children with mild LD and ASD without learning disability. T4-Adult LD inpatient unit and CAMHS YPU currently used.	Helen Downie Clinical Psychology Helen.Downie@nhslothian.scot.nhs.uk

				Tier 4	Proposal being considered for intensive community intervention service, to include clinical psychology, nursing, SLT and OT, in addition to tier 3 outpatient service.		
Orkney	19,890	*1-1.2*	Cover from Grampian consultant				Link to Dr Dee Rasalam Psychiatry adrasalam@nhs.net
Shetland	21,980	*1-1.3*	1 consultant psychologist			Covers all children's services	Link to Dr Dee Rasalam

							Psychiatry adrasalam@nhs.net
Tayside	396,942	*20-24*	LD/ASD Team 1.6 Psychiatry 1.0 Clinical Psychology 1.5 Nurse Specialists 0.2 OT 0.2 Family Therapy ASD Team < 0.1 Psychiatry 0.2 Clinical Psychology 2.5 Nurse Specialists 0.1 OT 1.0 SLT < 0.1 Paediatrician		CAMHS LD/ASD team for moderate to severe LD/ and ASD (with and without LD) Overlap with ASD assessment pathway for those with and without LD.		Dr Halina Rzepecka Clinical Psychology halina.rzepecka@nhs.net
Western	26,200	*1.3-1.5*			Community LD Nursing have role		Charlie Hill

Isles					across lifespan		Community LD Nurse charliehill@nhs.net

Appendix iv

Recommended staffing levels and specialist skills

'Key Issues in Meeting Mental Health Needs for Children and Adolescents with Learning Disabilities' (Department of Health, 2003) produced by the child and adolescent mental health and psychological wellbeing external working group made the following recommendations:

- 'Those working with children and adolescents with learning disability need expertise in three areas:
  - Working with children (and/or) adolescents
  - Working with learning disabilities
  - Working with the specific mental health difficulties presented'.

- 'Staffing levels for Tier 2/3 learning disability CAMH services will need to be of the order of 5-6 wte per 100,000 general population in order to provide accessible services equitable with those available to children and adolescents without learning disabilities. (These estimates are derived from the higher incidence of conduct disorders, attention and anxiety disorders, and autistic spectrum disorders within the learning disability child and adolescent population; from the higher incidence of co-morbidity in this population; and from projections from existing staffing levels.)'

- Tier 4 highly specialist outreach and inpatient services are also required for children and adolescents with learning disabilities, although there are different methods of provision. Indications are that 3-4 beds per million are needed for those with severe learning disabilities, 2-3 beds per million for those with mild to moderate learning disabilities, and 1 bed per million low secure adolescent provision'. They also note that medium secure provision needs to be considered.

In addition, the Royal College of Psychiatrists Report CR163 (Royal College of Psychiatry, 2010) gives detailed recommendations regarding workforce and service provision, including:

- For Psychiatry, the College suggests that a service to young people with severe learning disabilities requires a minimum of two sessions of adequately trained consultant time per 100, 000 population. The inclusion of young people with mild learning disabilities requires a further three sessions. This level reflects the demands of the high prevalence of pathological disorders, the community orientation of the work and the substantial amount of time spent in multidisciplinary and multi-agency liaison. These sessions do not include time for administration and training.

- In-patient provision for young people with Autistic Spectrum disorders or challenging behaviours may require higher staffing ratios than in other in-patient units, as well as robust and well-structured physical environment.

- In addition to Psychiatry and Clinical Psychology other professionals recommended for multidisciplinary teams include nurses (trained in Learning Disability, Mental Health or Child Health); Speech and Language Therapists for key problem of communication; and Occupational Therapists for interventions including sensory integration. Access to other CAMHS therapists from wider CAMHS service is also recommended, e.g. Physiotherapy, Music, Art and Play Therapy.

Appendix v

The LD CAMHS Scotland Network is a multidisciplinary network of clinicians working in the field of mental health with children and young people with learning disabilities. Regular national meetings are held which combine academic presentations and workshops with an opportunity for peer support and supervision, as well as sharing and developing good practice in service provision. A committee which contains representatives/links from all Health Board areas coordinates the network and is able to organise LD CAMHS representation for appropriate national committees and work-streams. Members are also able to comment and provide opinions when asked on matters relating to the mental health of children and adolescents with learning disabilities, gathering and representing the opinion of the majority of Scottish clinicians working in this field. The contact details for network representatives for each Health Board area are contained within the mapping appendix. Contacts for general enquiries are as follows:

Name	**Committee Position**	**Professional representative**	**Contact Details**
Lorna Fitzsimmons	Chair	Nursing	Lorna.Fitzsimmons@ggc.scot.nhs.uk
Tracy Watson	Secretary		tracywatson2@nhs.net
Susie Gibbs	Membership Secretary & mapping/Database coordinator		susie.gibbs@lanarkshire.scot.nhs.uk
Ellen Baird		Speech and Language Therapy	Ellen.Baird@borders.scot.nhs.uk
Nuno Cordeiro		Paediatrics	Nuno.Cordeiro@aapct.scot.nhs.uk
Fiona Gellatly		Occupational Therapy	Fiona.Gellatly@ggc.scot.nhs.uk
Alan James		Clinical Psychology	alan.james@aapct.scot.nhs.uk
Dee Rasalam		Psychiatry	adrasalam@nhs.net

Appendix vi

QINMAC Standard 3.4: Staff have the necessary competencies and resources to conduct assessments and arrange the next steps

3.4.1 - Young people are assessed by staff who have appropriate competencies in learning disability and mental health to conduct the assessment and co-ordinate next steps, or by staff who have appropriate supervision from professionals with these competencies

3.4.2 - Where assessments are made by a single practitioner, the clinician conducting the assessment is able to gain multidisciplinary input on the case as needed

3.4.3 - Staff who are involved in clinical assessments have an agreed pathway to facilitate prompt access to medical investigation

3.4.4 - Staff follow established protocols and good practice (e.g. NICE guidelines) when assessing young people with learning disabilities and mental health problems

Appendix vii

QINMAC Standard 8.1: There are sufficient numbers of appropriately skilled staff

8.1.1 - There are sufficient numbers of skilled staff to effectively meet the mental health needs of young people with learning disabilities in the locality

8.1.2 - The numbers of qualified personnel and support staff are determined by analyses of demand and capacity, set against the core business agreed between the service and its commissioner(s)

8.1.3 - Capacity calculations take full account of the time-intensiveness of the multi-agency co-ordination that is often required when working with young people with learning disabilities and mental

health problems

8.1.4 - The numbers of qualified personnel and support staff are determined by conducting a skill mix review, set against the core business agreed between the service and its commissioner(s)

8.1.5 - There are 5-6 staff per 100,000 total population who are designated to meet the needs of young people with learning disabilities

8.1.6 - There are 0.5 WTE psychiatrists per 100,000 total population who are designated to meet the needs of young people with learning disabilities

8.1.7 - A review of staffing needs is held at defined intervals and when there are changes in service provision

8.1.8 - Staffing levels reflect the commitments of staff to engage in training, supervision and mentoring and their requirements for continuing professional development

8.1.9 - Staffing levels reflect the commitments of staff who provide training and consultation to other services and who undertake additional duties

8.1.10 - When posts are vacant or in the event of long term sickness or maternity leave, prompt arrangements are made for staff cover

8.1.11 - Effort is made to ensure the workforce is representative of the community served

A3: METHODOLOGY

A3.1 Questionnaires used in the survey for clinicians

Questionnaire development

Questionnaires were developed by a project group and amended after comments were received from members of the LD CAMHS Scotland Network. The following survey guidance and final questionnaires can be found below in sections A3.1.1 to A3.1.4:

- 5 year survey guidance
- 5 year survey hospital admission
- 5 year survey non-hospital facility
- 5 year survey stayed at home or usual residence

Questionnaire distribution

Questionnaires and guidance were distributed as widely as possible to relevant clinicians across Scotland, including those from CAMHS, LD CAMHS, adult LD services and pediatrics. This included distribution via the following professional groups and networks (example covering email given in section A3.1.5):

1. LD CAMHS Scotland Network
2. Child and Adolescent Faculty of the Royal College of Psychiatrists in Scotland
3. Learning Disability Faculty of the Royal College of Psychiatrists in Scotland
4. Scottish Branch of the Royal College of Paediatrics and Child Health
5. CAMHS Lead Clinicians

The questionnaires and guidance were also distributed to the following email lists within Health Boards, with a request to distribute to relevant

clinicians and managers (example covering email given in section A3.1.6):

1. NHS Board Chief Executives
2. NHS Board Medical Directors
3. NHS Board Nursing Directors
4. NHS Out of Area Referral
5. Departments of Paediatrics and Child Health

A3.1.1: 5 year survey of need for psychiatric admission for Scottish children & young people with Learning Disability &/or Autism Spectrum Disorder

GUIDANCE NOTES

Children and young people with Learning Disability &/or Autism Spectrum Disorder are known to have difficulty in accessing in-patient psychiatric care in Scotland. This increases with the severity of their Learning Disability, the complexity of their co-morbid mental and physical health problems and the severity of any associated 'challenging behaviour' (e.g. self-injury, aggression, destructiveness, sexualised behaviours). Information is being gathered from a number of sources to identify the extent of the need for in-patient care for this group and the types of presentations which may require admission.

This survey aims to gather information on all those Scottish children/young people aged under 18 who have either had a Psychiatric admission in the past 5 years or required admission but were not able to access it. It will inform decisions about future provision of in-patient services for this group of children and young people.

We would be very grateful for you arranging for a survey form to be filled in for each patient from your Health Board who meets the following criteria.

Inclusion criteria

1. Aged 0-18 years
2. Diagnosis of Learning Disability &/or Autism Spectrum Disorder
3. During years 2010 – 2014 (inclusive) had one or more of the following:
    a. An admission to a hospital facility of any kind for mental health/behavioural reasons
    b. An admission to a non-hospital facility of any kind for mental health/behavioural reasons, where ideally a mental health admission was required
    c. Remained at home/usual place of residence, where ideally a mental health admission was required

Identifying patients for inclusion

It is likely that the majority of patients who were admitted to psychiatric hospitals will be relatively easy to identify, although Health Boards will need to contact their clinicians and service managers from a variety of services to ensure none are missed. These services should include CAMHS, LD CAMHS (where this exists), Adult LD services, Child Health and Paediatrics and Adult Mental Health services.

Clinicians from within these services should also be asked to carefully consider cases where admission would have been helpful/required, had it been available. This is to ensure that ‘hidden’ cases are also included, acknowledging that, where suitable local/regional units are not available, alternative arrangements may be made to try and ‘contain’ the situation locally. We intend to gather information about these cases and assess the impact on the child/young person, their family and local services.

To identify cases, you may find it helpful to also contact clinicians from the LD CAMHS Scotland Network from your Health Board. The Network will be made aware of the study in advance. The Network representatives from each Health Board are as follows:

Ayrshire & Arran: Alan James; alan.james@aapct.scot.nhs.uk
Borders: George Murray; george.murray@selkirkhc.borders.scot.nhs.uk
Clyde: Louise Loughran; Louise.Loughran@ggc.scot.nhs.uk
Dumfries & Galloway: Dawn Renfrew; dawn.renfrew@nhs.net
Fife: Tracy Watson; tracywatson2@nhs.net
Forth Valley: Dorothy Laing; dorothylaing@nhs.net
Grampian: Dee Rasalam; adrasalam@nhs.net
Greater Glasgow: Lorna Fitzsimmons;
Lorna.Fitzsimmons@ggc.scot.nhs.uk
Highland: Dr Morag Watson; morag.watson@nhs.net
Lanarkshire: Jo McCulloch;
Josephine.Mcculloch@lanarkshire.scot.nhs.uk
Lothian: Gill Kidd; Gill.Kidd@nhslothian.scot.nhs.uk
Orkney: Link via Grampian rep
Shetland: Link via Grampian rep
Tayside: Halina Rzepecka; halina.rzepecka@nhs.net
Western Isles: Charlie Hill; charliehill@nhs.net

Questionnaires

3 types of questionnaire forms are provided:

(i) For patients admitted to hospital

(ii) For patients admitted to a non-hospital facility

(iii) For patients remaining at home or their usual place of residence

Please arrange for the appropriate questionnaire to be completed for each patient. These should be:

- Typed into the questionnaire form, which will expand to fit the text
- Collected together by a nominated person from each Health Board
- Returned by secure e mail to katherine.collins@nhs.net **by Friday 27th February 2015**
- Where one patient has had more than one discrete admission/episode requiring admission, please fill in a separate form for each admission/episode but indicate that the forms refer to the same patient
- If a patient is transferred to more than one unit (hospital/alternative) during one episode, please indicate this and repeat the information for relevant sections for each unit.
- Under costs of admission, please consider all direct and indirect costs, e.g. cost of admission itself, additional staffing, adaptations to buildings, assessments, travel and expenses costs for families and professionals.
- Please attach any more detailed information you feel it would be helpful to share about any of the patients. E.g. anonymised pre-existing reports, root cause analysis etc. from any admission/alternative.

Many thanks for your time and support with this survey

Katherine Collins, Nursing & Quality Advisor, NHS National Services Scotland

Margo Fyfe, Nursing Officer, Mental Welfare Commission

Penny Curtis, Acting Head of Mental Health & Protection of Rights Division, Scottish Government

Susie Gibbs, Consultant Psychiatrist (NHS Fife) & LD CAMHS Advisor to Scottish Government. Please contact with any questions: susie.gibbs@nhs.net

A3.1.2: National Services Division/Mental Welfare Commission/Scottish Government 5 year survey of need for psychiatric admission for children with LD &/or Autism: (i) Hospital admission form	
Health Board completing form	
Year of admission	
Age at admission	
Sex	Male / Female
Ethnicity	
Looked after child?	Yes / No (if yes, please state reason)
Health Board of Residence	
Level of LD	None / Mild / Moderate / Severe / Profound
Autism diagnosis	Yes / No
Other Psychiatric diagnoses (please list)	
Self-injury	Yes / No
Aggression	Yes / No
Destructiveness	Yes / No
Sexualised behaviour	Yes / No
Police involvement at any stage	Yes / No (if yes, please state reason)
Other Physical Health diagnoses (please list)	
Other problems/ issues (e.g. housing, family issues, Child Protection concerns)	
Reasons for admission (please list)	
Health Board (or English city/ county) of admission	
No. weeks from identification of need for admission to date	

admitted	
Admitted from	Home / hospital / residential school / other (if other, please specify)
Type of ward admitted to	LD CAMHS / Adult LD / Child Mental Health /Adolescent Mental Health / Adult Mental Health / Paediatric / other (if other, please specify)
Type of hospital	NHS / Private sector
Type of hospital facility ideally required (brief description)	
Degree of security required	Standard / Low / Medium / High Was this available: Yes / No
Staff ratio required	Standard ward level / 1:1 / 2:1 / 3:1 / other (if other, please specify)
Any special adaptations required to ward	
Length of admission (weeks)	
RMO during admission	CAMHS / Adult LD / LD CAMHS / Paediatrician / other (if other, please specify)
Mental Health Act status	Informal / Short Term Detention / Compulsory Treatment Order / other (if other, please specify)
Discharge destination	Still an in-patient / home / another hospital / residential school / social care placement / other (if other, please specify)
Approximate total cost of admission	
Contribution to total cost per agency	Health Board of origin: Health Board where admitted: NSD: Local Council (Education): Local Council (Social Work): Other (please specify):

Details of clinician available to contact for further clinical information/clarification	Name: Position: Phone number: Email address:
Details of manager available to contact for further financial information/clarification	Name: Position: Phone number: Email address:

A3.1.3: National Services Division/Mental Welfare Commission/Scottish Government 5 year survey of need for psychiatric admission for children with LD &/or Autism: (ii) Admission to non-hospital facility form	
Health Board completing form	
Year when need for admission identified	
Age when need for admission identified	
Sex	Male / Female
Ethnicity	
Looked after child?	Yes / No (if yes, please state reason)
Health Board of Residence	
Level of Learning Disability	None / Mild / Moderate / Severe / Profound
Autism diagnosis	Yes / No
Other Psychiatric diagnoses (please list)	
Self-injury	Yes / No
Aggression	Yes / No
Destructiveness	Yes / No
Sexualised behaviour	Yes / No
Police involvement at any stage	Yes / No (if yes, please state reason)
Physical Health diagnoses (please list)	
Other problems/ issues (e.g. housing, family issues, Child Protection concerns)	
Reasons for need for Psychiatric admission	(please list)
Reason/s why not admitted to hospital	(please list)
Type of hospital facility ideally required	(brief description)
Health Board (or English city/ county) of non-hospital facility	
No. weeks from	

identification of need for admission to date admitted to facility	
Admitted from	Home / hospital / residential school / other (if other, please specify)
Type of non-hospital facility	Residential school / prolonged respite care placement / other (if other, please specify)
Organisation running facility	Council / private / 3rd Sector / other (if other, please specify)
Degree of security required	Standard / Low / Medium / High Was this available: Yes / No
Staff ratio required	Standard unit level / 1:1 / 2:1 / 3:1 / other (if other, please specify)
Any special adaptations required to facility	
Length of admission	(weeks)
Mental Health input during admission	(brief description)
Legal status	Informal / Mental Health Act / Supervision Order / Guardianship / other (if other, please specify)
Discharge destination	Still in facility / home / hospital / residential school / social care placement / other (if other, please specify)
Approximate total cost of admission to facility	
Contribution to total cost per agency	Health Board of origin: Health Board where admitted to facility: NSD: Local Council (Education): Local Council (Social Work): Other (please specify):
Details of clinician available to contact for further clinical information/clarification	Name: Position: Phone number: Email address:
Details of manager available to contact for further financial information/clarification	Name: Position: Phone number: Email address:

A3.1.4: National Services Division/Mental Welfare Commission/Scottish Government 5 year survey of need for psychiatric admission for children with LD &/or Autism: (iii) Stayed at home/usual place of residence form	
Health Board completing form	
Year when need for admission identified	
Age when need for admission identified	
Sex	Male / Female
Ethnicity	
Looked after child?	Yes / No (if yes, please state reason)
Health Board of Residence	
Level of Learning Disability	None / Mild / Moderate / Severe / Profound
Autism diagnosis	Yes / No
Other Psychiatric diagnoses (please list)	
Self-injury	Yes / No
Aggression	Yes / No
Destructiveness	Yes / No
Sexualised behaviour	Yes / No
Police involvement at any stage	Yes / No (if yes, please state reason)
Physical Health diagnoses (please list)	
Other problems/ issues (e.g. housing, family issues, Child Protection concerns)	
Reasons for need for Psychiatric admission (please list)	
Reason/s why not	

admitted to hospital (please list)	
Type of hospital facility ideally required (brief description)	
Usual place of residence	Home / residential school / foster care / children's home / other (if other, please specify)
Any special adaptations required to physical environment	
Estimated length of time that admission would have been required	
Mental Health input during this time period (brief description)	
Social care input during this time period (brief description)	
Education input during this time period (brief description)	
Legal status	Informal / Mental Health Act / Supervision Order / Guardianship / other (if other, please specify)
Still at usual place of residence?	Yes / No (if no, please state current situation)
Approximate total cost of additional support put into usual place of residence	
Contribution to total cost per agency	Health Board: NSD: Local Council (Education): Local Council (Social Work): Other (please specify):
Details of clinician available to contact for further clinical	Name: Position: Phone number: Email address:

information/clarification	
Details of manager available to contact for further financial information/clarification	Name: Position: Phone number: Email address:

Please email completed form to: katherine.collins@nhs.net

A3.1.5: Example of covering e mail to professional groups

To Royal College of Psychiatrists LD and CAMHS Psychiatrists
Sent: 29 January 2015 14:31
Subject: 5 Year Survey of Need for Psychiatric Admissions for Scottish Children & Young People with LD&/or ASD

Dear Colleagues

With apologies for any cross-posting, I wanted to ensure that you are aware of this survey, which is being carried out by National Services Division, Scottish Govt and Mental Welfare Commission to establish the need for mental health in-patient admissions for children and young people with LD &/or ASD over the past 5 years. The attached letter, questionnaires and guidance went out to Health Boards last week and you and may have already been contacted by your managers to identify patients and supply the information required.

The information gathered by this survey will be used to inform decisions about the need for regional/national service development for this group, including the need for specialist in-patient beds. Therefore the more info we can get back the better to make sure well-informed decisions are made. It is important that it is not just patients that have accessed specialist LD CAMHS services that are included in this survey but any children or young people who meet the attached criteria.

Please could you therefore think back and identify any patients of yours who have any degree of Learning Disability and/or ASD who have had - or required but not been able to access - inpatient care in the past 5 years. Please could you ensure that questionnaires are filled in and returned for all of these. Don't worry if you don't have all the info

requested by the questionnaire - we would rather have incomplete info on a larger number of patients than complete info on a small number.

Please see the attachment for guidance notes and the college website for questionnaires etc.

<http://www.rcpsych.ac.uk/workinpsychiatry/divisions/rcpsychinscotland/surveys.aspx>

I am more than happy to be contacted to clarify/discuss anything that arises.

With many thanks in anticipation.

Susie

Dr Susie Gibbs

Consultant Psychiatrist (Children and Young People with Learning Disabilities) LD CAMHS Advisor to Scottish Government Mental Health Division

A3.1.6: Covering letter to Health Boards

National Services Division

062
Gyle Square
1 South Gyle Crescent
Edinburgh EH12 9EB
Telephone 0131 275 6575
Fax 0131 275 7614
www.nsd.scot.nhs.uk

To:
NHS Board Chief Executives
NHS Board Medical Directors
NHS Board Nursing Directors
NHS Out of Area Referral Departments of Paediatrics and Child Health

Date 16 January 2015
Your ref
Our ref 07 HSS\Spec\Mental Health Service\CAMHS\LD CAMHS\Corres\2015-10-16 Survey Ltr
Direct Line 0131 275 6157
Email Katherine.Collins@nhs.net

Dear Colleagues

Psychiatric Admissions for Scottish Children and Young People with Learning Disability and/or Autism Spectrum Disorder

In December we advised Board Chief Executives, Medical Directors and Out of Area Teams of a small survey we are conducting. The survey will aim to gather information on all Scottish children or young people with Learning Disability and/or Autism Spectrum Disorder under the age of 18 who have either had a psychiatric admission in the last five years, or who have required one but have not been able to access it.

The request for information is being circulated to Board Chief Executives, Medical Directors, Directors of Nursing, senior CAMHS clinicians, senior LD clinicians and Departments of Paediatrics and Child Health. The short questionnaire should completed for each identified patient, and there will be a follow-up telephone interview to clarify any points raised, and discuss the more qualitative aspects of the cases. . It would be appreciated if the proformas for each NHS Board could be collated and returned by a nominated contact person. The information will be stored securely in NSD and analysed by Dr Gibbs. This is a relatively small patient group and we don't anticipate an onerous workload for any Board or individual. We would like this work to be completed early in 2015.

Three questionnaires and Guidance Notes are attached and I would be grateful if the appropriate questionnaire could be completed for each child or young person and returned to National Services Division using my email address Katherine.collins@nhs.net **by Friday 27th February 2015**.

Yours sincerely

Ms Katherine Collins

Nursing and Quality Adviser

A3.2 Questionnaires for families/carers

This questionnaire was developed by the project group, with particular guidance from ‘Kindred’, an organisation providing advocacy and information on services available to children with additional support needs and their carers.

This questionnaire and an accompanying letter (see below, sections A3.2.1 and A3.2.2) were distributed to clinicians who submitted information to the survey, with a request that they personalise and forward them, with a stamped addressed envelope, to the families/carers of the patients concerned. These were only sent to families of patients who were actually admitted to hospital.

In order to preserve patient confidentiality, family questionnaires were not actively linked to the related clinicians’ submissions.

A3.2.1: Parent survey letter

Dear Parent/Carer

Admissions to hospital for Scottish Children and Young People with Learning Disability and/or Autism Spectrum Disorder with mental health/behavioural difficulties

Children and young people with Learning Disability and/or Autism may experience difficulty in accessing appropriate hospital care when required for mental health and/or behavioural difficulties. The Scottish Government, Mental Welfare Commission and NHS Scotland (National Services Scotland) are carrying out a survey of Health Boards to find out how this has affected your child and family, and others in similar situations. We wish to look at the period 2010 to 2014. Health Boards are supplying us with anonymous information about all children under 18 with Learning Disability and/or Autism who have had an admission for mental health/behavioural reasons in the past 5 years, or who may have benefitted from an admission but been unable to access it.

(Clinician name), has identified your child (or the child you care for) as being suitable for inclusion in this survey and has provided anonymous information relevant to our work. They have not given us any identifiable information but have agreed to send this letter directly to you to ask for your help. We are very keen to hear about experiences of parents and carers in relation to this important issue.

We enclose a short questionnaire which we would be very grateful if you could fill in and return within 2 weeks in the stamped addressed envelope provided. You do not need to put your name on the questionnaire and your answers will not be shared in their full form with anyone outside the study group. Your answers will be put together with

those of other parents/carers so that information in the final report will not be identifiable. If your child had more than one admission in the study period, we will include extra questionnaires – please complete one for each admission.

We are working with Kindred, an independent organisation providing support and advocacy for children with additional support needs. We would like to offer you the opportunity to also discuss your experiences with Claire Edwards from Kindred in more detail in person, in order to increase our understanding and improve future services. Details of how to arrange this are given at the end of the questionnaire.

We would very much appreciate your help. Your information and views will help in consideration of in-patient services for Scottish children and young people with Learning Disability and/or Autism.

We look forward to receiving your completed questionnaire. If you need help in filling in the questionnaire, or have any queries, please contact us at the above telephone number.

Yours sincerely

Katherine Collins,

On behalf of the study group:

- Katherine Collins, Nursing & Quality Advisor, NHS National Services Scotland
- Deborah Dunn, Programme Manager, NHS National Services Scotland

- Margo Fyfe, Nursing Officer, Mental Welfare Commission
- Lauren Murdoch, Head of Mental Health Unit , Scottish Government
- Dr Susie Gibbs, Consultant Psychiatrist & LD CAMHS Advisor to Scottish Government
- Claire Edwards, Trainer & Consultant, Commissioned by Kindred

A3.2.2: Parent questionnaire	
About your Child	
Age at admission	Under 12 □ 12 – 15 □ 16 – 18 □
Sex	Male □ Female □
Level of learning Disability	None □ Mild □ Moderate □ Severe/profound □ Not sure □ If not sure, please comment:
Autism	Yes □ No □oNot sure □ If not sure, please comment:
About your family at time of admission	
Who usually lives at home? (e.g. Mum, Dad, siblings, others)	
Where do you live?	More than 1 hour from a major city □ Within 1 hour of major city □ In a major city □
The hospital admission	
What type of unit was your	Specialist Children's Learning Disability Mental Health Unit

child admitted to? (Please fill in a separate form if admitted to more than one unit)	□adult Learning Disability unit □child or Adolescent Mental Health Unit □adult Mental Health Unit □pediatric (children's medical) ward □another (please specify) □
Why did your child require admission?	
How long did you have to wait for admission?	
In what ways was the admission helpful?	
If admission was not helpful, why not?	

Do you have suggestions for improvements?	
How far (in terms of travelling time) was the unit from home?	Less than 1 hour □ 1 – 2 hours □ 2 – 4 hours □ More than 4 hours (please specify) □
Where was the admission?	Scotland □other □ England □n
How well were your child's needs understood and helped by the staff?	
As an individual	Excellent □ Good □ Ok □ Poor □ Very Poor □
As a child/ young person	Excellent □ Good □ Ok □ Poor □ Very Poor □
As a person with learning disability (if relevant)	Excellent □ Good □ Ok □ Poor □ Very Poor □
As a person with Autism (if relevant)	Excellent □ Good □ Ok □ Poor □ Very Poor □
Their mental	Excellent □ Good □ Ok □ Poor □ Very

health/ behavioural needs	Poor □
Their physical health needs	Excellent □ Good □ Ok □ Poor □ Very Poor □
Their family needs	Excellent □ Good □ Ok □ Poor □ Very Poor □
Their educational needs	Excellent □ Good □ Ok □ Poor □ Very Poor □
Comments	
What was the effect of the admission on:	
Your child's emotional well-being?	
Family contact?	
Discharge Planning?	
Transfer back home or to another	

placement?	
How long after discharge did benefits from the admission continue?	
Please tick the statement that most reflects your views	If my child needs hospital treatment I would prefer them to be in a specialist unit for children/ young people with Learning Disability/ Autism even if it is a long way from home. □ I would prefer my child to be in a more local hospital, even if they have to be on an adult ward, or a ward not specialist for children with Learning Disability/ Autism. □ Comments:
We are working with Kindred, an independent organisation providing support and advocacy for families of children with additional support needs. Web address: www.kindred-scotland.org. In order to get a fuller understanding of how	

admissions to hospital have affected children and their families, Kindred have asked Claire Edwards to talk with families. If you agree to take part, you can choose between meeting Claire at your house, or at another local venue, or having a telephone conversation. She will provide a report to us from her discussions with families/carers. We will not be able to identify the views of individuals from her report.

If you are happy for us to pass on your details to Kindred please complete your details here:-

Name:-

Telephone Number:-

E-mail address:-

If you do not want to give your details, but would like to contact Kindred directly to arrange to talk with Claire, please return this form to us without your details and contact Kindred via:

Sophie Pilgrim - Telephone: 0131 538 9354 or 0131 536 0360

E-mail: sophie.pilgrim.kindred@gmail.com

If you do not want to speak further about your experiences, please simply return the completed form without your contact details.

If you would like us to send you a copy of the final report please tick here and put your postal or email address here:

☐

If you want to give more detailed answers to any questions or add any further comments please use this space (continue overleaf if required):

Thank you for your time and help in completing and returning this questionnaire.

Please return it to Kathy Collins at NHS National Services Scotland at:

NHS National Services Scotland (Area 062)

Gyle Square

1 South Gyle Crescent

Edinburgh, EH12 9EB.

If you require a stamped addressed envelope please phone Amanda Saunderson on 0131 275 6884

A3.3 Telephone interviews with clinicians

Telephone interviews were offered to all of the clinicians who submitted information to the study; these interviews were all carried out by Dr Susie Gibbs. The primary reason for the interviews was to gather additional qualitative information about the admissions/alternatives described on the questionnaires, particularly with respect to:

1. Pre-admission processes
2. Impact on local services and other service users
3. Issues related to cross border transfers
4. Issues/concerns raised by patient or family
5. Outcome/impact for patient
6. Outcome/impact for family/carers
7. Additional information/ comments

Clarification of information from the completed questionnaires was also sought and any gaps addressed. A ‘crib sheet’ was used to guide and order the recording of the telephone interviews (see A3.3.1 below).

Notes were also taken on more general discussion related to inpatient provision for children and young people with learning disability and/or autism spectrum disorder. Opinions were sought on issues raised in previous interviews, in order to build up and develop themes.

A3.3.1: Crib sheet for telephone interviews with clinicians

1. Fill in any gaps on questionnaire
2. Elaborate with discussion on interesting points made in questionnaire
3. Qualitative comments on pre-admission process, including
    a. impact on other clinical work when complex/time-consuming
    b. impact on children and families/carers of preadmission process
4. Issues relating to cross-border transfers, including use of the Mental Health Act
5. Issues/concerns raised by patient or family regarding admission/alternative arrangements.
6. Impact of admission/alternative arrangements on local services & other service users
7. Impact of adolescent being in adult ward
8. Where on non-specialist adolescent unit, what would have been gained by admission to specialist LD /ASD unit?
9. Outcomes/impact for patient
10. Outcomes/impact for family/carers
11. Any further info/comments (including would they share any internal reports/root cause analysis etc.)
12. Alert to questionnaire to be passed on to families/carers

A3.4 Interviews with families/carers

Claire Edwards (working for ‘Kindred’) carried out face-to-face or telephone interviews with parents or carers who had agreed to be contacted when responding to the questionnaire sent via clinicians. The interviews were designed to provide an opportunity for parent/carers to build on their initial questionnaire responses, sharing their experiences and thoughts in greater depth.

An interview schedule (see Appendix 4.4) was used to guide the interviews, encouraging particular discussion of the following themes:

1. early experiences of mental health within the family
2. involvement of statutory and voluntary agencies outwith health
3. involvement of health agencies
4. inpatient care
5. experience or otherwise of specialist learning disability and autism spectrum disorder input
6. experience of treatment and care in settings at a distance from the family home (distance to be defined by the parent)
7. discharge processes
8. post discharge community support

Interviewees were informed of the purpose of the project as a whole and that the final report, which would include material from the interviews, had been commissioned by the Scottish Government. All interviewees requested a hard copy of the report once published.

Those who agreed to be interviewed were reassured that whilst direct quotes would be used within the report the speaker would not be identified beyond being a mother or father. All agreed that this was acceptable to them.

A3.4.1 Family Interview Schedule

Name of parent: **Date:**

Name of child: **Age:**

Setting the context for the questions	• Reference to invitation in introductory letter sent via doctor/NHS Board • Why we are asking for the information • What we will do with the information • Option to receive copy of the report
Background questions *- **acknowledging that some families have had to repeat their 'stories' many times and don't always find that helpful/can find distressing***	• Early experiences/diagnosis • What were the things you noticed that alerted you (or others) to potential concerns • Family circumstances (siblings/elderly parents etc.)
Social care	• Do you have social work involvement? if yes - • An allocated social worker? • What services have you received? • Do these/did they meet your child and

	family's needs? • How involved did you feel in decisions about what services you would receive? • Do you receive Direct Payments or other funding under Self Directed Support?
Voluntary organisations	• Have you received any support from a voluntary organisation? If yes - • How did you hear about it? • What support did you get?
Schooling/education	• Experience and input/support from Educational Psychologist • Who else was involved? E.g. ASL co-ordinator • What/who else would have been helpful?
Involvement of any of the following? ***- CAMHS*** ***- LD team*** ***- Community health***	• When involved? • What led you to seek involvement? • Any kind of mental health/behavioural interventions provided i.e. Intensive Behavioural Support

service ***- Any other health service***	• What was your understanding of the relationship between these services and school? • What did the school provide? Any increase in support?
Inpatient care	• Has your child ever been admitted to hospital for mental health or behavioural reasons? • What were the circumstances which led to admission to inpatient care? • Was the admission as result of a 'crisis'? • If so, was this a planned or emergency admission? • Where was your child admitted and for how long? • What was your experience of inpatient care? • What could have prevented your child being admitted to inpatient care? • Was there a time when your child would have benefitted from an impatient admission but couldn't access one?

	• How did you cope? • If they were taken into a non-health setting e.g. respite what was the impact of this on them/your family? • Was there a delay in transfer to in-patient care? If yes, what did you understand to be the cause? • Was there a delay in discharge? If yes, what did you understand to be the cause?
Transfers to English or distant services: ***Has your child ever been transferred to England or to a service away from your home? Is your child currently in England or away from home? If yes -***	• What would you define as 'distant'? How far away was it? • What impact did/does this distance/travel have on your family? • Hospital details • What rationale were you given for this setting being chosen? • Did you feel it was beneficial? • How specialist did you feel it was? e.g. autism specific? • What is the long term impact of this intervention?

	• Has any benefit being sustained? • What was/is the impact on your family of your child being cared for so far from home? • Any differences in the care your child received/is receiving in England?
Discharged from an English or distant setting	If your child has been discharged – • When was this? • What was the transition like out of inpatient care? • Were you confident about the care arrangements to be put in place? • What are the current arrangements? • What other support/services would have been helpful for you? • What did you hope for? • What was the reality? • What written information was provided for you? Was it helpful?
Anything else?	Any other aspect of the experience you need to

	share?
Would you like a copy of the report?	If you contacted Kindred directly, then we can send a copy of the final report to you directly.

Appendix 4.4.2 Approach to interviewing parents/families

Claire Edwards Training and Consultancy

Process:
Having reviewed collated questionnaires - themes will be identified that would feed into the development of the face-to-face/telephone interviews. Aim of the interviews is to capture parents' experiences and this will probably be best achieved by inviting the parent(s) to tell me about their child and then their experiences. In our prior discussion we will have identified issues/themes that want to hear about - should these not be addressed in the 'free flow' then I will pick these up towards the end and/or probe further if touched upon by parent.

Introduction:

I provide an outline of the purpose of the project -

- why we are looking at this issue
- who is involved in this project
- how important family perspectives are to a full understanding of the issue(s)
- what we are going to use the information for i.e. to inform models of delivery/service
- having agreed to be interviewed i am using their questionnaire as a starting point and therefore they don't have to repeat information, however, I may ask more about an answer they have given
- that I have some questions that I want answers and will use these to guide the interview
- that I will be taking notes
- the interview will take about an hour
- it can be ended by the parent at any point
- if they change their mind about being involved then my notes will be destroyed
- they will be asked to complete a consent form

Confidentiality:

I will reassure interviewees that their responses and experiences will be anonymised including identifying details about their children and avoiding geographical location etc.

I share the way this information will be presented i.e. numbers of girls and boys, age range, numbers of single households, ages and gender of

siblings, health boards included etc.
Processing of information:
• Each parent interviewee will be given a code e.g. PA, PB etc. • Each theme/issue will be given an alpha numeric code e.g. 1 and each element within that theme will be coded a,b,c etc. e.g. 1c • Information/quotes will be mapped onto the identified themes • As the interviews progress other themes may emerge these will be coded as above • When reporting the information it will be coded - e.g. PA/1a,b/3c • Information that falls outwith the identified themes will also be reported
Report:
Examples of my reporting style can be viewed at www.cen.scot.nhs.uk but i can also tailor this to another preferred style.

A4 RESULTS

A4.1 Introduction/overview

There was an excellent response to the study with submissions from almost all territorial Health Boards (13 out of 14) and from clinicians from a variety of services, including CAMHS, Specialist LD CAMHS, Adult LD (ALD), Adult Mental Health (AMH) and Paediatrics.

The survey took longer to complete than anticipated, due largely to the high numbers of submissions and telephone interviews. Reminder letters and more time were required to arrange interviews with families and to gather sufficient financial information. The wealth of quantitative and qualitative data obtained was time-consuming to organise and analyse.

Due to inclusion criteria for the study, all of those described as having no learning disability by definition had autism spectrum disorder. A small number (less than 5) of these did not have a formal autism spectrum disorder diagnosis, but autism spectrum disorder was either assumed or strongly suggested, or had a diagnosis of ‘atypical autism’ and was thus included.

All percentages given were rounded to the nearest whole number. Where numbers in any category were small (less than 5) and therefore there was a risk that individuals could be identified, numbers were not given, but ‘<5’ was indicated.

A4.1.1 Data management

An excel spread sheet was created to organise data on patient admissions or alternative. Column headings reflected the questions on the clinician questionnaires and the additional qualitative themes used to guide clinician telephone interviews. A separate row was completed for each admission (or alternative), with separate rows for each part of an admission if a patient was transferred between different hospitals. This data was coded into 53 separate variables that were able to describe patient and admission characteristics. Descriptive quantitative analysis was then performed using SPSS. This also enabled qualitative information to be cross-referenced with quantitative information to identify common themes and issues, e.g. pre-admission issues for children and young people with different degrees of learning disability.

In addition to discussing the patients and situations whose information was submitted to the study, clinicians offered additional general information and opinion related to the theme of the survey. These were collated and the themes which emerged fitted well with other qualitative data from the parent/carer interviews. The information was all incorporated with qualitative information about individual patients' situations. Clinician comment and opinion as to the need for a specialist Scottish unit, its important elements and role, were used to inform the recommendations section of this report.

Answers on parent/carer questionnaires were similarly collated. Insufficient numbers were returned to allow meaningful quantitative analysis. However, much useful information was obtained and incorporated into the qualitative section of the results, along with that from parent/carer interviews.

The feedback from parent/carer interviews was collated and mapped onto the broad themes of the study as identified in the interview schedule. The responses and issues raised by the interviewees highlighted emotional impacts on families and how this then affected their perspective on the processes and nature of the provision. This impact was also reflected in comments from some of the clinicians' interviews. Additional themes were therefore added to the results section to incorporate these issues, and others, which emerged from both sets of interviews.

A4.1.2 Questionnaire submissions

4.1.2 (i) Clinician questionnaire submission results – overview

Total number of submissions from clinicians about those requiring inpatient care (within study period): 153

- 32 submissions represented transfers within an overall admission.
- 8 submissions described situations where the child or young person required admission but remained at home.
- 7 submissions described situations where they required admission but went to residential school or a prolonged respite care placement.

Of the 138 submissions that detailed periods of inpatient care:

- 41% (56) were admitted to adult mental health units (including IPCUs and forensic)
- 22% (30) to a YPU
- 18% (25) to an adult LD unit
- 7% (9) to an LD CAMHS unit (including secure provision)
- 5% (7) to a pediatric ward
- 4% (5) to the National Child Psychiatry Inpatient Unit
- < 5 to a secure YPU
- < 5 to an Autism Unit (including secure provision)

Total number of admissions to a hospital unit described in the survey: 106

- This figure defines an admission as a total admission, which may include one or more transfer within that admission

- Where an individual patient has been admitted and discharged from hospital on more than 1 occasion, these are counted separately as different admissions

Total number of patients admitted to hospital on 1 or more occasion: 84

Variation between Health Boards

Submissions were received from all except one Health Board.

Numbers of patients included in the study whose home is in each of the following Health Boards:

- 20 Grampian
- 12 Lanarkshire
- 11 GGC
- 10 Fife
- 9 Tayside
- 8 Lothian
- 7 Highland
- 5 Dumfries & Galloway
- 5 Ayrshire & Arran
- 0 to <5 Borders, Forth Valley, Shetland, Orkney, Western Isles

Grampian was unusual amongst the larger Health Boards in submitting information on a significant number of patients without learning disability (with autism spectrum disorder) who required YPU care. Other larger Health Boards focused on those who required more specialist care than

available in the CAMH inpatient units in Scotland in their returns.

Excluding data for those submitting information on <5 patients:

- Highest total questionnaire submission rates proportionate to the population served came from Grampian, Dumfries & Galloway, Fife, Highland, and Tayside
- Highest reported total admission rates proportionate to the population served were in Grampian, GGC, Lanarkshire, Ayrshire & Arran, Dumfries & Galloway, and Tayside

Clinician characteristics

43 clinicians submitted data to the study, from a variety of professional backgrounds.

29 were consultant psychiatrists:

- 13 from generic CAMHS
- 7 from generic adult LD services
- 5 from LD CAMHS
- 2 from adult LD forensic services
- 1 from general adult mental health services
- 1 from CAMH liaison service

8 were nurses:

- 7 from CAMHS
- 1 from adult LD services

3 were pediatricians

2 were clinical psychologists

1 was a CAMHS associate specialist psychiatrist

4.1.2 (ii) Family questionnaire submission results – overview

Family questionnaire submission results summary

17 questionnaires described 18 admissions/parts of admission for 10 children and young people

Despite small numbers, demographic and diagnostic characteristics broadly matched those of the patients described by clinician questionnaires

Children and young people were admitted to a range of units and usually had long waits for admission. The majority had to travel significant distances from home (up to 8 hours)

Staff's understanding of children and young people's needs were variable, but with clear room for improvement

Some good outcomes were reported, but also significant difficulties and negative impact on children and young people's emotional well-being. Distance from home was a major issue.

17 questionnaires were returned, (16 by families and 1 by social care staff) regarding **18 admissions** (or parts of admission where the patient

was transferred during an admission). The information related to **10 individual children or young people**.

This section collates and summarises the information from family/carer questionnaires. More detailed qualitative comments have been incorporated into the appropriate parts of the main qualitative results sections.

Gender: 7 boys, 3 girls

Age: 5 admissions/parts of admission related to children aged under 12 years old, 4 to those aged 12-15 years old and 9 to those aged 16-18 years.

Level of learning disability: 2 did not have learning disability, 2 had mild learning disability, 4 had moderate learning disability, 1 had severe/profound learning disability and 1 was unknown.

Autism spectrum disorder diagnosis: 7 had autism spectrum disorder, 1 did not, 1 unknown.

Location of home: 1 lived in a major city, 5 within 1 hour of a major city and 4 lived more than 1 hour from a major city.

Units admitted to: Adult LD, adult mental health, LD CAMHS, YPU, National Child Psychiatry Inpatient Unit

Distance from home to the location of the admission:

Travelling time from home was (where information was given):

- <1 hour 3 admissions

- 1-2 hours 5 admissions
- 4-8 hours 5 admissions

2 admissions were to English units. These are included in the data above.

Parents were asked whether, on balance, they would prefer a specialist unit further away or a non-specialist unit close to home (if a specialist local unit was unavailable). 6 preferred a specialist unit, even if at a distance and 4 a non-specialist unit close to home. 1 parent who had had to travel a significant distance but described excellent care in a specialist unit said that their child's specialist needs overrode the challenges of travel and separation.

How long the child or young person waited for admission:

Where information was given, waiting time for admission to hospital was as follows:

- 2 waited a few days
- 2 waited several weeks
- 3 waited 2-3 months

Reasons for admission:

- psychosis
- anxiety
- behaviour
- severe agitation
- self-harm
- suicidal ideation
- medication

- safety

How well the child or young person's needs were understood and helped by staff:

The following table collates ratings from all the family/carer questionnaires

Need	Excellent	Good	OK	Poor	Very poor
As an individual	3	6	4	2	0
As a child or young person	2	4	6	3	0
As person with learning disability	5	1	3	3	0
As person with autism spectrum disorder	3	4	2	4	0
Mental Health/ behavioural needs	3	3	5	2	0
Physical health needs	2	7	3	3	0
Family needs	4	2	4	3	1
Educational needs	2	5	0	4	2

Effect of the admission on the child or young person's emotional well-being:

- Positives: good effect; improved; young person delighted to go in as wanted to get better; initially helpful due to medication change
- Negatives: traumatic; sometimes very upset; scared; anxious; well-being fluctuated or deteriorated; child hated separation from home (even when excellent admission otherwise)

Effect of admission on family contact:

- Parent's visits limited by distance (e.g. twice a month)
- Siblings and grandparents often had limited or no contact
- Difficult to maintain frequent contact when admissions became prolonged
- Difficult to manage with one child in hospital and other/others at home
- For more able patients, phone and social media contact with family was helpful in ameliorating the effects of distance

A4.1.3 Interviews with clinicians

Interviews with clinicians from a range of professional backgrounds and from all Health Boards that submitted questionnaires took place between March and May 2015. Of the 43 clinicians submitting questionnaires to the survey, 37 participated in interviews by telephone or in person.

Clinicians were generally keen to talk, discussing cases in detail, and expressing their views on the need for both mental health inpatient

provision and the building up of community LD CAMHS provision. Length of interviews were planned to be between ½ hour and 1 hour according to the number of submissions from the clinician. However, some clinicians required a prolonged interview or more than one interview and the longest extended to up to 3 hours in total.

A4.1.4 Interviews with families/carers

10 interviews were carried out with families and 1 with a carer. Those taking part had returned questionnaires and consented to contact, or had been contacted via existing links that Kindred had with families. All parents were telephoned and left a voicemail briefly explaining the reason for the call. This was then followed with an email with a fuller explanation, including a brief introduction to the interviewer.

One questionnaire was completed by a member of staff working in a residential setting and he was also interviewed. He identified himself as playing a key role in the care and planning for a young person primarily as a result of the ongoing mental health issues affecting the wider family.

Many of the families who responded to the request for interview were still dealing with the impact of their child's health. Understandably, the emotional impact of this was a motivation in their response, with parents who were interviewed making comments such as "*I don't want any other parent to have to go through this nightmare"* , " *there needs to be changes and to see things improve*" and *"anything I can do that might make it better for other families in the future".* One parent stated clearly that *"it will be too late for our family but maybe our experience can help to get a facility established in Scotland for young people with complex needs as it is frankly embarrassing, among other things, to have to cross the border to get care".*

On a positive note, one parent commented that the *"psychiatrist has been so helpful that I am very happy to help and support this project any way I can".*

Two presented themselves as 'survivors', able to describe and analyse what they and their family had been through and what they anticipated to be the next phase, in a reflective and measured way. Both identified that having strong networks of support had made a real difference and one had accessed counselling.

A4.2 Demographic information on patients included in study

Demographics – summary

>95% white British

63% male

- As the severity level of the learning disability increased, males were more likely to be over-represented: 55% were male where there was no learning disability, to 80% male where there was severe/profound learning disability

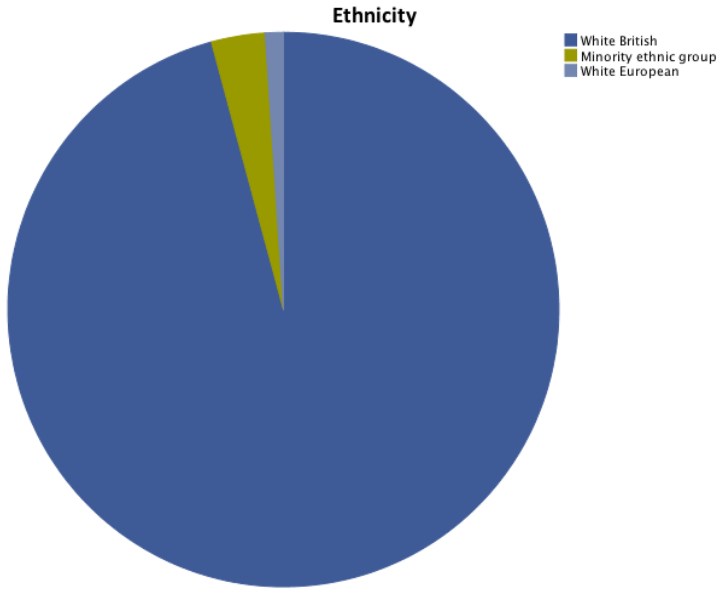
Age range 8-17; mean 14.9, mode 16

- those with moderate/severe/profound learning disability were more likely to have admission at a younger age

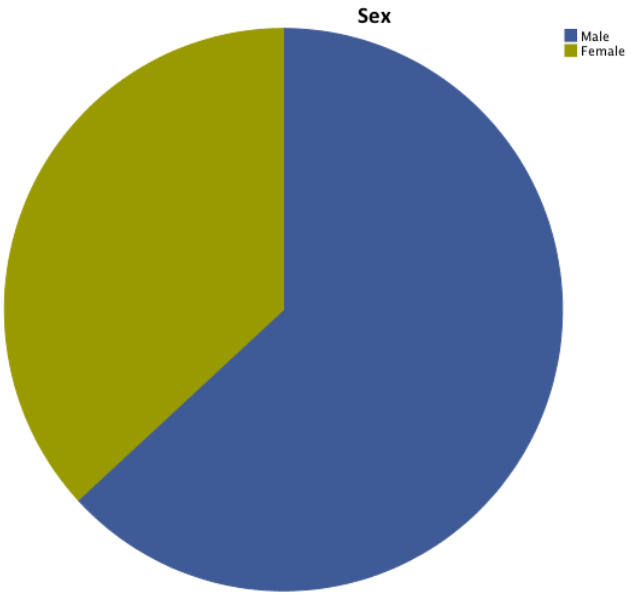
30% of submissions were for looked after and accommodated children

- highest rates for those with moderate learning disability

A4.2.1 Ethnic group (all patients)



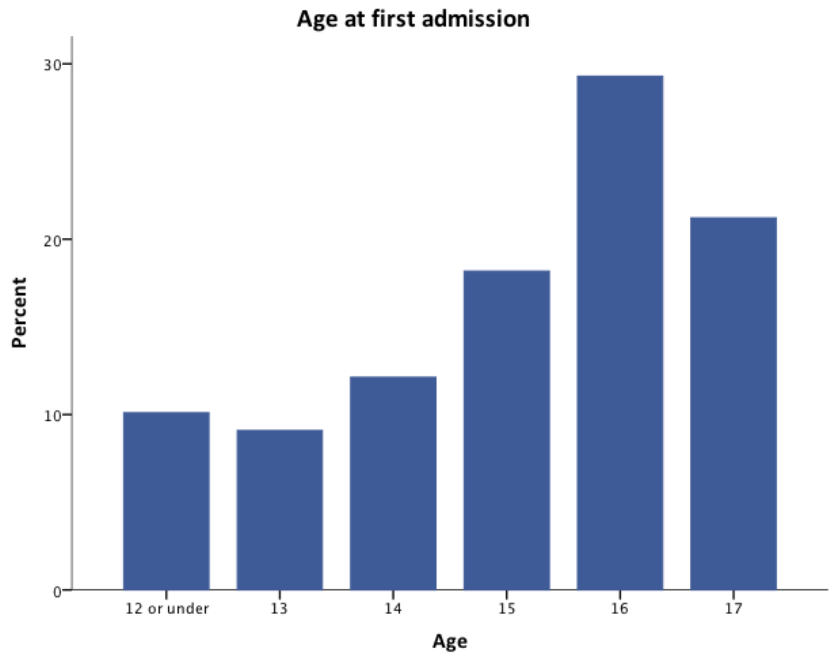
A4.2.2 Gender (all patients)



As the level of learning disability of a patient became more severe, the higher the male to female ratio became:

- No learning disability – male 55%, female 45%
- Mild learning disability – male 60%, female 40%
- Moderate learning disability – male 70%, female 30%
- Severe/profound learning disability – male 80%, female 20%

A4.2.3 Age (at first admission within study period for all patients)



- Mean age – 14.9 years (SE .2, SD 2.03)
- Mode 16
- Variance 4.1

Patients with moderate/severe/profound learning disability were more likely to have their first admission at a younger age, compared with those with no or mild learning disability.

A4.2.4 Looked-after children

30% of all admissions, including transfers, in the returned clinician questionnaires related to looked-after children. This includes those looked after by voluntary agreement of the parents, for example when attending residential school.

All children and young people with learning disability were more likely to be looked-after than those without learning disability. This was particularly high for those with moderate learning disability:

- No learning disability – 18% looked-after
- Mild learning disability – 29% looked-after
- Moderate learning disability – 39% looked-after
- Severe/profound learning disability – 30% looked-after

A4.3 Diagnoses

Diagnoses – summary

30% of patients had no learning disability, 30% had mild learning disability, 30% had moderate learning disability, 10% had severe/profound learning disability

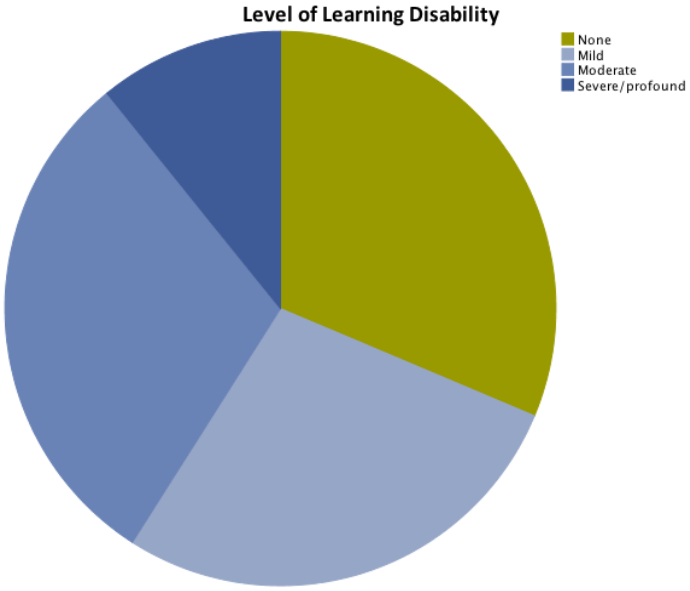
75% had autism spectrum disorder, including 100% of those with no learning disability, 52% of those with mild learning disability, 73% of those with moderate learning disability and , 90% of those with severe/profound learning disability

Multiple co-morbidities were common. Additional psychiatric diagnoses included:

- Affective disorder (24%)
- Anxiety and trauma related disorder (23%)
- Psychosis (21%)
- ADHD (15%)
- Other developmental disorders (6%)
- Other additional psychiatric diagnoses (13%)

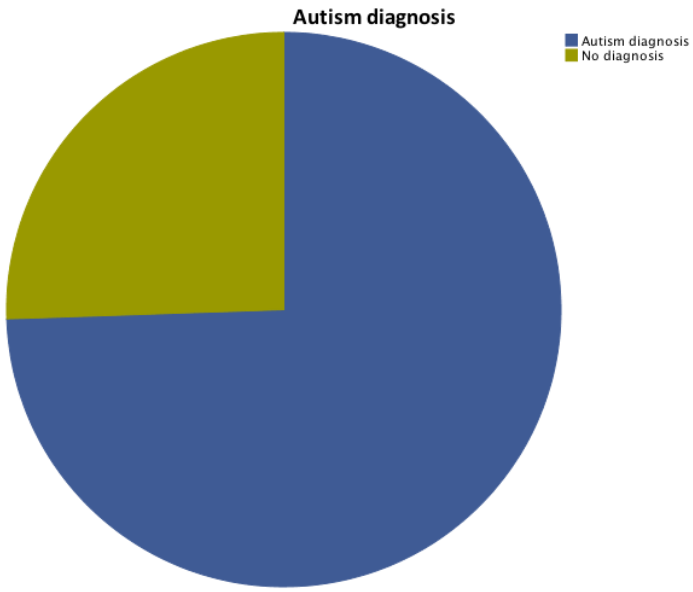
50% had additional physical health diagnoses, 15% having multiple physical diagnoses, the number of which increased with severity of learning disability.

A4.3.1 Level of Learning Disability (all patients)



A4.3.2 Autism spectrum disorder diagnosis

Of all patients in the study, 75 per cent had an autism spectrum disorder diagnosis



By definition, due to the inclusion criteria of the study, all of those without learning disability had autism spectrum disorder. For those with learning disability, the greater the severity of the learning disability, the more likely the person was to have an autism spectrum disorder diagnosis:

- Mild learning disability – 52% had autism spectrum disorder
- Moderate learning disability – 73% had autism spectrum disorder
- Severe/profound learning disability – 90% had autism spectrum disorder

A4.3.3 Additional psychiatric diagnoses

% of patients of varying levels of learning disability reported as having additional psychiatric disorders are given in the table below.

Level of learning disability	None	Mild	Moderate	Severe/profound	All patient
Affective disorders	30	20	30	20	24
Anxiety and trauma related disorders	24	32	23	0	23
Psychosis	28	16	16	20	21
ADHD	7	28	12	0	15

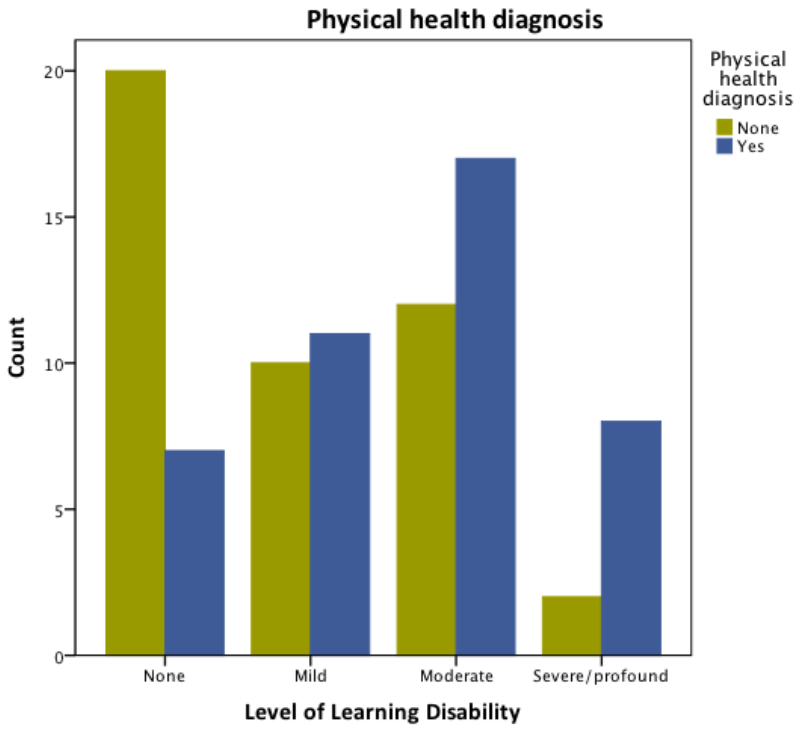
Note: Some of those with more severe levels of learning disability were reported as having hyperkinesis but not a formal ADHD diagnosis.

Other developmental disorders contributing to presentation were reported to be present in 6% of all patients. Numbers were too small for meaningful comparison between those of varying levels of learning disability. Other additional psychiatric diagnoses were reported to be present in 13% of all patients.

A4.3.4 Physical health Diagnoses

Other physical health diagnoses were present in 51% of patients. 15% had multiple physical health diagnoses.

One or more additional physical health diagnosis was increasingly noted to be present as the severity of the person's learning disability increased.



4.4 Presenting behaviours and admission characteristics

Presenting behaviours and admission characteristics- summary

Presenting behaviours:

- 65% had self-injury (100% where severe/profound learning disability)
- 67% had aggression (100% where severe/profound learning disability)
- 51% had destructiveness (80% where severe/profound learning disability)
- 28% had sexualized behaviour (42% where mild learning disability)

41% had police involvement at some stage (52% where mild learning disability)

Steady admission numbers reported from 2012 – 2014. Less for 2010 and 2011.

Reasons for admission:

- Most common across all levels of learning disability were:
    - Mental health assessment and stabilisation (58-67%)
    - Risk management (excluding suicidality/deliberate self harm) 50% of those with no learning disability, 70-80% of those with all levels of learning disability
- Suicidality/deliberate self harm: 37% of those with no learning disability, very low rates in all levels of learning disability
- Medication management: 16% of those with no or mild learning disability, 29% for moderate learning disability and 35% for severe/profound learning disability

- Home/care placement breakdown was a common reason for admission only for those with moderate learning disability (23%)

53% of patients noted to have been detained under the Mental Health Act for all or part of an admission

Staff: patient ratio - limited information given, but >15% needed more than 2 nurses per patient

A4.4.1 Presenting behaviours

% of patients of varying levels of learning disability reported as having specified behaviours are given in the table below.

Level of learning disability / Behaviour	None	Mild	Moderate	Severe/ profound	All patients
Self-injury	79	46	59	100	65
Aggression	56	68	70	100	67
Destructiveness	37	48	58	80	51
Sexualised	19	42	24	20	28

A4.4.2 Police involvement at any stage

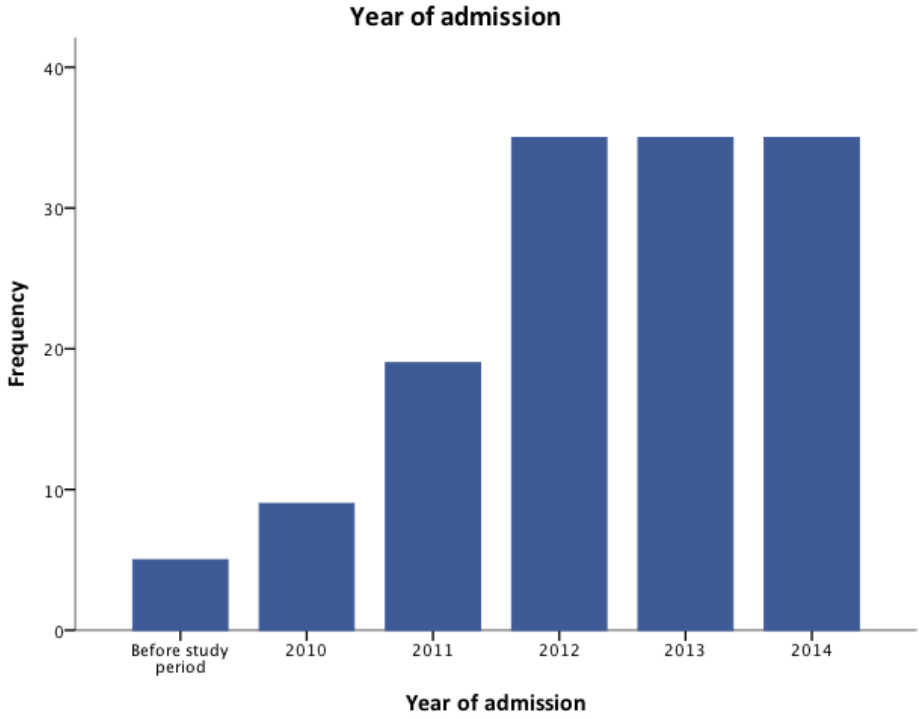
A total of 37 patients out of 90 in the study were known to have had police involvement at some stage. There were various reasons for police involvement, including support for behavioural disturbance, taking to a place of safety, as well as arrests.

Police involvement was particularly high for those with mild learning disability. For the different levels of learning disability, police involvement was as follows:

- No learning disability – 41%
- Mild learning disability 52%
- Moderate learning disability – 40%
- Severe/profound learning disability – 20%

A4.4.3 Year of admission

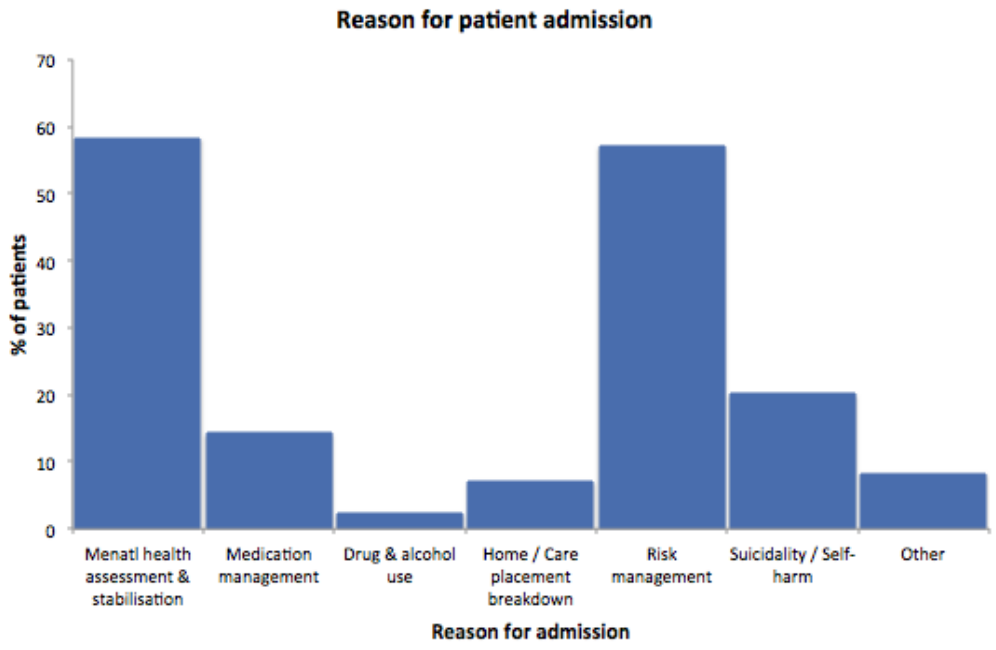
Although 5 patients were admitted before the study period, they were included as they remained inpatients into 2010 or beyond. Figures exclude those who stayed at home or who were admitted to a non-hospital unit.



A4.4.4 Reasons for admission

There was frequently more than one reason for any one admission

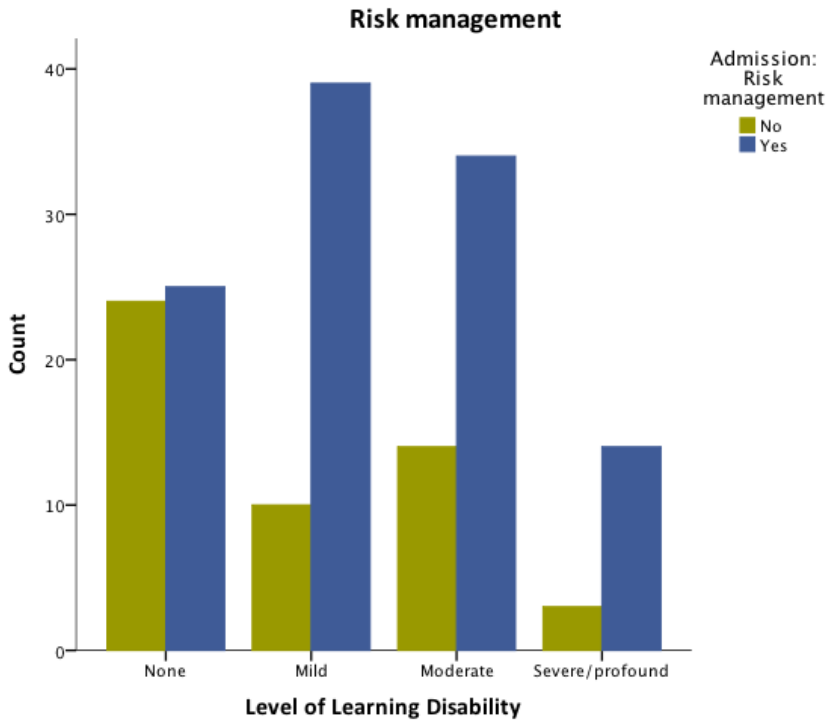
For all admissions:



Comparison for those with different degrees of learning disability:

- **Mental health assessment and stabilisation** was a very common reason for admission across patients with all levels of learning disability and none, ranging from 58-67%.
- **Medication management** was a reason for admission in 16% of those with no or mild learning disability, 29% for moderate learning disability and 35% for severe/profound learning disability.
- **Home/care placement breakdown** was a common reason for admission only for those with moderate learning disability (23%) .
- **Risk management** was a common reason for admission across all groups, but varied as follows: no learning disability 51%, mild learning

disability 80%, moderate learning disability 71%, severe/profound learning disability 82%.



- **Suicidality/self harm** was a reason for admission in 37% of those with no learning disability and 4% for those with each degree of learning disability. This was separated from other risk management for the purposes of these results as the nature differed from self-injury seen in those with more severe levels of learning disability. The latter was included under risk management.

A need for behavioural assessment and implementation of behaviour management strategies was rarely given as a reason for admission. However, these were common interventions, particularly within learning disability and learning disability child and adolescent mental health inpatient units.

A4.4.5 Detention under the Mental Health Act

53% of patients were detained under the Mental Health Act for all or part of an admission.

A4.4.6 Staff: patient ratio required during admission

For all admissions where this information was available:

- Standard ward level 16%
- 1:1 23%
- 2:1 14%
- 3:1 (<5)
- 4:1 (<5)

A4.5 Pre-admission issues

Summary of pre-admission issues

Very high threshold for admission, much higher than for adults with learning disability or for children and young people without learning disability. Admissions were usually undertaken only in absolute crisis, when the risk of staying in the community exceeded the risk of an inappropriate ward. Children and young people, therefore, endured **long periods of untreated illness and distress** at home and families were exhausted from caring for them and managing challenging behaviour.

There was a **lack of community mental health services** to support, with 'cobbled-together' arrangements and gaps being filled by other services. **Risks were unacceptably high** in the community from aggression, self-injury, destructiveness, use of high levels of

psychotropic medication without the ability to safely monitor, and from families having to use unsafe physical restraint.

There were **particular difficulties for vulnerable patients**, including those with learning disability and more complex needs, and looked-after children and young people in out-of-area placements.

Families had to make difficult decisions. They were fearful of admission, especially when no appropriate unit and/or they had had previous negative experiences. It was difficult to hand over care, especially to staff inexperienced in working with children and young people and/or those with learning disability.

Situations **impacted on clinicians and other patients.** Each admission was a time-consuming and stressful 'special arrangement', with knock-on effect on the care of other patients and on the personal life of clinicians.

A4.5.1 Time taken from identification of need for admission to admission

This information was only given for 48 of the admissions in the survey out of 106. Therefore numbers were small for any meaningful comparison between patient groups.

- 24 patients admitted immediately (<24 hours)
- 11 admitted 24 hours to 1 week after need for admission identified
- 5 admitted 1 to 4 weeks after need identified

- 8 were admitted more than 4 weeks after need identified, some more than 3 months after.

A4.5.2 Positive pre-admission experiences

Sometimes a wait of several weeks was acceptable where there was a planned admission with time needed to make appropriate arrangements. Also, teams delayed some admissions, attempting other strategies in the community first, including intensive treatment services (ITS) where available. Families often drew on their extended family and friends to increase natural support to try and prevent admission.

Even when there was not an appropriate mental health unit available, there were a couple of examples of where admissions were relatively straightforward. For example, a young teenager was admitted to a pediatric ward in a crisis, because the teenager was well known to the ward and neurology team. Also, an older teenager was admitted to an adult LD ward because the adult LD community team was involved and a bed was available. The National Child Psychiatry Inpatient Unit was seen as responsive to requests for support and most admissions there were relatively straightforward to arrange.

A4.5.3 Pre-admission issues where an existing ‘generic’ young person’s mental health inpatient unit (YPU) was required

Securing a bed for any young person in an age appropriate mental health bed could take time, with regional YPUs frequently full. There were examples of young people requiring an YPU bed having to wait days or weeks, either at home or on an adult mental health ward. Difficult decisions could be required from families regarding whether a young person (e.g. with autism spectrum disorder and mild or no learning disability) would have been better in a local adult mental health

ward or a more distant regional YPU. Local general adult psychiatry consultants were generally supportive and helpful where young people had to be admitted to adult mental health units.

A4.5.4 Pre-admission issues where a specialist LD CAMH inpatient unit was required

The most major difficulties described in this section were experienced by patients, families and services in the pre-admission period where a specialist LD CAMH inpatient unit, secure LD CAMH inpatient unit or non-LD ASD unit was required. Information is summarised from interviews with clinicians about 27 patients, all except one of whom had learning disability. 6 of these had mild learning disability and required secure LD CAMH inpatient provision. 6 had moderate or severe/profound learning disability (all with co-morbid autism spectrum disorder) and required a robust, individualised autism spectrum disorder-specific LD CAMH inpatient setting. <5 had autism spectrum disorder without learning disability and required a secure autism spectrum disorder adolescent mental health inpatient unit. Clinicians managing these situations in the community were from a variety of services (adult LD, mainstream CAMHS, Paediatrics and LD CAMHS) as specialist LD CAMHS community provision is very variable across the country.

The impact of a lack of any suitable inpatient mental health beds for children and young people with more severe levels of learning disability/complexity was reported as far reaching. Admissions were almost never at the appropriate time, young people and their families frequently endured weeks of distress at home as the thresholds for admission to inappropriate units were so high. Families of children and young people with learning disability tended to be used to dealing with

very high levels of need. This meant that when they were no longer able to cope, the situation being presented was often at a critical level. Admissions were therefore almost always in crisis rather than planned but, despite this, could take considerable time to arrange, each admission being a ‘special arrangement’.

The only option for admitting one young person with learning disability, autism spectrum disorder and probable major mental illness with an extreme presentation was an adult IPCU (Intensive Psychiatric Care Unit). As this was so clearly inappropriate he was only admitted when things became completely unmanageable.

A4.5.5 Trying to avoid admission and managing while waiting for a bed

In cases where children and young people with learning disability were eventually admitted to non-specialist units, such as adult mental health, adult LD and YPUs, particularly intensive input was given in the lead-up, in an attempt to prevent admission. Thresholds for admission to non-specialist units were very high, so children and young people with learning disability were almost always admitted much later and at much higher levels of need than children and young people without learning disability, or adults with learning disability. The levels of risk to the young people and their families were usually “way above acceptable levels” by this stage. One adult LD Psychiatrist expressed his concern that, due to a lack of an appropriate inpatient facility, children and young people with learning disability were almost never admitted for clinical reasons, but only when the risk to them of staying in the community exceeded the risks to them of being in an adult ward.

In one case, multiple attendances at A&E (Accident & Emergency Department) occurred while waiting for a bed, with family desperate for 'time out'. A&E staff were supportive, but there were significant problems due to destructive behaviour and the young person grabbing things off other patients.

A4.5.5 (i) Response from out-patient teams

Clinicians described teams 'pulling out all the stops', knowing patients would be better off at home with familiar people in their usual routines and environment, than in a non-specialist setting. Adult LD services frequently felt pressure to be drawn into managing complex situations regarding under 18's, where they didn't have the remit, time or expertise to do so, describing trying to make the best out of a difficult situation for individuals. Clinicians in some areas felt there was a lack of 'ownership' of these children and young people by CAMHS services, and a lack of support from service managers, due in part to a lack of historical involvement with children and young people with learning disability.

A4.5.5 (ii) Intensive community treatment services

Only one Health Board (Lothian) has an intensive LD CAMH service. Intensive 'mainstream' CAMHS services, when present, often exclude or lack skills to work with those with learning disability. Despite best efforts, very small LD CAMH services (where these even exist) struggled to provide anything approaching an intensive community response. For example, a patient who should have been seen at least weekly by a psychiatrist with additional nursing visits between could only be seen every 2-3 weeks by a psychiatrist, with phone calls in between. Clinicians described being therefore unable to safely monitor and manage the required medication at home. They had to balance the risks

and distress of inadequately managed symptoms with the risks of using relatively high doses of psychotropic medication without safe monitoring.

Where an LD CAMH intensive service was available, this did not prevent hospital admission in all cases. A situation was described where school could not manage the young person's behaviour, despite creation of a 'bespoke' educational resource. When this and a large package of specialist respite broke down, he was just at home and the family could not manage. Despite adult LD nurses working in the family home for 3-4 months, the situation became unsustainable and the level and intensity of challenging behaviour meant that a hospital placement was unavoidable.

A4.5.5 (iii) Paediatric and social care services

Pediatricians were sometimes left managing psychiatric/behavioural presentations in children and young people with learning disability in the community and on pediatric wards where LD CAMH community provision was limited. For example, in one Health Board, CAMH psychiatrists did not see children and young people with learning disability and learning disability psychiatrists did not see children and young people, leaving a gap which had to be managed by pediatricians. Considerable time, energy and stress was involved in prolonged debates about who should take responsibility.

One child remained in A&E overnight while the pediatric ward decided whether they could manage his disturbed behaviour, in the absence of a mental health alternative.

The added physical, neurodevelopmental and mental health complexities of children and young people with learning disability mean that psychiatrists have to work closely with pediatricians to assess

physical and mental health contributors to severely disturbed behaviours. A psychiatrist described spending up to half of a working week on a pediatric ward to support an admission where physical causes of behavioural problems were being assessed prior to transfer to a psychiatry ward. Mental health nurses were also ‘drafted in’ to support.

Social work and education departments often had to put in considerable resources to support patients who should have been in hospital, to the detriment of services to other children.

One patient, who waited 12 weeks for a secure LD CAMHS bed, was only manageable because he was in a secure care unit where staff tolerated his behaviour as he was so obviously mentally unwell. Staff were described as ‘superb’, particularly as they were not experienced in managing young people with learning disability.

A patient who waited more than 6 months for a bed in an LD CAMHS unit in England had to be managed between home and a local respite unit, with the local pediatric ward and regional YPU being considered unsuitable due to her severe learning disability and autism spectrum disorder. Respite staff struggled to manage, even with 3:1 staffing levels. There were teams of staff at respite and school dedicated just to her, at high cost and at the detriment of work with other children.

A4.5.6 Looked after children and out of area placements

Particularly complex situations arose when children and young people requiring admission were ‘looked after and accommodated’ outside their home Health Board. Some patients had extremely prolonged and complex journeys over months or years through a number of social care, secure units, residential schools and various inpatient units prior to

eventual admission. Delays of up to 2 years were described while referrals were made and considered. A case was described where the clinician felt that clear treatment plans with admission where required to an appropriate Scottish inpatient unit would have prevented numerous crisis admissions and months/years of uncertainty.

The availability and location of residential schools set up for children and young people with severe/complex needs meant that some children and young people with learning disability (and usually autism spectrum disorder) were accommodated out of their Health Board area. Specialist mental health input to such schools is variable and they may be in Health Boards with underdeveloped or no specialist LD CAMH services. When mental health issues arose for these children, and/or behaviours escalated to a level that the school could not manage, extremely difficult situations arose with, for example, young people being admitted in crisis to adult mental health or adult LD wards local to the school but away from their Health Board area. As well as difficulties of geographical distance from family and home area professionals, there were boundary issues about who takes "ownership" of the patient's situation. Professionals and families found themselves involved in very time consuming and stressful battles over service provision, particularly around the time of transition to adult services (social and health). For patients in care where there was no ongoing family involvement, there was some concern from psychiatrists that no-one was advocating effectively for their needs.

There was difficulty accessing a forensic LD CAMH assessment for a young person in secure residential care away from his home Health Board. A lack of expertise in both Health Boards was complicated by CAMH psychiatry cover coming from Health Board of the residential

home but financial responsibility coming from the home Health Board. An adult LD forensic psychiatrist carried out an assessment, recommending inpatient care in a medium secure LD CAMH unit in England, but lack of action from the home Health Board meant that the referral process took many months. Local CAMHS closed the case and involvement from home Health Board clinicians could not be intensive due to distance. A major crisis led to urgent admission to a highly inappropriate adult setting, pending transfer to the previously recommended medium secure adolescent setting.

A patient with learning disability, autism spectrum disorder and a highly complex and challenging presentation was accommodated in a specialist residential school outside of their Health Board of residence. With no local LD CAMH service in the Health Board in which the school was located, a psychiatrist from their home Health Board had been to give an opinion 2 years before the admission. However, no local follow up or support for implementation had been possible and difficulties escalated until admission was unavoidable and had to be arranged to an inappropriate Adult LD hospital.

A4.5.7 Impact of pre-admission difficulties on children, young people and their families

Where children and young people had to remain at home or in care provision for weeks or even months while an appropriate (or even an inappropriate) hospital bed was found, this was an extremely stressful and distressing time for them and their families. There were high levels of distress, agitation, self-injury, aggression, destructiveness and sleep disturbance, causing injuries and high risk of serious harm to children and young people, their parents and siblings. Families sometimes had to

use unsafe physical restraints to attempt to manage the risks. In a number of cases, respite provision and/or school placement had already broken down due to the severely challenging behaviour so there was a reduction of usual supports.

A teenager with learning disability, complex physical and mental health problems was unwell for weeks in the community, with no available intensive home treatment provision and no suitable inpatient unit to admit to. In the days leading up to an emergency admission, she was almost continually distressed night and day, often stripped naked, screaming, sleeping as little as 3 hours a night and pulling everything apart in the house. Her family were exhausted and distressed. Psychiatric medication was already at higher doses than could be safely monitored and managed outside a hospital setting.

The full impact on children and young people themselves of these extended periods of distress, untreated mental illness, uncertainty and debate about who should help them and where they should go could not be directly ascertained from this study. The severity of learning disability of many would have made it difficult for them to verbalise this. However, one more verbal young man with mild learning disability, whose psychiatrist had spent weeks persuading him to go for assessment at an YPU, felt hugely rejected when they said they could not admit him.

Some families found it intrusive when clinicians had to carry out frequent home visits to safely monitor a child or young person waiting for admission. The preadmission time was even more difficult when there were young siblings, parental mental health issues and marital problems. Parents may have had negative experiences of hospital or care themselves, which made them more fearful of hospital admission.

Where there were additional complex family issues with high expressed emotions or child protection concerns, this added to difficulties in managing the situation. Families had often managed very challenging behaviour over many years at home and it could be difficult for them and professionals to decide when to draw the line. So when a difficult decision to admit had been made, to then have to wait for a bed was very hard.

As young people were often admitted in crisis when families were no longer able to cope, the parents struggled with the decision to admit their child to hospital. This was much harder when they had to admit them to an inappropriate adult ward, when they were aware that staff were not used to working with children, and fellow patients may include adults with aggression and who have committed sexual offences. Parents of children with complex and serious physical health needs who had provided very high levels of care all their lives found it particularly difficult to hand over their care. They often had spent years developing relationships and trust with education and respite staff but were having to effectively trust strangers with their child who was unable to communicate their own needs.

A4.6 Admissions to different types of ward - overview

This data is for all ‘submissions’, i.e. different parts of an admission, such as when a patient was transferred between units within an admission, are separately counted.

Admissions to different types of ward – summary of statistics

Highest rates of admission were to adult mental health wards, followed by YPUs and adult LD wards.

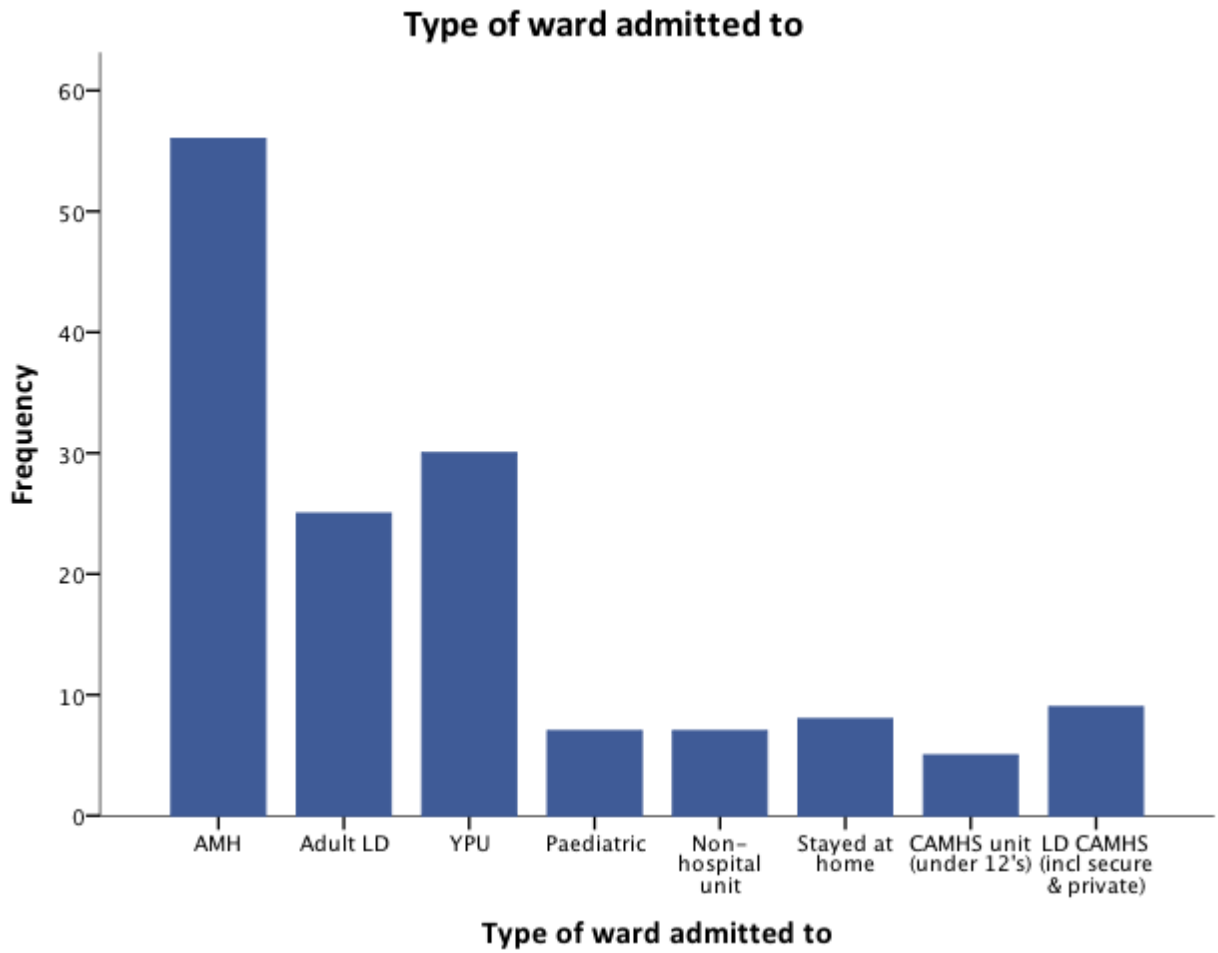
Few patients in the survey were admitted to learning disability child or young person’s mental health inpatient unit, autism spectrum disorder mental health inpatient units, pediatric wards and the National Child Psychiatry Inpatient Unit.

Patients with increasing levels of learning disability were more likely to be admitted to adult LD wards, but only 2/3 of those even with severe/profound learning disability were admitted to a learning disability specific ward, with ½ of these being an age-appropriate facility.

The most common age for those admitted to adult MH, adult LD, YPU and LD CAMHS (including secure) wards was 16-17 years. Those remaining at home or admitted to non-hospital placements tended to be younger teenagers.

Rates of autism spectrum disorder varied according to the type of ward admitted to.

A4.6.1 Type of ward admitted to for all admissions



Note that admissions to Secure Adolescent ('Secure YPU') and to Autism units (including Autism secure units) are omitted from the above graph as there were less than 5 admissions to each of these types of units. 'AMH' refers to adult mental health.

A4.6.2 Profile of patients admitted to different types of ward

A4.6.2 (i) Level of learning disability

There was variation as to which wards children and young people were most likely to be admitted to according to their level of learning disability:

No learning disability	AMH (61%) YPU (16%) ALD (0%)
Mild learning disability	AMH (39%) YPU (21%) ALD (21%)
Moderate learning disability	AMH (17%) YPU (28%) ALD (24%)
Severe/profound learning disability	AMH (0%) YPU (0%) ALD (36%) LD CAMHS (29%)

Note: AMH = adult mental health; ALD = adult LD

For each level of learning disability, the % of children and young people admitted to age-appropriate mental health units (including YPUs, the National Child Psychiatry Inpatient Unit, LD CAMH and autism spectrum disorder-specific provision) were as follows:

No learning disability:	27%
Mild learning disability:	36%
Moderate learning disability:	33%
Severe/profound learning disability:	43%

For the main types of ward that patients in the study were admitted to, levels of learning disability varied as per the following table (numbers are for admissions or parts of admissions where transfers occurred).

Type of ward admitted to by level of learning disability

Level of learning disability → Type of ward ↓	None	Mild	Moderate	Severe/ profound
Adult mental health	30	17	8	<5
Adult LD	0	9	11	5
YPU	8	9	13	0

Numbers admitted to other types of ward were too small to provide meaningful/non-identifiable breakdowns of levels of learning disability.

A4.6.2 (ii) Age at admission

The age of patients admitted to the various types of units varied. The most common age-groups for patients admitted to each type of units were as follows:

Adult mental health:	16-17 (78%)	14-15 (20%)
Adult LD:	16-17 (68%)	14-15 (28%)
YPU:	16-17 (63%)	14-15 (30%)

The following had small numbers but trends are given:

- Paediatrics: mostly aged 13 and under
- Non-hospital placement: mostly aged 14-15

- Stayed at home: mostly aged 14-17
- National Child Psychiatry Inpatient Unit: all under 12 by definition
- Secure YPU: all aged 14 and over
- Autism unit (including secure): all aged 14 and over
- LD CAMHS (including secure): ranged across all age groups but most commonly 16-17 years

A4.6.2 (iii) Autism spectrum disorder diagnosis

High rates of autism spectrum disorder diagnoses were found amongst children and young people admitted to all types of units in the survey. All of those admitted to specialist units in England had autism spectrum disorder. Ratios of autism spectrum disorder to no autism spectrum disorder, in the 3 main types of units admitted to, were as follows:

- Adult mental health: 4:1
- Adult LD: 2.25:1
- YPU: 1.5:1

A4.6.3 Summary of issues and outcomes to currently available Scottish units

Some positive experiences and good outcomes were reported by clinicians and families for patients and families from admissions to all types of existing Scottish mental health wards. However, these were often the results of ‘cobbled-together’ arrangements, with huge support and input from community clinicians, with detrimental effects on other

patient care. Outcomes for those with more than mild level of learning disability and/or with high levels of challenging behaviour or forensic needs were much less good. The following tables summarise issues and outcomes for patients admitted to Scottish units from the survey from sections 4.8-4.13 of the results.

Summary of issues on adult LD and mental health wards

Positive experiences and outcomes

Issues common to adult LD and adult mental health wards related to **keeping children and young people local**, allowing family contact, continuity with local multiagency professionals, facilitating discharge planning and transition to adult services

Adult LD wards only:

- **Good staff knowledge and experience** of learning disability and autism spectrum disorder.
- **Took in children and young people with highly challenging behaviour** when no other wards able to.
- **Services flexible** in adapting physical environment and staffing.
- **Successful multidisciplinary assessment, diagnosis and management** of mental and physical health conditions and challenging behaviour for some children and young people.
- Sometimes **reduced medication, restraints, and use of seclusion, greater access to community and development of self-care skills.**

Difficulties and poor outcomes

Issues common to adult LD and adult mental health wards:

- **Difficulties keeping separate from adult patients:** Some children and young people therefore felt unhappy, anxious and intimidated, with exposure to aggressive or sexualized behaviour from adult patients. Children and young people with milder learning disability and less supervision were socially and sexually vulnerable.
- **Difficulty providing robust, 'autism friendly' physical environment and consistent staff team** for those with highly challenging behaviour. Staff struggled to manage high levels of aggression and some children and young people had to be nursed in very restrictive settings, leading to isolation and risk adverse practice.
- **Lack of a specialist age-appropriate multidisciplinary team:** staff lacked confidence and expertise in learning disability and/or autism spectrum disorder; had difficulty recognising atypical presentations of mental illness and had insufficient understanding of family expertise, dynamics and systems, attachment and the impact of puberty.
- **Lack of access to education, appropriate peer group, play and activity**, including fresh air and physical exercise.
- These issues could combine to result **in escalation of behaviour, with high use of medication and restraint.** Medication side effects and lack of exercise led to weight gain, including metabolic syndrome.
- Some patients were **discharged too quickly** due to concern about being in an adult setting, with inadequate assessment and treatment. Others were transferred precipitously to other hospitals after breakdown of care.

Adult LD wards only:

- **Lack of progress over months or years, remaining in extremely restricted ward environment** for some, with missed opportunities for education and development.
- **'Delayed discharge'** of some patients due to lack of suitable care and/or education placements.
- **Significant impact on other adult patients**, e.g. adults at risk from their aggressive and destructive behaviour, or distressed by noise and disturbance; beds/ward space closed to adult patients for long periods; ward staff had less time available for adult patients who also had reduced access to activities.

Adult mental health wards only:

- **Disproportionately difficult for children and young people with learning disability and/or autism spectrum disorder**, due to them being developmentally younger, with poorer communication skills. Harder to provide developmentally appropriate activities.
- **Parents especially concerned and anxious about lack of staff expertise** regarding learning disability and autism spectrum disorder on these wards.
- **CAMHS struggled to support when no specialist LD CAMHS** to advise.
- Repeated admissions to inappropriate AMH wards in crises contributed to **escalation of difficulties** for some patients.

Summary of issues on child and adolescent wards

Positive experiences and outcomes:

Common to YPUs and the National Child Psychiatry Inpatient Unit:

- A number of families gained a greater understanding of their children's needs.

YPU wards:

- One YPU managed a number of children and young people with moderate learning disability with **training and support from the local LD CAMH team**, also **employing learning disability trained staff** which improved staff confidence and expertise.
- **Able to manage majority of children and young people with autism spectrum disorder but no learning disability/mild learning disability.**

National Child Psychiatry Inpatient Unit:

- Personalised assessment, diagnosis, treatment and management of children with **highly complex mental and physical health needs.** Close links with Paediatrics helpful for physical co-morbidities.
- Staff experienced in **neurodevelopmental disorders.**
- **Families learned practical strategies** to support their children.
- Good pre-admission and follow-up **support to local services.**

Paediatric wards:

- Provided **respite** for some families.
- **Medical investigations** carried out.

- Sometimes a degree of **assessment by CAMHS** of the child and their family situation was possible, as was **medication monitoring and change.**

Difficulties and poor outcomes

YPU wards:

- Unable to manage those with **forensic/secure needs.**
- Patients with **highly challenging behaviours** generally not admitted.
- Mixed reports of staff expertise and confidence about **autism spectrum disorder.**
- Lack of access to **specialist education** for autism spectrum disorder and learning disability needs.
- **Unequal access** as support from LD CAMH teams unavailable for admissions of children and young people from outside the Health Board in which the YPU is located.

National Child Psychiatry Inpatient Unit:

- Some children with severe learning disability and autism spectrum disorder only manageable as **day patients** and ultimately requiring specialist LD CAMHS unit admission.
- **Practical and financial difficulties for families** from remote parts of Scotland having to travel to national or regional unit.

Paediatric wards:

- Ward staff **lacked confidence and skills** in dealing with mental health problems and acute behavioural disturbance.
- **Families generally had to give 24 hour care** to their children in hospital, which was stressful, sometimes feeling unsupported by ward

staff.

- In some cases described as **‘holding place’** pending transfer, or as **ineffective** due to distress of child in that setting.
- Very **time consuming for pediatricians.**

Summary of other issues

Positive experiences and outcomes

Common to adult LD, YPU and adult mental health wards: included managing acute risks and medication in a safe environment, providing relief for families, identifying care needs and supporting discharge.

Common to adult mental health and YPU wards: better outcomes for patients with no/ mild learning disability with good communication skills and typical mental illness presentations. Also cases where treatment commenced, or behaviour/situation stabilised, pending move to a specialist unit.

Difficulties and poor outcomes

Common to adult LD, YPU and adult mental health wards: included lack of age-appropriate learning disability/autism spectrum disorder specific assessment, no change (‘holding place’ pending transfer), children and young people remaining unwell for prolonged periods, and families very unhappy about admissions, with long-term consequences on future engagement.

Common to adult mental health and YPU wards:

- **Struggled to manage those with moderate/severe/profound learning disability** - problems understanding implications and

impact of learning disability (and in some cases autism spectrum disorder), the relevance of symptoms, using appropriate communication and managing behaviour.

- **Significant treatable difficulties persisted after discharge** due to lack of thorough learning disability-specific multidisciplinary assessment/treatment.

A4.7 Admissions to adult learning disability wards

Summary of characteristics of patients admitted to adult LD wards:

- **Level of learning disability:** None with no learning disability, 9 mild learning disability, 11 moderate learning disability, 5 severe/profound learning disability
- **Autism spectrum disorder : no autism spectrum disorder ratio:** 2.25:1
- **Age**: 68% were 16-17 years, 28% were 14-15 years

A4.7.1 Positive aspects of care

There were some good outcomes from admissions to adult LD units and it was apparent that staff worked hard and creatively to try and support young people as well as possible, under difficult circumstances. Considerable support and advice was often given by local CAMHS or LD CAMH clinicians during admissions and this was valued. Where an intensive LD CAMH community service existed, nursing staff from that

team ‘moved in’ with their patient and nursed them in a segregated part of the adult LD ward. In other areas, adult LD psychiatrists recognised the lack of local LD CAMH expertise and provision and attempted to ‘fill the gap’ for young people who would become their patients anyway in the next few years.

Staff understanding and experience of learning disability was a key advantage over adult mental health and YPU units. They were more likely to understand the impact of the young person’s learning disability on mental health and behavioural presentations. Learning disability-specific environments, appropriate communication and behavioural approaches all helped. A parent commented that all of their child’s needs were covered in one place and the young person was treated fairly, equally and with dignity and respect. Staff took ownership but were welcoming to parents and involved them in decision-making.

Generally, adult LD units were closer to home than the regional YPUs. This was important to families, allowing more frequent visits, particularly when their own health problems or other caring responsibilities restricted travel. For those young people close to age 18, transition planning to adult LD and social care services was facilitated. For example, in some cases local providers identified to provide future care visited regularly to get to know the young person and provide activities. In others, staff from their existing school or social care agency maintained contact, working with young people on the ward.

A4.7.2 Patient safety and impact on children and young people

Adults with learning disability admitted to hospital usually have extremely acute mental health and behavioural problems themselves. Young people on adult LD wards were almost always nursed on constant 1:1 or

greater observation levels and some were isolated altogether from adult patients. However, even when physically protected by 1:1 nursing care, they sometime saw/heard aggression and inappropriate sexualised behaviour from the adults, even if this was not directed towards them. Young people were sometimes inadvertently exposed to inappropriate TV programmes being watched by adult patients.

Despite safeguards some young people felt intimidated by the adult patients. Others felt that they did not ‘belong’ there, e.g. living alongside elderly patients with dementia. Others were particularly sexually vulnerable. Great care was taken to protect young people, including restricting movement and activities of adult patients. There was concern about these understandable safety measures leading to unnecessary isolation of the young person, with staff running the risk of becoming ‘suffocating custodians’. A young person whose discharge was delayed due to a lack of a placement to move on to became bored, depressed and confused as to why they were still in there when feeling better. Their parents felt terrible about this and powerless to help.

The very high levels of disturbance of some of the children and young people themselves also meant that they were a risk to adult patients. Even experienced adult learning disability psychiatrists had not previously seen the levels of aggression and destructiveness shown by some teenage patients. Some young people who repeatedly assaulted staff due to inappropriate environments required regular restraint. This was felt in at least one case to have had a negative impact on the person’s self-esteem and development.

A4.7.3 Lack of age-appropriate environment and interventions:

On adult LD wards, young people could not mix with those of similar age, thus lacking the important developmental challenges of a peer group. Environments and staffing were often not geared up to supporting the development of self-care skills. Safety concerns and limited staff confidence and expertise with young people led to risk adverse environments, further limiting developmental opportunities.

Families and clinicians shared concerns about staffing levels, lack of age appropriate activity and absent or minimal access to education. Lack of physical freedom and access to outside space and exercise were major concerns. One young man had to be contained in a single room for months on end due to his extreme challenging behaviour, risk of absconding and because there was no safe outdoor area for him to use.

There was also a lack of access to age appropriate multidisciplinary assessments/therapeutic interventions. Even when a CAMH/LD CAMH psychiatrist acts as 'RMO' (Responsible Medical Officer) during admissions, other disciplines from children's services, e.g. nursing, clinical psychology, allied health professionals were usually not able to retain active involvement. Some were able to visit occasionally to advise, but this was not the same as being an active member of a ward multidisciplinary team. Different cultures, ways of working and emphasis between children's and adult professionals sometimes lead to time-consuming complications in such arrangements.

A4.7.4 Parental concerns and relationship with services

Parents described a range of emotions upon their child's admission to an adult LD setting including *"relief that they were safe", "grateful that we had a chance to sleep at last"* and *"hope that things would get better".*

However, this was often short-lived with parents describing developing anxiety when "*the setting turned out not to be ok", "I became concerned about her care"* and *"the admission became prolonged because there was no where appropriate for her to be discharged to".*

Clinicians reported that some families were deeply upset and opposed to the admissions from the start; although most accepted that there was no alternative. Other families, whilst having concerns about many aspects of prolonged admissions, did eventually see and acknowledge positive outcomes. Clinicians felt that admission was very traumatic for some families. Antagonistic relationships developed between services and families, e.g. with one family who wanted their child to be in hospital but then wanted them discharged due to concerns about the lack of age appropriate activities and the degree of restriction and security on the adult ward.

A number of psychiatrists specifically commented on the difficulties relating to systemic family issues around adolescence. They recognised the huge dedication and commitment of the vast majority of families and the stresses they have often been under for many years. Adult LD inpatient teams had limited experience of issues for families with children and adolescents and clinicians usually have no formal family systems training. Clinicians reported that many of the most challenging admissions of young people involved difficult family issues. Professionals not experienced in working with children and their families struggled when families had strong beliefs about the cause of their child's difficulties or were convinced that something had been missed. Clinicians recognised that parents may have been struggling with attachment issues and trusting others to care for their child, and that this was a natural process.

Some parents reported a lack of acknowledgement on the part of the staff of their expertise and knowledge of their child, and felt insufficiently included in conversations about them.

"I explained his needs to the staff but the hospital had 'to do it their way' which I feel was upsetting for my son"

"Maybe the hardest part was feeling that the health professionals took over the function of being the parent, that our views and experience of her no longer seemed to matter"

Difficulties of trust were exacerbated when there was poor communication from ward staff, including inadequate documentation and explanation of bruising and poor coordination of care.

Whilst staff on adult LD wards tried to accommodate parents spending time with their child, this could be difficult from a practical perspective in terms of staffing and physical environment, including keeping the parents safe from other patients. This limited the amount of time some were able to spend together.

The difficulties associated with managing highly complex young people on inappropriate adult wards resulted in breakdowns of relationship and trust between some families and local services, which negatively impacted on the patient's future care.

Families were usually strong advocates for their children and most worked collaboratively with staff teams to make admissions as successful as possible. Clinicians described concern for 'looked after children' and for those whose families were unable to support and advocate for them due to their own social and mental health vulnerabilities. These parents could become extremely distressed about

issues such as prolonged seclusion, lack of appropriate facilities and lack of access to appropriate activities. However, staff struggled to engage well and support these families effectively while at the same time managing complex and time-consuming admissions.

A4.7.5 Complex/severe presentations and staff expertise

Adult LD ward staff were usually very experienced and concerned to provide the best care to young people when they are admitted. However they struggled to manage those who had very high levels of aggression, self-injury and destructiveness. This may have been partly due to an unsuitable environment, particularly for young people who couldn't cope with being around other patients. Higher nursing ratios and a small consistent core team of staff around an individual patient was often required, rather than a traditional big nursing team for the ward.

Adolescents with learning disability (often also with autism spectrum disorder) were noted to show particularly severe self-injury, aggression and destructiveness, even compared to their adult counterparts. Staff on adult LD wards reported feeling de-skilled and lacked confidence in their ability to support young patients in the way they would have liked to. Some had limited understanding of childhood development, the impact of puberty and inadequate knowledge of and links with Children's services. There was concern due to inexperience about using control and restraint techniques, tranquilisation etc., particularly in younger teenagers and children. There are differences in the presentation of mental illness, developmental disorders and behaviours at younger ages and these were unfamiliar to staff. Early onset mental illness can be particularly severe and complex, e.g. a patient with early onset treatment resistant psychosis had one of the most difficult presentations ever seen

by one adult LD psychiatrist. There were cases where illnesses such as depression were not picked up during admission.

A4.7.6 The physical ward environment

The adult LD wards' physical environment was not suitable and robust enough for a significant number of young people, particularly those with additional autism spectrum disorder and highly aggressive and destructive behaviours.

Considerable and costly adaptations to the physical environment had to be made for a number of the patients admitted to open adult LD wards. Extensive reinforcement of all fittings and securing of furniture was often required. In a number of cases the need for space separate from the adult patients closed access to beds and living space for adult patients for months or even years. Office space was converted for others, and there was an example of the use of staff bathroom facilities for a patient, with knock-on effects on services and staff hygiene. One teenager had to be nursed for well over a year in isolation in an environment completely stripped of any furniture and fittings. Numerous ongoing repairs (sometimes on a daily basis over a period of months) had to be made to ward environments in a number of cases, including regular call-outs of emergency joiners.

A highly expensive bespoke robust suite of rooms had to be built to accommodate a patient with particularly destructive behaviour. The design and building of this was complex, and the patient was meanwhile nursed in one room over a lengthy period. The patient had to live, eat and carry out education and all activities in one room. There was a lack of natural light and air conditioning at times due to damage from

destructive behaviour. Considerable practical issues were faced, including how to make repairs and clean the space, particularly as the patient was regularly urinating and smearing faeces in the room.

Part of an adult LD day hospital had to be closed and adapted for the admission of a young person, limiting access to other patients and holding up development plans for that unit.

A4.8 Admissions to regional young people's units (YPUs)

Summary of characteristics of patients admitted to YPU wards:

- **Level of learning disability:** 8 no learning disability, 9 mild learning disability, 13 moderate learning disability, 0 severe/profound learning disability
- **Autism spectrum disorder: no autism spectrum disorder ratio:** 1.5:1
- **Age**: 63% were 16-17 years, 30% were 14-15 years

A4.8.1 Positive aspects of care

It was generally felt by clinicians that the YPUs were able to appropriately manage the vast majority of admissions for young people with autism spectrum disorder without learning disability, or with mild learning disability. There were good outcomes for most of these young people. However, when YPU beds were unavailable, it was hard to manage the complex needs of these young people in the community or in local adult mental health wards. Some families were relieved when their young person was admitted or transferred from adult mental health units to YPUs. A number of clinicians reported families being happy with

care provided. There was more developmentally appropriate activity than on adult LD wards. Clinicians reported that YPU staff were more confident managing young people with mild learning disability and/or autism spectrum disorder when the main presentation was of severe mental illness. To support one young person, they were able to up-skill themselves with help from LD CAMH community clinicians in communication needs, the use of visual timetables and in how to support self-help skills.

A4.8.2 Patient groups with less access to YPUs

Of those with mild or no learning disability in the study, it was mostly children and young people with forensic/secure needs who could not be admitted to YPUs. Generally, YPUs were not considered 'a good fit' for patients with moderate to severe learning disability and a number were not admitted, even if beds were available. Good outcomes for those with more severe levels of learning disability tended to be gained only with extremely high levels of support from local LD CAMH community services. One of the YPUs had been supported in this way to successfully manage a number of young people with moderate learning disability. In that YPU, there was also learning disability expertise in the inpatient staff group itself, with one post-split between the unit and the LD CAMH team.

Clinicians commented that the lack of specialist learning disability input into the Regional YPUs for those outside the Health Board where that YPU is located was a difficulty. In Greater Glasgow and Clyde and in Lothian, there are specialist LD CAMH community services and in Lothian an Intensive LD CAMH service. These services could provide

support for their own community patients when admitted to the regional YPU situated in their Health Board, but not usually for those admitted from other regional Boards. This meant unequal access to the regional YPUs for those with learning disability, particularly with moderate learning disability who had more complex presentations and more severe challenging behaviour.

A4.8.3 Parental concerns/relationships with services

Distance was an issue for some families, even to regional units. As well as making travel difficult, it also affected liaison with local services. Families who may have been relieved when an admission was arranged became concerned that staff were not trained on the YPU to meet their young person's needs with respect to their learning disability.

Clinicians reported at least one family had a number of concerns about the patient's care and there were difficult relationships between them and the inpatient team and community Services. Another was critical of social work services such that a patient ended up in hospital due to a lack of other resources. Concern was raised about lack of education arrangements appropriate to a young person with autism spectrum disorder.

A4.8.4 Staff expertise and experience

YPU staff struggled to manage and understand the behaviour of some young people with learning disability, assess the relevance of their symptoms and to cater for their level of need. Staff lacked confidence in working with those with more severe communication difficulties and had difficulty managing high levels of aggression.

This was a highly complex presentation which the adolescent unit struggled with. It was difficult for them to work out the role of the obsessions and the anxiety in a patient with learning disability, autism and psychosis.

Several clinicians were concerned that YPU staff misattributed behaviour that was due to young people's learning disability and mental illness as them exhibiting 'oppositional' or 'teenagery' behaviour.

In one YPU, the local LD CAMH community team had given intensive support and training to staff over a number of years around several admissions. Their expertise and confidence noticeably improved over that time, reducing the need for community team input. An LD CAMH clinician working as part of the ward team also contributed to improved care and led to greater recognition of undiagnosed learning disability and autism spectrum disorder in patients.

Contrasting views of the YPUs expertise on autism spectrum disorder were given, with one clinician noting that they have moved on hugely in recent years in an understanding and management of people with autism spectrum disorder. However, a parent reported that the YPU their child was admitted to had little knowledge about young people with autism spectrum disorder and "*the staff were inconsistent in their approach, it seemed to be about who was on duty and that isn't really good enough. You need to feel there is a shared understanding and a consistent approach being taken".* Another setting was reported as "*being fully aware of my child's needs and how her autism affected her behaviour. We had long conversations so did the consultant. They offered a place in the knowledge of the challenges she presented. Two weeks in they announced they couldn't manage her."*

A4.8.5 The physical ward environment

Few young people with more severe levels of learning disability and highly challenging behaviour were admitted to YPU beds. One major limiting factor to their admission was the lack of availability of a separate, quiet part of the ward on which they could be nursed separately from other patients for safety reasons. This was also a problem for those of all degrees of learning disability and none whose autism spectrum disorder meant they could not cope with being around other patients. However, a small number admitted to one YPU used a secured segregated area with extensive reinforcement of all fittings and doors. This was built to accommodate one specific patient, who was nursed in isolation with staff sitting outside the door. One young person with autism spectrum disorder but no learning disability also required this area, due to their sensory needs and need for containment. This was too restricted for their overall care and a specialist secure autism spectrum disorder unit was required.

A4.9 Admissions to the National Child Psychiatry Inpatient Unit

Numbers of admissions were too small to this service to give a meaningful breakdown of patient characteristics.

The National Child Psychiatry Inpatient Unit was identified as managing well some young people with significant levels of learning disability and/or autism spectrum disorder. Descriptions were given of admissions of highly complex patients where there was excellent assessment and treatment, with detailed handover, practical instruction and guidance to families and local services. These proved helpful even a long time after discharge. Follow-up over extended periods via conference calls and

occasional out-patient appointments was valued. A clinician from a remote rural area felt their service was well supported, with advice from the unit prior to admission, a quick response and prioritisation for admission due to difficulties for local services managing in their geographical setting.

For <5 children with severe learning disability (who also had autism spectrum disorder), only day patient attendance was possible, as they were unable to be safely managed alongside other children. A separate part of the ward usually used for other purposes was used to provide a quiet, individualised environment. This took a long time to arrange in one case due to concern about whether the ward could manage the patient's complexity in that environment. These children ideally required a specialist LD CAMH inpatient unit and despite helpful and detailed multidisciplinary assessment it was not possible for full assessment and treatment in the National Child Psychiatry Inpatient Unit. One went on to receive this in an English LD CAMH unit. However, other parents objected to distant cross-border admissions for their children, which therefore did not go ahead.

Chronological age rather than development stage cut offs were viewed by some clinicians as unhelpful. There were young teenagers with learning disability and/or autism spectrum disorder who some clinicians felt would fit better with the National Child Psychiatry Inpatient Unit model than that of the YPUs. Their social skills and developmental needs would suit better the younger age group. A clinician illustrated this concern based on experience with a young teenager at an YPU who had misinterpreted and copied other people's behaviours, presenting quite a challenge to the unit.

A4.9.1 Parental concerns/relationships with services

Some difficulties were highlighted in supporting families from remote parts of Scotland with admissions and one admission was cut short as the family could not maintain the travelling to visit. Another family found negotiations difficult around the expectation for the whole family to visit regularly for family therapy sessions. Families struggled with the expense of travelling to and staying in Glasgow. Expenses were paid by their Health Board for the time the hospital stated was required. However, families may choose to visit more frequently or stay on longer to make a trip worthwhile and to spend more time with their child. At least one family ran up a lot of debt due to the admission. For those attending as day-patients, this could be time-consuming for the family, impacting on time available for other children.

A4.9.2 Staff expertise and experience

Good outcomes for children were put down to staffing skills, greater experience of neurodevelopmental disorders and availability of one to one care, which was viewed by some clinicians as more personalised and individual compared to what is offered in the YPUs. Being on the site of a highly specialist childrens' hospital allowed crucial access to and liaison with a range of pediatric medical specialties. This was valuable for a patient group with frequent complex medical co-morbidities.

A4.10 Admissions to adult mental health wards, including intensive psychiatric care units (IPCUs)

Summary of characteristics of patients admitted to adult mental health wards:

- **Level of learning disability:** 30 no learning disability, 17 mild learning disability, 8 moderate LD, <5 severe/profound learning disability
- **Autism spectrum disorder: no autism spectrum disorder ratio:** 4:1
- **Age**: 78% were 16-17 years, 20% were 14-15 years

Due to distances involved and bed availability, young people with or without learning disability and/or autism spectrum disorder often had to be admitted in crisis to their local adult mental health units, with subsequent assessment by their CAMH psychiatrist and transfer when possible to their regional YPU. This could be a difficult process for any young person; however, it was particularly difficult for those with learning disability and/or autism spectrum disorder.

Admissions to adult mental health inpatient units were often helpful in the short term to manage immediate risks and medication. Young people and others were kept safe in crisis situations and there was containment of anxiety. However, lack of ability to carry out overall needs-assessment, multidisciplinary treatment and management meant that often little progress was made in terms of longer-term outcomes. As for those with learning disability and/or autism spectrum disorder admitted to YPUs, admissions were most helpful for those with no or mild learning disability, good communication skills and more typical mental illness

presentations. Some admissions to adult mental health wards, including several to IPCUs (intensive psychiatric care units) were extremely challenging. Some serious staff injuries were reported.

Being close to home was an advantage, allowing continuity with local clinicians and facilitating discharge planning. For some of those very close to 18 and with mild/no learning disability and autism spectrum disorder, who were about to move on into mainstream adult mental health services, it was felt little would have been gained by admission to the more distant regional YPU. This was similarly the case for brief admissions to local adult mental health wards for those with autism spectrum disorder (but no learning disability) where crisis management was all that was required.

Clinicians were aware that some young people did not like being on an adult ward and felt anxious there. One young man with moderate learning disability was extremely unhappy on an adult mental health ward and made allegations of aggressive behaviour against him by a nurse.

An admission for a young person with moderate learning disability and autism spectrum disorder went well due to 'luck and circumstance', as a new IPCU was available which happened to be quiet. Adult LD nursing staff were brought in, nursing him separately from adult patients and were able to bring behaviour under control. Had either appropriate staff or the amount of space in the ICPU not been available, this patient's behaviour could have escalated and he could have become stuck in hospital for a prolonged period.

A4.10.1 Patient safety

The vast majority of young people admitted to adult mental health wards were nursed 1:1, often in their own room, according to protocols designed to keep them safe, e.g. from exploitation by adult patients. Some clinicians commented that this also gave them more attention than the adult patients and perhaps gave them greater access to activities and recreation to keep them occupied. However, if inexperienced or unconfident staff were responsible for the 1:1 observations then it could feel counterproductive.

A number of those with mild learning disability and/or autism spectrum disorder were felt to be particularly sexually vulnerable due to immaturity, social naivety and in some cases disinhibition. Risks were mitigated by the 1:1 observations but it could be difficult, e.g. on a small IPCU, to keep young people entirely away from adult patients. Others with mild learning disability, whose presentation could not justify constant observations, made connections with young adults on the ward and were vulnerable to their influence, e.g. going out of ward with them and coming back drunk.

A lack of appropriate environment and expertise also put young people at risk of high use of psychotropic medication. Weight gain and metabolic syndrome were a problem for some, exacerbated by inactivity due to lack of access to fresh air and space for exercise.

A young person with mild learning disability who was severely mentally unwell required a secure LD CAMH hospital due to high risk of violence to others. The LD CAMH team responsible for his care for nearly 2 months on a local AMH unit were completely unable to adequately assess and manage his symptoms in that environment. The risk levels

meant it was too dangerous to attempt medication change so the patient remained very distressed and unwell while awaiting transfer.

A4.10.2 Parental concerns/relationships with services

Quite a number of families were reported by clinicians to have been happy with care provided on adult mental health wards, including one on an IPCU. There was relief at admission as things were so difficult at home, but also worry about their children being in an adult environment. Families were concerned that staff lacked confidence and experience not only with young people, but particularly with those with learning disability.

Several families were reported by clinicians to have been very negative about admission and developed very difficult relationships with medical staff. Families had concerns about various aspects of management, including restraint. Unhappiness about admissions had an impact on families' ongoing relationships with services.

A4.10.3 Lack of age-appropriate environment and interventions

There was a lack of access to education and structured and purposeful activity for young people on adult mental health wards and the issues here were very similar to those described above for young people admitted to adult LD wards.

A4.10.4 Staff expertise and experience

In addition to the lack of experience of nursing staff with children and young people, there was a lack of access to age-appropriate allied health professionals, in particular occupational therapists and speech and language therapists. Advice and input from CAMH psychiatrists and nurses was often provided.

For those with no learning disability but with autism spectrum disorder, a lack of understanding of autism spectrum disorder by staff was a problem, for example understanding of communication needs; understanding the need of one patient to pace (leading to overuse of medication). Ward staff reportedly did not understand that a young person was reverting to younger behaviour due to stress, and they were not thought to be as nurturing and understanding as an YPU would have been. There were difficult diagnostic challenges regarding one patient's presentation and either a specialist autism spectrum disorder unit or advice from multidisciplinary experts would have been helpful.

For those with mild learning disability with or without autism spectrum disorder, it was reportedly difficult for staff to engage with some patients; therefore assessment of their needs, including level of understanding, was not possible. Ward staff lacked experience in understanding developmental issues in general. Where there was CAMHS rather than LD CAMHS in-reach, CAMH staff also felt under-skilled in one case and not confident in treatment decisions. They lacked familiarity with the presentation of psychosis in a young person with learning disability. Essentially they 'held' the situation pending transfer to an adult LD ward. In another case, ward staff felt 'out of their depth', not only managing a young person rather than an adult, but one whose learning disability made them developmentally much younger still.

For those with moderate and severe learning disability, very variable attitudes and levels of understanding were reported amongst staff on adult MH wards. Staff who lacked confidence could become very anxious about their ability to manage patients with high levels of complexity and challenging behaviour who were so different from their usual patient group. Constant support was required from CAMHS staff. It

was also difficult for hospital staff to understand family dynamics and issues and impact of puberty on young people's presentation.

A young person with severe learning disability, admitted in crisis to an adult MH ward showed very high levels of aggression which the ward struggled to manage. A local review of service provision was required and Mental Welfare Commission involvement.

A patient who had autism spectrum disorder but no learning disability and required medium security was admitted to an IPCU. The very repeated aggression to IPCU staff meant the patient had to be isolated in one room and the whole admission was treated as a critical incident.

A4.10.5 The physical ward environment

The main 'adaptation' required for those young people with autism spectrum disorder without learning disability who were admitted to adult mental health units, whilst needing YPUs, was the need for them to be in a single room (1 specified near to the nursing station) due to their vulnerability in an adult environment. One was given the exclusive use of a 4 bedded area during the day, but was able to share the sleeping area at night. Another required a hoist and other specialist equipment due to physical immobility and health problems.

Six of the young people admitted to adult mental health units who needed an LD CAMH inpatient unit were noted as needing special physical adaptations to the ward. All of these had mild or moderate learning disability and the majority had additional autism spectrum disorder. Some of these ideally required secure LD CAMHS settings.

A patient was isolated in a segregated part of an adult mental health IPCU (Intensive Psychiatric Care Unit).

A young person was nursed on a bare mattress with no furniture, to reduce aggression and destructiveness.

The environment for a patient was adapted to make it more 'autism-friendly', taking into account the individual's sensory hypersensitivities and obsessions with/destructiveness of electrical items.

The environment was not suitable for the admission of one young person with severe learning disability. The patient required higher staffing nursing ratios and consistent care, rather than from a big team of staff. Staff struggled as the patient could not cope with others being around him and showed extremely high levels of aggression and self-injury.

A4.11 Admissions to pediatric wards

Numbers of admissions were too small to these wards to give a meaningful breakdown of patient characteristics.

Children and young people with mental health/behavioural problems admitted to pediatric wards (where LD CAMH inpatient units were required) needed to be nursed separately in side rooms. Families of the majority stayed with their child or young person 24 hours a day to provide care and this was stressful for them. One patient had use of a family suite, usually used for critically ill babies. Their family and care staff moved in too. Some families accepted admission to a pediatric ward as their only option, where things were unmanageable at home and suitable school and/or respite facilities unavailable.

A patient with autism spectrum disorder but no learning disability was already familiar with pediatric ward and team. The family were fully

supportive and the patient happy to go in. No beds were available in the YPU, but it would not have been easy for him there anyway due to his autism and other difficulties. The patient also struggled with the noise, change and busy environment on the pediatric ward, despite having his own cubicle.

Parents of a young person with severe learning disability hated the admission, feeling that the pediatric ward staff took "nothing to do with him". To reduce the patient's distress levels, the carers had to go out to push him in his wheelchair around the grounds, including in the evenings.

Nursing and medical staff lacked confidence and skills to deal with young people with acute behavioural disturbance and mental health problems. They were anxious about how to manage aggression. Pediatricians sometimes had to use psychotropic medication, outside their area of expertise and without support from psychiatrists, in an attempt to manage situations. These situations could be very time consuming for Pediatricians, having to review the patient on the ward several times a day.

Community CAMHS, LD CAMHS or pediatric liaison psychiatry teams tried to support these admissions. A psychiatrist noted how generous their local pediatric ward was in allowing admission for mental health reasons, but that it needed to be heavily supported by CAMH staff visiting daily. Sometimes bank staff with mental health experience were brought in from elsewhere to support.

A4.12 Admissions to specialist mental health inpatient units in England

There were a total of 17 patients admitted to mental health inpatient units in England. 9 were admitted to LD CAMH inpatient units, including secure LD CAMH inpatient units. Other units included Secure Adolescent mental health inpatient units and autism spectrum disorder - specific inpatient units.

All patients admitted to mental health inpatient units in England had autism spectrum disorder. The number of patients of each level of learning disability admitted to units in England was as follows:

- No learning disability: 5
- Mild learning disability: 5
- Moderate learning disability: (<5)
- Severe/profound learning disability: (<5)

Summary of issues related to admissions to specialist inpatient units in England

Positive experiences and outcomes

- Comprehensive age and learning disability/autism spectrum disorder specific multidisciplinary assessment giving better understanding of patient's needs
- Significant improvements in mental health, anxiety levels and well-being
- Improved sleep pattern for patient and therefore family when discharged home

- Effective behavioural, communication and sensory interventions allowing reduction of medication for anxiety/agitation
- Safe ‘autism friendly’ environment with age and developmentally appropriate activities, exercise, education and peer group
- Demonstrating what improvement is possible for complex children and young people
- Sharing information and strategies with families and local services
- Supporting local services in planning long-term support packages
- Assessments continued to inform some local management plans several years later
- Often relatively rapid, with assessment/treatment complete in 3 months in some cases
- Useful pre-admission assessments, informing local management even when admission not recommended

Difficulties and poor outcomes

- Majority of difficulties related to distance:
    - Family concern about the distance, especially ‘across the border’
    - Some families’ objections meant referrals not made, sometimes leading to the child or young person having long periods untreated in community or in inappropriate adult wards.
    - Lack of local services and prolonged debate about appropriate course of action could damage relationships between clinicians and families
    - Less contact possible with family leading to distress and anxiety for patients, immediate family and extended families and friends

    - Some families in debt from cost of visiting
    - Difficult for local services to engage and fully benefit from admission to distant units
    - Families and local services needed to build relationships again for discharge
- Difficulty accessing beds, almost never available in emergency
- Complex and time-consuming cross border issues in relation to Mental Health Act
- Difficulties for local services to provide appropriate care after time-limited admissions, with expectations created that could not be followed immediately
- Where local multiagency services unable/ unwilling to follow advice, patients deteriorated again following discharge
- Some prolonged admissions with delayed discharge due to difficulties securing appropriate long term care placement
- Looked after children and young people may have been living out of Health Board area even before admission to England so home services had limited knowledge of them, complicating discharge planning

A4.12.1 Pre-admission issues

Pre-admission issues are discussed in this section, rather than in section A4.5 because specific and different issues apply compared with pre-admission issues to other units. Patients were often already in inpatient care, and the admission to a specialist unit in England was a transfer.

Most families were unhappy about the need for their child/young person to go at great distance to England in order to be admitted to a suitably specialist unit. Some parents found the idea of their child crossing the border to receive care particularly difficult. Their objections in some cases meant that clinicians did not make referrals for care that was clinically indicated. These patients either remained for long periods in adult wards in Scotland or in the community with inadequate assessment and treatment. Practitioners reported ‘struggling-on’ when what was needed was a specialist inpatient assessment to properly assess the child's mental state and offer multidisciplinary interventions. Where clinicians felt they had no choice but to go against parents’ wishes, this led to lengthy and difficult negotiations and legal appeals.

Having a child going to distant specialist hospitals usually came after a long period of uncertainty and stress for them and their families. Families were usually very committed to keeping their child or young person at home, but it was simply not safe. By the time the need for a specialist admission was identified, families had often already had months or years of severe behaviour disturbance at home, sometimes compounded by inadequate education, social care or housing. During the actual wait for a specialist bed, families had been either trying to manage their child or young person at home or had been very worried about their care in more local but inappropriate hospital settings. These factors, along with the distance of the specialist unit (and often having to transport their child there themselves), contributed to hugely traumatic experiences for families.

Beds at specialist units in England were not easily available and almost never for emergency or urgent admissions. Whilst colleagues from English units were helpful and responsive to referrals, the process of

assessment by and arranging admission to the units usually took several months.

A4.12.2 Cross-border transfers and the Mental Health Act

Some younger patients were admitted to units in England informally, with parental consent. However, the Mental Health Act was frequently required for admissions and this led to lengthy and time-consuming discussion, organization, tribunals and paperwork. Where patients were not already in hospital in Scotland but needed to be detained to transfer to an English hospital, then complex arrangements had to be made to detain a patient into a Scottish hospital, even though they were not actually admitted, in order to legally transfer them for admission under the English Mental Health Act. There are differences between the English and Scottish mental health acts which also led to complications, such as the role of the named person.

Transfers were particularly complex where there were forensic issues. Patients on some Criminal Justice orders cannot be transferred across the border. Lengthy discussions were required with the Procurator Fiscal for at least one of these cases to allow a transfer under the Mental Health Act.

Transfers themselves could be very difficult to arrange, especially where they required to be facilitated by nurses skilled in working with young people with complex behavioural and/or forensic needs.

A4.12.3 Benefits of specialist LD CAMH inpatient units

Specialist LD CAMH inpatient units had multidisciplinary teams with clinicians skilled and experienced in working with children and young people with learning disability and autism spectrum disorder, and an

appropriate physical environment, for example, robust building, furniture and fittings, and/or low sensory stimulation environments with access to suitable physical activity and exercise. This allowed safe and comprehensive assessments, with the ability to take young people off all medication where required in order to properly assess. Children and young people benefitted from the full range of nursing, psychological/behavioural, psychiatric, communication, sensory and occupational interventions. There was appropriate specialist education provision.

Where psychotropic medication was being given primarily for anxiety/agitation and associated behaviours, rather than for mental illness, medication doses were able to be reduced significantly. This will have reduced the risks associated with long term side effects. Significant improvements were seen in patients' mental health, anxiety levels and general well-being. For complex young people, e.g. with severe learning disability and self-injury, improvements in a very controlled, supportive environment showed their potential in the right environment. Local services benefitted greatly in terms of overall understanding of patients' needs and this allowed good long-term multiagency plans to be put in place.

Numbers were small to make generalisations but clinicians generally reported that, once there, families were happy with the assessment and care provided at the NHS specialist LD CAMH inpatient units in England. Detailed hospital assessments and recommendations continued to inform local multiagency management plans several years after discharge.

There were examples where assessments from specialist units did not result in admission being recommended. However, they helped local health services and their multiagency partners to better understand the child or young person's presentation and what was required to support them.

A4.12.4 Distance and its impact

Despite best efforts, families and local services were not able to visit often enough to learn as fully as possible from the admissions. In a number of cases, families were therefore not able to take on board recommendations on return home. However, local services described being able to use the recommendations to continue to work with some families who, over the longer term were able to change their management of their child or young person at home to good effect.

Similarly, recommendations from the units were not always taken up by one Local Authority at discharge and some children and young people were returned to the same suboptimal education and social care packages. The multiagency services required to support these young people are very complex, often including several professionals from within each of the main agencies (Health, Social Care, Education and Third Sector). Liaising with all of these services at a distance was very challenging. One Local Authority did not permit their local school staff to attend meetings at the unit in England, which impeded proper communication and planning. Examples were given of patients deteriorating again on discharge, requiring psychotropic medication for anxiety and agitation which would not have been required if the right environment had been provided for them. In one case, recommendations from inpatient assessments had to be repeatedly

made by the LD CAMHS team and in the longer term appropriate changes were made to the young person's local management and school environment with positive outcomes.

Distance was a major issue for families. Young people could be in hospital as far as 500 miles away from home. Families could not visit frequently, particularly if they had other young children and other caring responsibilities. Parents would usually visit as often as they could, but maintaining contact with wider family and friends was generally not possible. *"we are only able to visit once a fortnight. It is a 7 hour journey each way. Our child has not seen her siblings, aunts or grandma in over six months"* Young people with mild learning disability who had a better understanding of time and distance, were reportedly homesick, missing their parents and were sad and agitated after family contact. It was difficult to be sure of the effect on those who had more severe levels of learning disability and communication problems and of their understanding of the situation.

It was difficult for parents not being near enough to visit their child quickly if something happened, e.g. if they were hurt or unexpectedly physically unwell. Parents were not able to see the child for themselves to reassure themselves they were alright. Speaking on the phone was not an option for those with greater degrees of learning disability. Some families went into debt or increased pre-existing debt due to the cost of travelling to visit. Where time limited admissions occurred, the distance had a more limited impact. However, it was harder when admissions were prolonged, especially due to lack of suitable social care/education resource to move on to. Families felt anxious and angry that they were losing control in these situations. Where parents had their own

vulnerabilities and difficulties engaging with services, this could also be exacerbated by distance.

A4.12.5 Discharge planning

Admissions to some English units were time-limited to 3 months, allowing assessment, treatment and recommendations, but then discharge, to prevent beds being blocked while patients awaited care packages. One situation was described where, despite a will from all agencies to implement recommendations, they could not replicate the right environment locally in time due to a lack of trained staff. There was therefore an inevitable immediate deterioration post-discharge and it took many months to recruit and train staff to develop a suitable care package. With this in place, the young person is doing really well now, several years on.

Clinicians felt that it would have been helpful for the inpatient units to have had a greater understanding of local issues to inform their assessments and recommendations, for example, the feasibility of implementing plans in a remote/rural location. More consultation and advice on the practicalities of this and on developing highly specialist individualised packages in the communities would have been appreciated.

Discharge planning was particularly time-consuming, complex and difficult to manage when young people were at the point of transition to adult services. A number were admitted from children’s services but discharged to adult care packages. There were examples of successful outcomes due to careful planning, but distance and a lack of familiarity of local services with the unit complicated the process and meant adult LD professionals had limited opportunity to get to know the young

person and their needs prior to discharge. Where relationships between services and families had been damaged by difficult situations in the lead-up to admission, this impacted on families' engagement with service, during discharge and transition planning and beyond.

Looked-after children were again particularly vulnerable to difficulties associated with being in distant hospitals. Where they had been living in care/residential school outside their own Health Board area prior to admission, services in their own Health Board often had limited knowledge of them and sometimes did not take active-enough responsibility, further complicating discharge-planning.

A4.12.6 Other issues and concerns

In secure units, some families were concerned about restrictions on their young person's freedom and a more homely environment for visiting would have been helpful. Access to the local community seemed overly limited for one patient whose behaviour became more challenging than it had been in a local 'bespoke' arrangement using adult LD facilities and staff.

On isolated occasions, due to a lack of beds anywhere in the UK in known units, young people had to be admitted to relatively unknown, usually private facilities. Examples were given where care was either suboptimal or just provided a 'safe place' in an emergency. Local psychiatrists had to maintain a high degree of involvement as they were concerned about the care their patients were receiving, or to arrange transfer to a more suitable unit. This was very difficult at a long distance. Parents and clinicians were both concerned about the vulnerability of young people who could not tell them what was happening at these units and distance prevented them from visiting regularly. Sometimes young

people were taken home again due to high levels of concern and local services had to ‘cobble together’ support or admit to local adult wards.

Relationships between services and families were damaged by many of the situations described in this section. In some cases formal complaints were made and/or families went to their MSPs or the press.

A4.13 Not admitted to hospital when it was required

Consultant psychiatrists and other clinicians across disciplines stated that children and young people with learning disability and/or autism spectrum disorder who required hospital assessment/treatment were regularly managed in the community instead. The high threshold for admission to non-specialist units for these children and the high risks taken by families and services in avoiding admission has been described above. In addition, there were sometimes no available beds in specialist LD CAMH/ASD inpatient units in England, or their distance was considered prohibitive by families and/or clinicians.

Of the submissions to this survey, 8 (5%) were concerning patients who remained at home with families or in their usual place of residence (e.g. residential school). 7 (5%) concerned those who went into alternative, non-hospital provision such as residential school. These had a range of levels of learning disability and none, but half those staying at home and 5 out of 7 of those going to alternative provision had moderate learning disability. 2 of those remaining at home had interventions from an LD CAMHS Intensive Community team which ultimately prevented the need for admission.

There were some good outcomes, but at very high cost to services and families managing under difficult circumstances. For example: "*Fortunately good outcome but unacceptable risks taken along the way"; "This turned out to be the best case scenario eventually available under the difficult circumstances"; "Cobbled together arrangement which worked well for this young person but may not be repeatable for others".* However, despite best efforts, outcomes for patients could be poor.

Summary of issues and outcomes for those not admitted to hospital when it was required

- A large proportion had **moderate learning disability**
- Tended to be **younger teenagers**
- Those remaining at home usually had **major mental illness**
- All had **highly challenging behaviour**
- **Main reasons for not being admitted:**
    - lack of suitable age-appropriate LD CAMH/ASD ward
    - distance to travel to suitable English ward
    - cross-border Mental Health Act issues

There were **some good outcomes**, e.g. improved mental state and doing well in residential care, or reduced medication due to behaviour management strategies.

Difficulties and poor outcomes:

- **Prolonged period of illness and distress**, some still ongoing, with unnecessary recurrences of illness
- **High risks to patients, families and staff** from self-injury, aggression and destructiveness

- **Unsafe managing medication** outside hospital setting
- **Highly stressful and exhausting for families**, may be reduction in usual support services if unable to manage
- **Costly** to social care services
- **Difficult balancing risks** of admission to unsuitable ward with risks of not admitting
- **Lack of a thorough holistic multidisciplinary assessment**
- **Assessment/treatment took longer**
- **Escalating behaviour**, so child or young person moved to care settings with escalating levels of security
- **Move to out of area residential placements:**
    - Distant from family
    - Difficulty managing mental health assessment and treatment
    - Complicated transition planning
    - Sometimes later breaking down leading to hospital admission
- **Limited access to education**

A4.13.1 Profile and presentations of those not admitted to hospital when required

To preserve confidentiality with relatively small numbers, trends rather than statistical data are reported in this section. These patients ranged in age from 13-17 years, had a range of levels of learning disability and none, but half of all of them (and the majority of those who went to an

alternative, non-hospital provision) had moderate learning disability. All had additional autism spectrum disorder. The majority of patients ideally required an LD CAMH (including secure or individualised) specialist hospital admission, although some were thought to require YPU admissions (with autism spectrum disorder expertise available) or a secure autism spectrum disorder hospital.

The majority of those remaining at home had major mental illness with severe symptoms, e.g. severe depression, bipolar disorder, catatonic symptoms and schizophrenia. Those who went to non-hospital placements had high rates of suspected or confirmed epilepsy and some had additional physical health diagnoses. All had highly challenging behaviour, particularly self-injury, aggression and destructiveness. Some also had sexualised behaviour, smearing of faeces, were refusing to eat, drink or attend to personal hygiene, isolating themselves (e.g. refusing to come out of the house for 2 years) or were stripping. Sleep was usually highly disturbed. Some type of police involvement was common due to the severity of behaviours displayed.

A4.13.2 Reasons admissions were required:

Clinicians described their patients as needing admission for specialist age-appropriate multidisciplinary assessment and treatment, including:

1. Assessment and monitoring of mental state, particularly where major mental illness present or suspected
2. Medication management: a safe environment in which to make changes and monitor medication and its side effects
3. Review of mental health and developmental diagnoses, including learning disability and autism spectrum disorder

4. Assessment of the cause of the person's learning disability
5. Psychological/behavioural assessments and interventions, including functional analysis
6. Communication assessment and interventions
7. Sensory processing assessment and interventions
8. Assessment of impact of abuse and attachment disorders on presentation and advice on management
9. Assessment of medical co-morbidities and their role, especially epilepsy
10. Risk assessment and management advice, including forensic risk assessment
11. Crisis management, e.g. school exclusion from specialist residential school due to behaviour and family struggling to cope with behaviours at home
12. Recommendations to guide future placement, including care needs and risk management

A4.13.2 Reasons for not being admitted:

The main reasons were a lack of suitable beds and the distance to travel to suitable beds.

In some cases where a young person could have been managed on a local adult LD ward or regional YPU, there were no beds available. Others were considered to be:

- too young for the local adult LD ward;

- to have too severe a level of learning disability for the regional YPU to manage;
- unsafe to admit to YPU due to high levels of aggression;
- inappropriate to admit to local adult mental health unit due to level of learning disability and/or autism spectrum disorder.

Clinicians noted that there were no appropriate beds in Scotland for these children and young people. They attempted to assess and treat at home as the ‘least restrictive option’ where a suitable specialist ward was not available. They had to balance risks and decided in some cases that it was better to keep a patient at home or in the care of specialist residential care staff who knew the complex young person very well prior to their additional mental illness. This was as opposed to admitting to a non-specialist hospital setting with staff inexperienced in learning disability/autism spectrum disorder.

The distance to specialist beds in England was a problem, for example, where patients became acutely unwell in the space of a few days. Urgent admissions to NHS LD CAMH beds in England are not possible. Some children became too unwell to travel. However, clinicians noted that a specialist unit in Scotland would have been worth travelling to in some cases, but it was not thought worth the risk to travel to a non-specialist unit which would not have met their needs. Some parents chose to keep their child at home where the nearest suitable bed would have been in England at great distance.

Other reasons for lack of admission included lack of a specialist LD CAMHS psychiatrist locally to assess the patient and advise on what was required. There were also complexities about differences in the

Scottish and English Mental Health Acts and cross-border arrangements which prevented admission in some cases.

A4.13.4 Interventions during time when admission was required

A4.13.4 (i) Health interventions

High levels of intervention from CAMH, LD CAMH or adult LD clinicians were given to attempt to manage these patients at home, or in alternative social care/education provisions. Despite close involvement in crisis situations, there was an inability of mental health services to provide hands-on intensive support.

Psychiatrists monitored patients' mental state, carried out medication monitoring and changes to medication. The latter was complex and time-consuming due to children and young people with learning disability having high propensity to side effects. A lot of multiagency liaison and planning was required. In some cases, community LD nurses from adult LD services visited the patient's home regularly and assessments were carried out by clinical psychologists and speech and language therapists. Where there was no specialist LD CAMH psychiatry locally, CAMH psychiatrists sometimes sought advice and joint working from adult LD psychiatrists. In other cases, CAMH psychiatrists reported that they were simply unable to give the intensity of working required for such complex patients, including the time-consuming multiagency liaison and meetings.

Young people in some residential schools also had increased visits from their general practitioner or school doctor to assist in monitoring and

managing the situation. In a case where no LD CAMH psychiatry was available, a pediatrician maintained very high levels of involvement to support a temporary social care placement. They were concerned about advising on mental health issues and psychotropic medication outside their area of expertise.

Particular difficulties occurred when a child or young person was away at residential school or in a care placement out of their Health Board area. Their local CAMH services could not remain involved when they were away and if such placements broke down quickly leading to exclusion it could be difficult for them to make urgent assessments. In some cases where there was a move to an out-of-area residential school for a young person who required hospital treatment, that residential school was itself in an area with poor access to LD CAMH community services. Therefore, although the school placement was suited to manage challenging behaviour, the young person had less access to mental health support which could have helped in the assessment and management of their difficulties. Clinicians reported having to travel to such placements at great distance to provide assessment and support, with a knock-on effect on their ability to carry out their other work.

A young person needing a secure LD CAMH inpatient admission was instead admitted in crisis to a social care placement in a distant Health Board. CAMH colleagues in that Health Board helpfully followed up mental health aspects but there was no LD CAMH service and this took much longer than it would have done on a specialist hospital ward. Complex ongoing negotiations were required between clinicians and managers in both Health Boards and the local Council around assessment and treatment. This was exacerbated by the young person

approaching transition to adult services, increasing the number of teams and agencies involved.

A4.13.4 (ii) Social work and education interventions

Where patients stayed at home or their usual place of residence, clinicians described close joint working with social work colleagues to attempt to assess and manage ongoing needs. Extra trained staff were put on shift in school/care settings, where there were sometimes also reduced numbers of staff changes for the individual young person. Living environments were adapted, for safety reasons and to reduce sensory stimulation, e.g. reinforced windows, conversion of bathroom to wet room. Staff who knew the young person well were often very helpful in monitoring their mental state.

Extra social care input was also put into the home, or families supported via additional respite. Families too had to adapt their living environment, e.g. by removing things that could be destroyed or living in one room.

Usually there was limited or no access to education during these times. Sometimes access to usual respite and other services was reduced during these periods as services were unable to manage the child or young person’s heightened levels of distress and challenging behaviours. Therefore supports were withdrawn at times that families needed them most.

Where a child or young person could not be maintained in their home or usual place of residence, a number of social care and educational provisions were made in the absence of available hospital treatment. These included:

- Specially commissioned short-term packages of care from local respite care providers, e.g. using a high level of staff known to the patient, in a familiar physical environment, but without other children or young people present. These could impact on the capacity of providers to provide their usual respite care to other young people.
- Residential social care, extended respite care, secure care, or school placements, using the existing facility or ‘bespoke’ individual placement without other young people present.

High levels of staff (often 2:1) were generally required. These placements were mostly outside of the child or young person’s home Health Board area and could be for lengthy periods, such as more than 1 year. Some young people were moved between a number of units across several different Health Boards, moving up to higher levels of security as behavioural problems escalated. These young people sometimes had multiple brief crisis admissions to non-specialist inpatient psychiatry wards along the way. Clinicians commented that going to a specialist LD CAMH inpatient unit or autism spectrum disorder unit could have allowed for proper assessment and management and prevented these escalations.

A teenager with learning disability, *autism spectrum disorder required admission to psychiatric hospital for additional major mental illness, associated with severe self-injury, aggression, destructiveness and smearing of faeces. It was decided to keep him at his residential school where staff knew him well, rather than admit him to a non-specialist hospital. The physical environment was made more robust, extra staff put on shift and a lot of extra input was given from the local general practitioner, LD CAMH psychiatrist and school doctor. Effectively an*

inpatient unit was created using these health professionals and expertise from within the school. The outcome was good but would not be replicable in other settings and had a big impact on all services.

A4.13.5 Impact on patients and family

These situations resulted in high levels of distress and untreated mental illness for individuals for prolonged periods. Parents took time off work for several weeks, effectively nursing their child at home themselves, while also trying to support siblings. They had to make changes to their homes for safety reasons. It was a stressful and difficult time for many families as they tried to support very unwell and distressed children and young people, as well as manage highly challenging behaviour. They expressed frustration and anger due to lack of resources. Some families were grateful with what had been pieced together under difficult circumstances but were described as being at the ‘end of their tether’.

A4.13.6 Patient safety

Patients as well as their families and/or staff were at risk from high levels of challenging behaviour, including aggression, self-injury and destructiveness in an unsafe physical environment.

There were safety issues regarding the use and monitoring of relatively high dose psychotropic medication in the community. Clinicians had to choose between their patients remaining highly distressed or risking potentially dangerous side effects in the home setting.

A patient who became rapidly unwell was managed at home “on a wing and a prayer” in a very dangerous situation. The patient was not eating and drinking and required significant doses of psychotropic medication

to manage their mental illness. The psychiatrist was unable to do blood tests, ECGs, and other appropriate observations. They felt that this situation was borne out of "desperation" and unacceptably high levels of risk were managed due to lack of an appropriate LD CAMH inpatient resource. It would have been completely unmanageable had the family not been extremely competent and easy to work with and the patient not too aggressive.

A4.14 Patient pathways

Patient pathways – summary

Length of admission:

- 85% spent >/= 1 month in inpatient care
- 44% (32 patients) spent > 6 months in inpatient care

Those with learning disability were more likely to spend longer in hospital than those without, with a trend of longer stays the more severe the learning disability

Transfers between inpatient units within an admission:

- 73% of patients remained in one ward for duration of their hospital treatment
- 23% experienced 1 transfer to a different inpatient unit during treatment
- <5 patients experienced between 2 and 7 transfers
- No patients without learning disability had more than 1 transfer and those with mild learning disability were most likely to have at least one transfer.

Repeat admissions by individual patients:

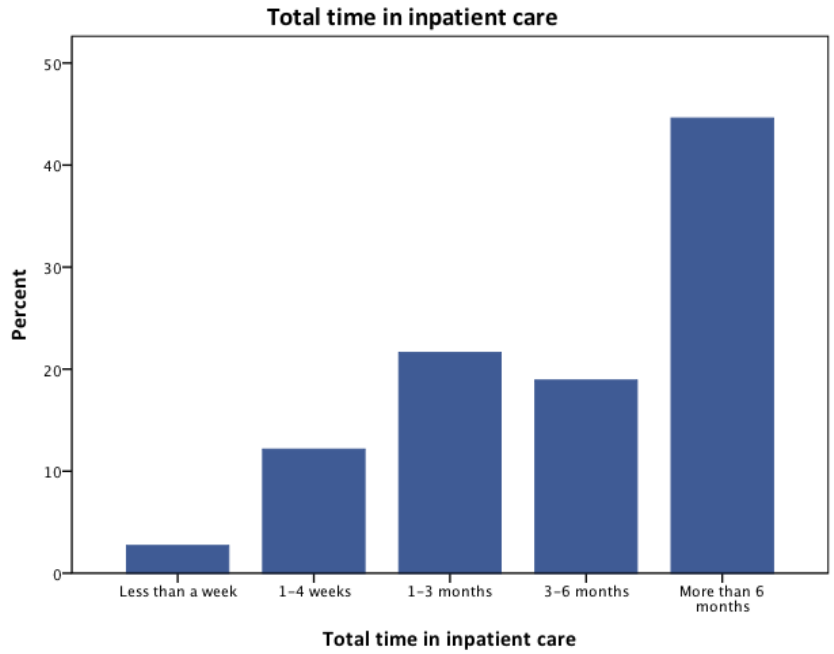
- 84% of patients had 1 admission
- 10% had 2 admissions
- 6% had between 3 and 7 admissions

There was a wide variety of complex pathways for patients requiring specialist LD CAMH, adolescent secure or ASD-specific secure provision, which only a minority actually received in specialist units in England.

A4.14.1 Length of admission

This relates to total time in inpatient care per patient (including transfers within an admission and readmissions). For all admissions for which total admission time was given (74):

- 85% spent a month or more in inpatient care
- 44% (32 patients) spent more than 6 months in inpatient care



Those with more severe levels of learning disability tended to spend longer in hospital. Figures are % of those with each level of learning disability who spent more than 1, 3 or 6 months in hospital:

Time in hospital/ level of learning disability	>1 month	>3 months	>6 months
None	76	48	28
Mild	87	65	48
Moderate	91	68	55
Severe/profound	88	88	50

A4.14.2 Transfers between inpatient units within an admission

- Average number of transfers per admission .38 (SE. 1, SD .90)
- 73% of patients remained in one ward for duration of their hospital treatment
- 23% experienced 1 transfer to a different inpatient unit during treatment
- <5 patients experienced between 2 and 7 transfers

No patients without learning disability had more than 1 transfer and those with mild learning disability were most likely to have at least one transfer.

A4.14.3 Repeat admissions by individual patients

- Average number of admissions per patient:1.27 (SE .09, SD .84)
- 84% of patients had 1 admission
- 10% had 2 admissions
- 6% had between 3 and 7 admissions

A4.14.4 Pathways for patients requiring specific types of units

- **Those ideally requiring YPU**

A number of patients (mostly with autism spectrum disorder but no learning disability) who ideally required YPU admissions were not able to access them immediately due to a lack of beds available on regional YPUs. The majority of these completed their whole admission on adult mental health wards, but some were transferred during admission to their regional YPU. A number had repeat admissions to various combinations of YPU, adult mental health or both.

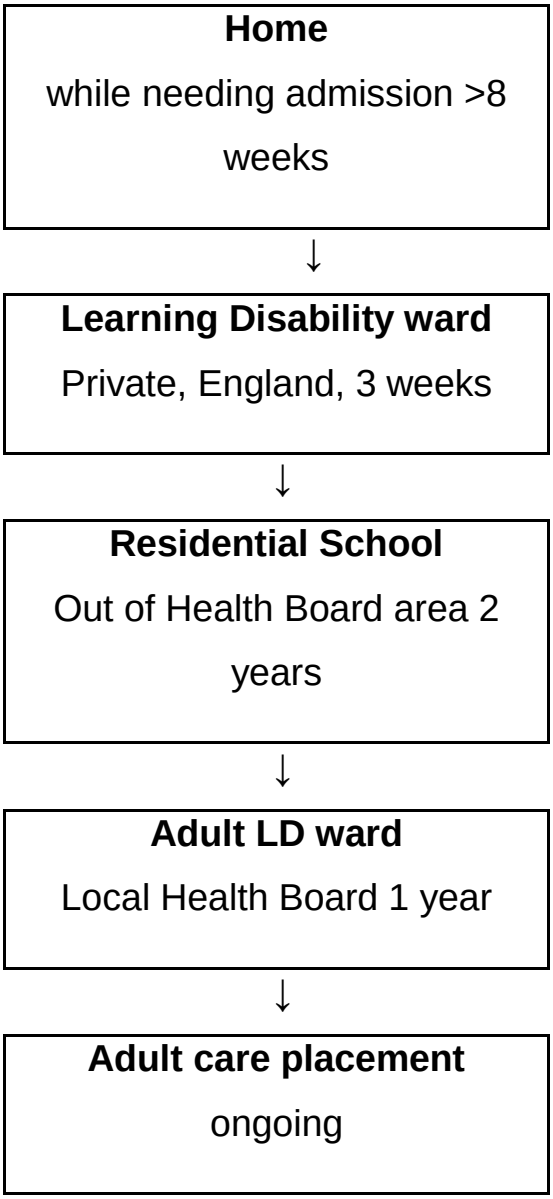
- **Those ideally requiring specialist units currently unavailable in Scotland**

There was a wider variety of often complex pathways for patients requiring specialist LD CAMH inpatient admission (including those requiring secure or individualised provision), adolescent secure or ASD-specific secure provision, which only a minority actually received in specialist units in England. Patients often spent considerable periods making no or limited progress at home, in residential care, on one or more inappropriate ward (or some combination of all of these), whether or not they eventually had a specialist admission to hospital.

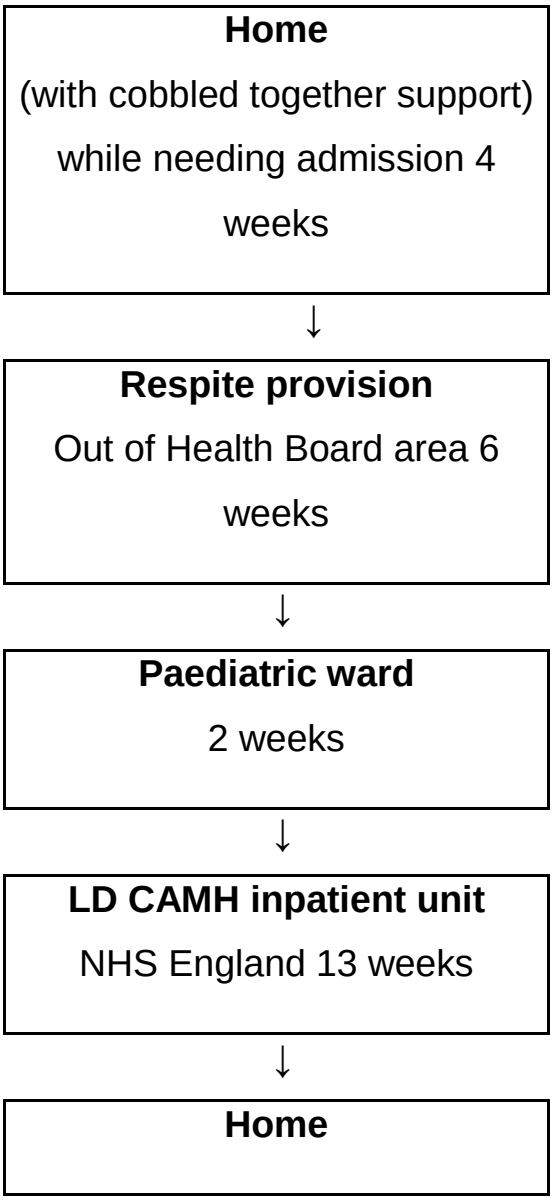
Some patients had only very brief (sometimes multiple) crisis admissions to unsuitable wards, remaining in non-hospital provision or at home between times. They therefore did not get the full assessment and treatment that a specialist unit would have given.

Examples of pathways followed by patients requiring specific types of units are given below. They are based on real situations but the information given is a composite to protect patient confidentiality.

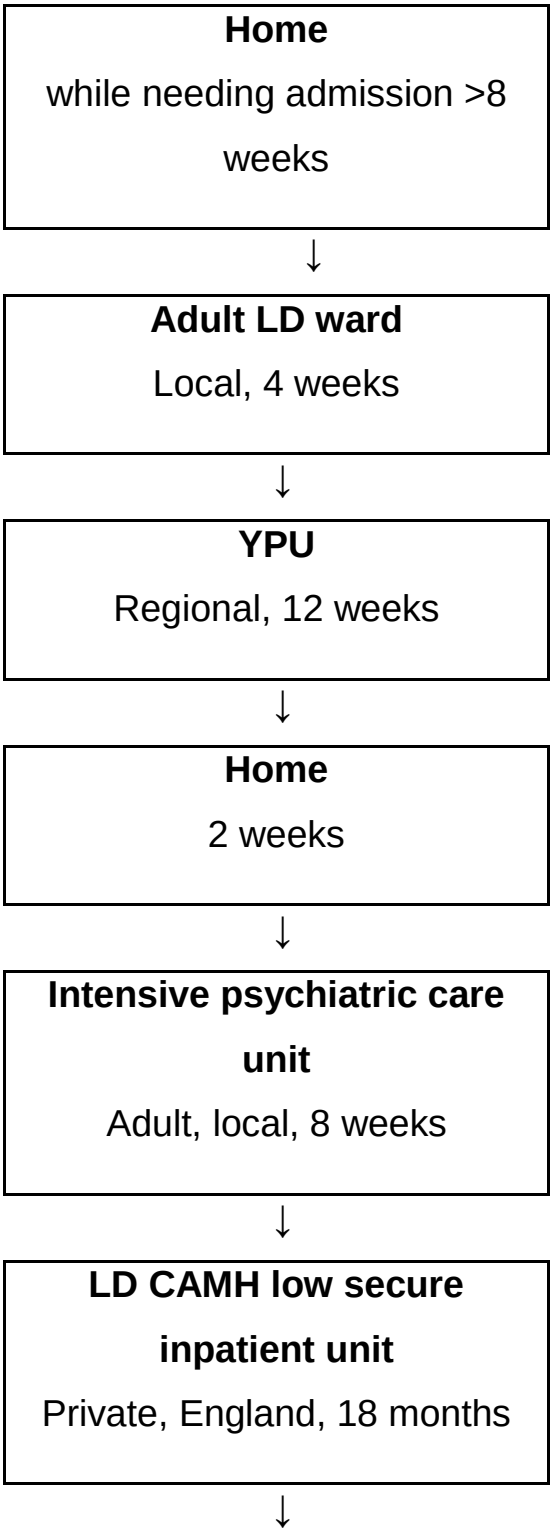
Patient 1 (example of patient ideally requiring non-secure LD CAMH inpatient unit)



Patient 2 (example of patient ideally requiring non-secure LD CAMH inpatient unit)



Patient 3 (example of patient ideally requiring secure LD CAMH inpatient unit)



Adult LD low secure inpatient unit

Regional Scottish provision, aged 18, remains inpatient

Patient 4 (example of patient ideally requiring secure LD CAMH inpatient unit)

Secure care placement

Out of Health Board area for 4 months while requiring admission to secure inpatient care

↓

LD CAMH inpatient medium secure unit, NHS England

16 months

↓

Local adult LD ward

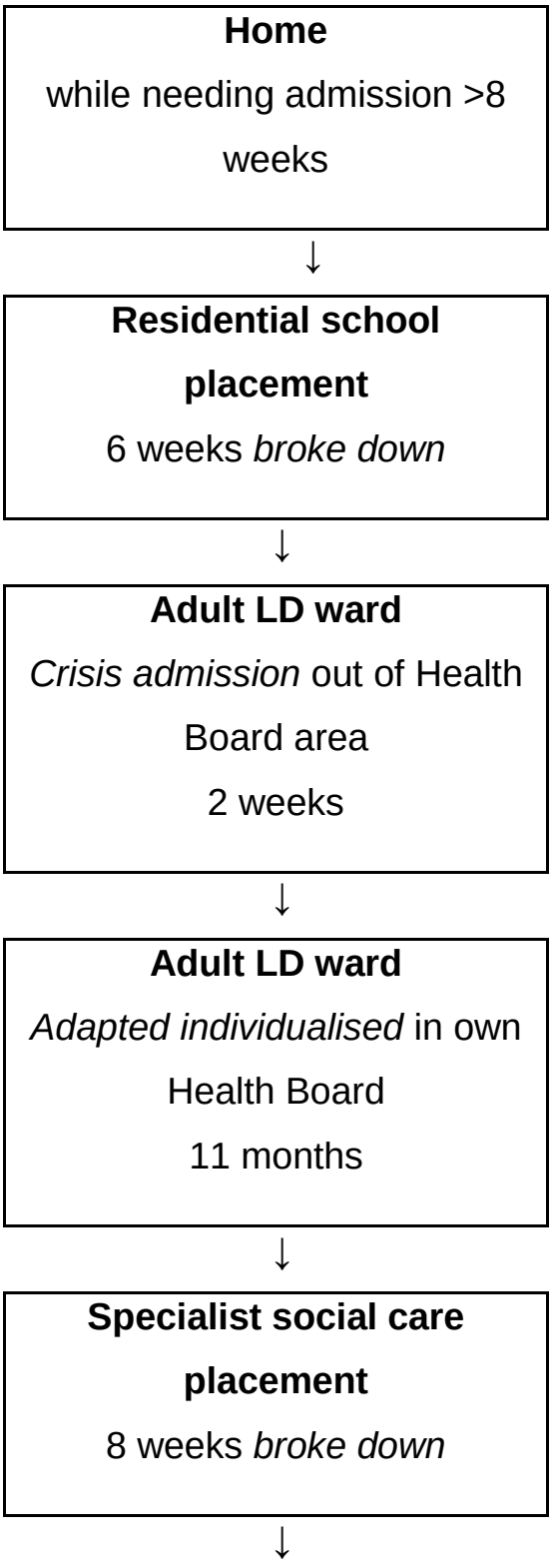
6 months

↓

Home

With social care support

Patient 5 (example of patient ideally requiring individualised LD CAMH inpatient unit)



Adult LD ward

Adapted individualised in own Health Board

20 months

↓

LD CAMH secure inpatient unit

NHS England, ongoing

Patient 6 (example of patient ideally requiring mainstream CAMH secure adolescent inpatient unit)

Residential School

Out of Health Board area for 4 months, while needing admission

↓

Intensive psychiatric care unit

Out of Health Board area, 20 weeks

↓

Residential school

Out of Health Board area, 6 months

↓

Adolescent mental health medium secure inpatient unit, England- private

4 months

↓

Adolescent mental health medium secure inpatient unit, England- NHS

1 year, ongoing

Patient 7 (example of patient ideally requiring ASD specific secure adolescent inpatient unit)

Residential school

In Health Board area for 9 months, while needing admission

↓

Adult mental health ward

Multiple brief admissions over 2 year period

↓

Home

2 months

↓

Reinforced part of YPU

Emergency admission 4 months

↓

ASD secure inpatient unit, England- private

1 year, ongoing

A4.15 <u>Discharge</u>

Information on discharge destination at end of last admission in the study period was available for 78 of the 84 patients admitted to hospital.

For patients of all levels of learning disability and none:

50 (64%) Discharged home

14 (18%) Discharged to social care or residential school placement

14 (18%) Remained as inpatients

Comparing patients of different degrees of learning disability:

Discharge destination → **Level of learning disability ↓**	**Home**	**Not at home** (still inpatients or discharged to residential social care or school placement)
None	18 (75%)	6 (25%)
Mild	14 (67%)	7 (33%)
Moderate	12 (55%)	10 (45%)
Severe/profound	6 (55%)	5 (45%)

Some young people remained in hospital due to a need for ongoing treatment. However others were ‘stuck’, with their discharges delayed due to lack of available specialist residential education or social care resources to move on to. The individual numbers of these patients may have been small but the situations had a large impact on young people and their families, with relationships between families and staff becoming strained as a result. One parent describing the longer term effect of her young person being 'stuck' in a generally agreed inappropriate setting, "*the staff became less compassionate basically and seemed unwilling to recognise his distress as being in response to his feeling 'trapped'. He was isolated from the general population because of his age. The longer this went on the harder he found it and would 'kick off' and we kept being told how difficult he was being but without any real acknowledgement of what was behind it. We feel so guilty every time we have to leave him with those people".* Impact was

also described on other patients needing to use inpatient resources as well as outpatient CAMH/LD CAMH services who had to do in-reach work to support them.

A4.16 Community context

The focus of this study was inpatient care. However, it was clear from interviews with both families and clinicians that any discussion about the need for inpatient provision could not be divorced from community service provision. Detailed information and opinion was given as to current community LD CAMHS and related services, and how this impacted on current and future inpatient provision. This is summarised in A4.16.4 and A4.16.5. This section, however, begins with a summary of information/opinion provided by participants about community services and more detail (A4.16.1 – A4.16.3) on issues most directly related to inpatient care.

Summary - Community LD CAMH services provision

1. Despite children and young people with learning disability having some of the most severe and complex needs of any group, they have inequitable access to mental health service provision and behaviour management advice:
    a. Compared to children/young people without learning disability
    b. Compared to adults with learning disability
2. Children and young people with learning disability need improved access to:
    a. Early interventions
    b. Multidisciplinary community teams
    c. Intensive treatment services

3. Where there are no specialist LD CAMH services in place, CAMH teams lack the multidisciplinary experience and expertise to offer adequate assessment and treatment. This risks overuse of psychotropic medication in the absence of alternative interventions.
4. Need for admission or intensive home treatment (and the associated complexity of establishing arrangements) takes over the working life of clinicians and impacts on their care of other patients in the community.
5. Likely to be considerable hidden and unmet need due to lack of referrals to existing CAMHS services that are not set up to meet the needs of those with LD.
6. Pediatricians, schools and social care services are often left to manage without appropriate mental health support.
7. A need for more individualised robust, 'autism-friendly' physical environments across health, education and social care settings.

A4.16.1 Local provision and access to specialist knowledge

There was a general view amongst participants that access to community mental health /behavioural services needs to be improved for children and young people with learning disability and/or autism spectrum disorder in Scotland. Limitations were described in adult LD services, but this was felt to be far more so for children and adolescents with learning disability. A need was described for more "pairs of hands" in local services to reduce the need for admission and to implement recommendations from any specialist unit, both via consultation for outpatients and for those discharged following admission. Concern was

expressed by one clinician that developing a specialised in-patient service did not take the focus away from the pressing need to develop adequate community services, including provision of physical health care and co-ordination of services.

Very much earlier outpatient/intensive interventions may have altered the course of this child's difficulties which continued to escalate throughout childhood and adolescence. The lack of access to LD CAMH services within the residential school was also a key factor.

Clinicians from remote/rural areas tended to very much see it as their role to see all children and young people with learning disability and/or autism spectrum disorder, recognising the relative rarity of those with very complex needs. However, they were also amongst those most keen to have support and consultation from a specialist centre.

Several clinicians mentioned the complexity of mental health /behavioural issues for children with learning disability and/or autism spectrum disorder. The majority also have complex physical and mental co-morbidities. The detailed work required to assess and provide interventions in the community is therefore very time intensive. Clinicians advocated that adequate resources were required for CAMHS to be managing these cases appropriately in the community as well as during inpatient care.

A4.16.2 Intensive community LD CAMH services

The development of community CAMH intensive treatment services (ITSs) has been encouraged across Scotland and there has been some success in reducing the need for inpatient care for some young people. However, these services generally have little expertise in working with children and young people with more severe levels of learning disability

and autism spectrum disorder, particularly with high levels of complexity and challenging behaviour. Some exclude children and young people with learning disability altogether from their service. Outpatient clinicians reported therefore being left alone to handle complex and crisis cases, who warranted ITS or inpatient services.

Participants in the study advocated for LD CAMH ITSs to be developed to prevent the need for some admissions. Where present (so far only in Lothian) these services have helped prevent a number of admissions. Two examples were specifically given as submissions to the study where support by nursing staff in the family home, respite or residential school/care facilities successfully prevented admissions to hospital. These were both for young people with moderate learning disability and autism spectrum disorder with highly challenging behaviour but no additional psychiatric illness. Key to the success of one situation was the availability of an individualised, robust environment where specialist social care staff could care for the young person, closely supported by ITS staff.

However, LD CAMH ITSs were considered unlikely to prevent all admissions, for example where families are unable to implement strategies, even with support. It was not always practical or appropriate to have professionals (‘strangers’) spending long periods of time in a family home, including overnight, depending on its size, layout and the presence and needs of siblings. Some families find having professionals providing intensive health or social care support in their homes intrusive and difficult to engage with, thus limiting the effectiveness of services.

The Lothian LD CAMH Intensive Treatment Service has been affected by the need for nurses from the team to support admissions to hospital

when these have been required. Some young people did require these hospital admissions, which have generally been to local adapted individualised facilities within adult LD units. However, a lack of suitable community social care provision for them to move on to has meant prolonged delayed discharges, seriously impacting on the LD CAMH ITS's ability to work with other children and families in the community.

A4.16.3 Individualised specialist environments in the community

It was not possible in interviews for clinicians and parents to describe mental health/behavioural services for children and young people with learning disability and/or autism spectrum disorder in isolation from social care and education partners. Whilst service configuration varied hugely across the country, it was clear that statutory and third sector organisations played a crucial and often leading role in behavioural support. It was evident that a lack of appropriate services in one part of the multiagency system had a knock-on effect onto others.

A lack of individualised, robust, 'autism-friendly' physical environments was a common issue across health, education and social care (e.g. respite) settings. This was particularly for young people whose needs and behaviours meant that they needed to be separate from their peers for the majority or all of the time. Even where staff were highly skilled in working with young people with learning disability and autism spectrum disorder, the appropriate physical environment was often unavailable.

In a Health Board where such environments were more available and which had a developed LD CAMH service, there were very few hospital admissions primarily for 'challenging behaviour'. Only a relatively small number of cases were identified as requiring specialist LD CAMH inpatient admission and these cases had additional diagnosed mental

health problems. In the case of another Health Board, it was felt that the majority of admissions would have been shorter and some avoided had robust, individualised community support packages been available for the LD CAMH community service to support patients in.

A4.16.4 Staff experience of learning disability and autism spectrum disorder

In those larger Health Boards where mainstream CAMH services see all children with learning disability, the lack of local specialist community LD CAMH services was seen as a problem. A consultant CAMH psychiatrist felt that a lack of training and expertise within the service means that multidisciplinary clinicians were nervous of this type of work. The psychiatrist in a team could be left managing cases, which felt isolating and hard to deal with on top of their usual work load.

CAMH psychiatrists usually had very limited experience with working with children with learning disability, although increasingly they may have had a 6 month placement with a specialist LD CAMH team during their training. Others may have had a 6 month adult LD training placement, but this may have been much earlier in their training. While this experience helps, it was clear that it was difficult to manage complex cases in the absence of a multi-disciplinary LD CAMH team.

In fact, it was notable in interviews that those who had such experience recognised and were able to articulate what was missing in their area and how the children would have benefited from such a service. Their training may therefore allow them to recognise what kind of assessments and interventions are required rather than have an ability to provide these. Frustration was expressed that they had to prescribe

psychotropic medication in the absence of behavioural or other non-medical therapeutic interventions.

As the majority of respondents to this survey were psychiatrists, little information was gained for this study about the experience of those of other disciplines within CAMHS during their training of working with children with learning disability. Parents reported concerns about the skills and knowledge generally within the workforce for children and young people with learning disability and autism spectrum disorder.

In Boards where there was no specialist LD CAMH service, it appeared that referrals to CAMHS tended to be of those with milder degrees of learning disability. Community pediatrics would generally be quite involved, especially with children/young people with severe learning disability. Paediatric colleagues were left managing the more complex cases. This threw up concerns about safety and governance issues where psychotropic prescribing was being overseen by non-psychiatrists, for patients who have not had an appropriate psychiatric assessment.

Service configurations made for difficult 'boundary issues' between services, e.g. clinical psychology being provided from within CAMHS for those with autism spectrum disorder and co-morbid mental health problems, but from child health for those with learning disability. There could be difficult relationships across these services with children getting caught between them. Where professionals from different disciplines were not from one specialist team, multidisciplinary assessment, formulation and management of cases was less effective.

Where specialist LD CAMH services existed, clinicians commented on their fragility. Where there were very few clinicians with LD CAMH

expertise, services and therefore children were vulnerable when these clinicians were off sick/ on leave. One remote rural area noted increasing gaps in learning disability expertise, particularly psychiatry across the age span. There were also a significant number of children and young people with autism spectrum disorder in that area who may not have a learning disability but where lack of knowledge and interventions from CAMHS created long standing issues. Many of these remained “under the radar” of health services with support given by education during school years. Some CAMH services reportedly struggled with those with autism spectrum disorder but no learning disability.

A4.16.5 Multiagency community services

It is not possible to describe or develop mental health/behavioural services for children and young people with learning disability and/or autism spectrum disorder in isolation from social care and education partners. Whilst service configuration varies hugely across the country, it is clear that statutory and third sector organisations play a crucial and often leading role in behavioural support.

Clinicians described many excellent local schools and respite services going well beyond their remit to support children and young people with severe and complex mental health/behavioural problems. They also provided high levels of support and advice to families. These partner agencies have often had to manage highly complex situations, including children/young people with undiagnosed mental illness/ neurodevelopmental disorder without adequate access to specialist mental health services. With a lack of coordinated multiagency strategic planning, specialist residential schools taking children from across the

country with severe and complex problems have been set up in areas that lack LD CAMH services to support them.

Concern was expressed in this study about recent reductions in local authority and third sector resources for children with learning disability, e.g. schools having less access to auxiliary support. This was leading to systems breaking down more quickly and the perception reported was that local authorities were responding more slowly than in the past. This resulted in some young people, families and clinicians being in a form of limbo and with difficulties escalating to crisis point. Similarly, a lack of early intervention and LD CAMH community services across the tiers of service contributed to an escalation of problems for some young people. This eventually culminated in home and school placement breakdown and children being accommodated in residential schools far from home with untreated mental health problems persisting because of a lack of access to specialist mental health input in some of these schools as noted already.

Conversely, an example was given where an innovative robust support package from a third sector organisation meant that admission was not required for one young person, despite very high levels of challenging behaviour. As a result only an outpatient service, not even intensive level of involvement, was required from the LD CAMH team.

Parents' experience of education and voluntary organisations reflected some of these concerns in terms of how their young person was treated at school and in accessing it once in a mental health setting. A young person's education was described as *"basically stopping at 14, he was left to struggle and when he couldn't maintain it any longer he was*

allowed to drift off. Since then he has really been too unwell to engage with any educational input".

A parent described the laissez-faire attitude of her child's school even when she tried to address with them some of her daughter's issues. Even after the daughter was admitted to hospital there was no follow-up or even an acknowledgement that she was no longer in school.

A parent talked about the lack of appropriate local schooling for her autistic child. The choices were very limited and the eventual placement *"probably contributed negatively to the situation we are in now, his mental health seemed to decline once he was there".*

Another parent's positive experience of her child's school illustrates how important it is for parents to have someone to talk to who understands the challenges their children can present, *"the head teacher was fantastic, so supportive, and always ready to listen and to offer guidance. I know there were times when I only got through the weekend because I knew I could talk to her on the Monday".*

Individual parents identified local voluntary organisations that were helpful to them primarily in providing emotional support and an understanding of the parenting challenges they faced. However, what worked for one family did not work for all. One parent reported how great the local carers' centre had been whilst another felt clearly "*it was not for her".*

A4.17 Concerns raised by families via interviews

Quotes and commentary from the parent /carer interviews have been incorporated into appropriate sections throughout the rest of the results section. Feedback which did not easily fit within other sections is included here.

Summary of additional concerns raised by families

1. Lack of emotional support to deal with a mental health diagnosis
2. Barriers to communication with professionals add to the stress for families
3. Need for written information about processes and provision needs to be available to support families' understanding
4. A focus on one aspect of a young person's difficulties can create further problems in meeting their needs
5. The lack of therapy, education and other interventions

Many of the parents interviewed reported being "*traumatised*" by their experiences and would 'well up' as they were speaking. Some were obviously overwhelmed by the various processes they had to engage in. Questions about their involvement in planning meetings for instance received responses such as "*what can I do about it?"* and "*I am not sure what the plan is now".*

Clinicians reported that families they had worked with had tried lots of ways of expressing their views but still felt their views have not been taken into account. They described parents struggling with the difficult adjustment to being parents of an adult when some decisions, including

about medication, may ultimately no longer be up to them. Some parents found multiagency meetings and mental health tribunals distressing, even when they agreed with decisions being made, due to having to talk about the range and extent of their child's difficulties in such big meetings.

A4.17.1 Managing the implications of diagnosis

Parents described a feeling of *"being abandoned to deal with the feelings"* that came from their child being diagnosed with mental ill health. No parent identified being offered specific support to deal with the emotional impact (although two sought out counselling for themselves).

There was little guidance given as how to behave or discuss the situation as a family and with the young person themselves. Parents described "*feeling de-skilled"* and being advised to *"treat her as if she had not been in hospital"*. Some parents said they were left with more questions than answers*. "How then were they to explain the last few weeks/months? What were we supposed to answer when our child asked us what had happened? How did we deal with the impact on their siblings? What did we say about their brother and his behaviour?"*

A4.17.2 Communication and involvement

Strong communication skills were identified by parents as one of the key competencies for staff working with their children. Where communication was poor and staff seemed unwilling to take on board information about their young people, parents felt extremely anxious and questioned the appropriateness of the setting. Not understanding what

was going on themselves and struggling to get information was also a common problem for all the parents interviewed.

One parent described repeated attempts to speak with the consultant about his child, "*we felt the nurses were 'gate keeping' and were told 'he'll call you' but he didn't. It was so frustrating; we just wanted the chance to ask questions. Of course we came across as 'demanding', but it really was like hitting your head against a brick wall at times".*

One parent felt very strongly that poor communication on the part of the professionals had negatively affected her relationship with her child, *"he has completely 'lost faith' in us finding him a better place. How this makes us feel as parents is beyond description, and despite us regularly complaining to those involved...no progress has been made".*

However, some parents reported positive and helpful communication and emphasised "*how helpful this was, all my questions were answered honestly and I was given proper information and kept up to date".*

One parent referred to an incident where initially information was withheld from her, she complained and received a written explanation, *"it was really not a big issue but just don't hide things from me".* This situation led to a more positive relationship between the parents and the professionals, conversations became more open and continued to develop positively *"as if ground rules had been established".*

Another parent referred to how good *"the GP was at keeping us informed. They had knowledge and understanding of autism spectrum disorder and were very sensitive, helping us to make sense of things".*

A4.17.3 Lack of written information about processes

Parents reported being given very little in writing about the processes they and their young people were going through. Written information of itself couldn't replace information provided in discussion with a practitioner, but could be "*very helpful later when you want to go over what has been said and try to get the whole picture"*.

When issues had been discussed that were upsetting and emotive it was natural for people to forget or not take in some details. This caused misunderstandings between parents and professionals and upset on all sides. Having written information as a 'back up' would have given both family and professional a shared point of reference.

Parents talked about having to find out things for themselves. Several referred to the Mental Welfare Commission website as *"extremely useful"* but said they were "*not signposted to it, more luck than anything".*

One parent talked about having fairly regular meetings with the staff but there being "*unclear agendas, vague outcomes being set with no real timeframe, we were sent brief minutes but no real actions seemed to be up for discussion or recorded. We really didn't know what was supposed to happen next and it never seemed to get any clearer".*

Young people were placed in a range of settings including pediatric wards, adult LD wards, secure and forensic settings, YPUs and general hospital wards. One mother whose child was transferred between a number of these settings said *"I was hardly ever introduced to the setting, what it could provide or really why we were there. Of course sometimes I knew it was because nothing else was available".* She contrasted this with a *"time we were taken through the reasons for being*

admitted by a doctor and what kind of timeframe she was expected to be there for. In the midst of all the awfulness that was so helpful to us both. Everything feels so out of control it was like we could see some way ahead".

A4.17.4 A non-holistic perspective of the young person

Parents talked about one aspect of their young person, their learning disability or a particular behaviour, being addressed rather than a whole person approach.

The needs of a young person with autism spectrum disorder who also had an eating disorder were a powerful example. The parent talked about a management approach being taken which disregarded the young person's need to know what she was about to eat. The need to know what was planned and in what order things would happen was not recognised by the staff. The young person was able to explain this need and was supported by the parent but both were told that was *"not how eating disorder is managed here".*

Parents reported that their young people with autism spectrum disorder who could articulate their distress at how they were being managed were characterised by some staff as being *"attention-seeking"*.

A4.17.5 A lack of therapeutic input and other interventions within settings

Parents talked about being surprised at the limited access to therapy for their young people. Where it was made available parents had seen it as something positive. One young woman had received group therapy and worked with an art therapist, "*this really seemed to be helpful, she*

enjoyed it. When she was transferred nothing was offered in the new setting, it seems a shame".

Two parents were told that their young people "*wouldn't benefit from it*" but did not feel they were given an adequate explanation for this statement. One parent said her child had received 1:1 therapy *"but because he couldn't remember it I was told 'we won't waste our time', he may not have remembered but I saw a real improvement in his mood when he was getting that input".*

When young people were in any setting for a while parents reported becoming increasingly concerned as *"to what was happening, other than medication what else was being done to help them?"* A parent said "*after a while I realised he was just being contained, maybe that is ok for a short while to get over a crisis but eventually a lack of intervention and interaction just seemed to be making things worse*".

A4.18 Impacts on services, clinicians and their other patients

The impact on children and young people themselves and their families of the current situation has been illustrated throughout this report. In addition to this and the financial costs to Health Boards and NHS Scotland, a high cost in terms of impact on services, clinicians and their other patient was apparent.

Impacts on services, clinicians and their other patients – summary

- Each admission a ‘special arrangement’
- Clinicians anxious about patients inadequately managed in community

- Time consuming and stressful for clinicians, who often felt isolated and unsupported
- LD CAMH psychiatrists retaining responsibility for inpatients over long periods – not expected of other community-based psychiatrists
- Many additional unpaid hours worked over long periods
- Impact on time available for care of other patients in community
- Inpatient teams ‘cobbled together’ for individual patients, building up working relationships ‘from scratch’
- Some serious staff injuries
- Inpatient nurses often anxious due to inexperience
- ALD patients lost access to inpatient care and facilities

A4.18.1 Impact of pre-admission issues

Managing patients at home or in alternative placements while arranging admission (see Section 4.7) could be extremely time-consuming and stressful for clinicians. Without access to support from intensive services, out-patient psychiatrists and other clinicians attempted to provide intensive input themselves, monitoring mental state, titrating and monitoring medication and attempting to manage risk. Community nurses (often from adult LD services due to lack of expertise/capacity in CAMHS) were sometimes ‘drafted in’. Complex and time consuming liaison with other agencies and potential inpatient units was required. Where there was no local specialist LD CAMH team, CAMH

psychiatrists, pediatricians and others struggled to manage these complex cases and often felt isolated and unsupported.

A severely mentally unwell young person had to be managed for weeks at home by their family and LD CAMH psychiatrist, when an YPU had considered the patient unmanageable in their unit. The psychiatrist visited the house 4 times a week over 2 months, including carrying out blood tests at home.

Finding a bed could be difficult when a mainstream YPU bed was required. However, where a more specialist unit was ideally required, trying to arrange admission to either an inappropriate unit locally or a specialist unit in England was far harder. Admissions were often preceded by prolonged and time-consuming negotiations between clinicians and managers from the various services. A lack of clear lines of management responsibility for children and young people with learning disability within some Health Boards meant a lack of management 'ownership', leaving clinicians unsupported. Looked-after children and young people, particularly those residing out of their home Health Board area were disproportionately affected in these situations.

A young person from one Health Board went to residential school in another and when this broke down moved to care placement in a third. A lack of ownership of their mental health care and lengthy debate and discussion ensued. Eventually the CAMH psychiatrist from the second Health Board had to travel to the third to detain the patient who was admitted to an YPU in a fourth Health Board. Even that eventual placement was not appropriate as the patient required an LD CAMH individualised setting. Significant senior clinician time was spent on these arrangements, to the detriment of their usual work.

Each admission became a special arrangement, adding to the stress for all concerned. Clinicians described a lot of uncertainty, ‘trying to work out what to do’, phoning around, organising and attending multiagency meetings. Psychiatrists who were not LD CAMH specialists particularly struggled, having no experience of the types of units available or required. Experienced LD CAMH consultant psychiatrists reported having to ‘beg’ adult LD colleagues to help them arrange a bed. Where admissions to England were arranged, clinicians also had to learn about referral processes, funding via Health Boards and/or NHS Scotland and cross-border Mental Health Act arrangements.

A psychiatrist described a patient with severe learning disability and extremely high levels of distress who should have been admitted 5 weeks earlier had a suitable facility been available. After weeks of trying to manage in the community, it was clear that the situation at home was completely untenable, but it took the psychiatrist nearly 8 hours of phone calls to secure a bed, even to an inappropriate adult LD hospital. This included finding an out of area bed, agreeing funding from the home Health Board and securing emergency alterations of the registration of the facility to allow a person under age 18 to be admitted.

When admission was the only option, it was stressful having to advise uncertain families to accept this, particularly when clinicians themselves were not confident about the expertise in an available unit.

A4.18.2 Impact of admissions to Scottish wards

A4.18.2 (i) Adult wards

LD CAMH or CAMH psychiatrists usually had to continue to be the ‘Responsible Medical Officer’ (RMO) for their patient during admissions to adult LD and adult mental health wards. Additional paid sessions for

this work were rare, more often doctors worked many extra hours in their own time, with significant and prolonged impact on clinicians' personal lives. There was inevitably also an effect on time available for care of their other patients. Where nurses from Intensive CAMH or LD CAMH services had to work into the ward to support admissions, they were also unable/very limited in their ability to provide their usual services, risking escalation of other patients' problems.

The time required to support these complex admissions was substantial, e.g. for reviewing the patient, attending weekly team meetings, overseeing the use of the Mental Health Act and regularly liaising with staff and families. For relatively brief admission to adult mental health wards, CAMH clinicians could spend up to half of their working week in a ward supporting an admission. One CAMH psychiatrist described this as now happening routinely as 'part of the job'.

During the admission of a young person with severe learning disability, there was impact on the care of other CAMHS patients, as at that time there was very little protected time for crisis work within the CAMH service. The CAMH team visited the ward and gave direct nursing care. More input was needed than for other young people without learning disability who went onto the adult ward, due to the severity of the learning disability and communication problems.

For longer admissions (often to adult LD wards), more than a whole day a week of Consultant Psychiatry time was usually required in the first months of an admission, and at least half a day a week for ongoing care. Wards were often at a distance from their usual base. For example, to support an admission a consultant LD CAMH psychiatrist visited a ward 3 days a week and other colleagues 2 days a week over a 7 week

period. For another patient, a psychiatrist visited a ward twice a week for over a year at a considerable distance from base.

It was time-consuming and stressful for psychiatrists being RMO, working with unfamiliar teams who were anxious and inexperienced in working with this patient group. Relationships and effective joint working had to be built up with staff groups, often from scratch for each admission.

There were prolonged negotiations with a family over where was most suitable for their young person. A local team had to be 'cobbled together' to support a local admission of a very complex young person. This was inevitably time consuming and difficult for staff who did not usually work together. The huge local input over months was unsustainable as it had a massive impact on other clinical work and ultimately little progress was made.

Admissions of children and young people to adult LD wards had an inevitable knock-on effect on services for adult patients. Beds and day facilities for adult patients were restricted for months or years on end. More adults than usual who required admission had to be maintained at home or admitted to inappropriate AMH wards. Adult inpatients were distressed by noise and activity levels in the ward where children and young people with highly disturbed behaviour were managed. Some were directly at risk from or upset by the behaviour of young patients. A small number of young people made a very serious impact on other patients, ward function and the physical facility, e.g. due to highly destructive behaviour and/or frequent serious physical assaults on staff and occasionally other patients.

Providing 1:1 or higher staff levels or developing core consistent staff teams around individual young people was complex and expensive to arrange, impacting on staffing levels and care of other patients. Adult in-patients had less access to their own usual activities, e.g. forensic patients not being allowed into the area used for joint activities with non-forensic patients due to the presence of a young person.

Admissions of children and young people with learning disability to adult mental health wards also sometimes had an impact on adult LD services, with adult LD nurses brought in to support admissions of young people to adult mental health wards or IPCUs.

Adult LD psychiatrists commented that there was always tension among ward staff when children and young people were on their wards. The responsible consultant psychiatrist often felt more confident, either being an LD CAMH psychiatrist working into the ward, or an adult psychiatrist getting consultation support from CAMH psychiatry colleagues. However, nursing staff did not often get similar support. Staff on AMH wards who lacked confidence could also become very anxious about their ability to manage patients so different from their usual patient group. On both types of ward, staff were generally apprehensive, concerned about whether they are doing things correctly, sometimes contributing to risk adverse and overly restrictive management.

Serious injuries were sustained by a number of adult LD nurses. This led to further depletion of staff due to sick leave and in one case contributed to severe impairment of the functioning of an entire ward. Some staff reportedly still felt traumatised several years after such admissions and fearful of another similar situation arising. Health and visiting care staff were distressed and anxious about needing to nurse some young people

in highly restrictive settings due to lack of suitable alternatives. Multiple repairs and costly adaptations to ward facilities were required.

A4.18.2 (ii) Age-appropriate admissions

Community CAMH psychiatrists did not generally retain RMO responsibility for patients admitted to YPUs. However, LD CAMH psychiatrists needed to provide high levels of input for the majority of their patients. It was not uncommon for LD CAMH psychiatrists and nurse therapists to visit an YPU 2-3 times a week or even more for up to a year to support admissions. Community clinicians for patients without learning disability would generally only be expected to visit for ward reviews once every 4-6 weeks. When an LD CAMH ITS became a patient's inpatient team in a segregated area of an YPU, this hugely reduced their capacity for work with other young people in the community.

Clinicians did not report much impact on other YPU patients in the survey, but one commented on others being upset by a patient's noise and level of distress. Some YPU staff injuries were reported.

Generally less active and intensive input was required from community clinicians to support admissions of children with learning disability and/or autism spectrum disorder to the National Child Psychiatry Inpatient Unit compared to other units. Appropriate attendance at regular meetings was required for liaison and discharge planning.

Psychiatrists noted how generous their local pediatric wards could be in allowing admission for mental health reasons, but that they needed to be heavily supported. Community CAMH, LD CAMH or pediatric liaison psychiatry teams supporting these admissions could find it time consuming, impacting on care of other patients.

A4.18.3 Admissions to English specialist units

Where a specialist NHS LD CAMH inpatient unit was used, local clinicians knew the service and had good working relationships with the consultant psychiatrist, time taken on liaison was limited, e.g. telephone calls and a day every 3 months attending multidisciplinary review meetings. In other cases where there was concern or uncertainty about care provided, psychiatrists visited more frequently, even at great distances to ensure that assessment and treatment was appropriate.

A4.18.4 Patients not admitted when required

High levels of intervention from CAMH, LD CAMH or adult LD clinicians to manage patients where admission was required but not possible have been described in Section 4.15. This was also time-consuming with impact on clinicians' care of other patients and personal life for similar reasons to those described above. A number of situations were described where there was single-handed input from LD CAMH psychiatrists where children and young people with learning disability were excluded from local CAMH ITS (intensive treatment service) provision. Examples were given of very high levels of input, such as those below.

An LD CAMH consultant psychiatrist provided daily visits of 2 hours including travel time over a 4 week period to support a young person with learning disability and mental illness at home. This was done unpaid and out of working hours to limit the impact on other patients, with considerable impact on the clinician's personal life, including paying additional childcare fees.

A CAMH consultant psychiatrist gave at least ½ day a week over a number of months to a child with severe learning disability and autism

spectrum disorder who required a hospital admission that was not available. This level was not adequate for the needs of the child but no more was possible within local service provision. Adult LD nurses were drawn away from their usual work to provide intensive input into the family home but this was not successful.

Psychiatrists described being extremely anxious, sometimes for months on end when managing very unwell patients in high risk situations at home, when they should have been in hospital. Professionals from across agencies felt helpless due to an inability to offer appropriate responses to the children and young people and families they worked with.

A4.19 Data on clinicians' opinions on type of hospital ideally required by their patients

This data is for patients included in the study, not individual admissions. It represents the views of the clinicians submitting information as to the type of ideal hospital unit required by the patients described. It includes 5 of the patients that were not admitted to hospital but required to be.

- **45 patients required an LD CAMH inpatient unit**
    - 9 of these required a secure LD CAMH inpatient unit
    - 7 of these required an individualised environment

- **37 patients required a 'mainstream' adolescent mental health inpatient unit (not LD or ASD specific)**
    - 29 of these required YPU
    - 4 of these required a secure YPU/adolescent inpatient unit

    - 4 of these required YPU but with additional learning disability-specific support

- **5 patients required an ASD-specific provision** (including secure)

- **2 patients required CAMH under 12's inpatient unit**

- **4 patients required 'other'** (these included a small number whose psychiatrists felt that they were appropriately placed on an adult LD ward as they were very near to their 18th birthday and this aided transition planning for ongoing services).

Therefore, of patients in the study, at least 35 were considered suitable for existing Scottish resources and 54 patients required inpatient units not presently available in Scotland.

A4.19.1 Actual admission destinations for those requiring specialist LD CAMH inpatient unit

The 45 patients identified by their clinicians as requiring a specialist LD CAMH inpatient unit had 76 periods of inpatient care, mostly due to transfers during 1 continuous admission, but some requiring more than one separate admission.

Of those periods of care in Scotland:

- 23 were to adult LD wards (including secure)
- 21 were to adult mental health wards (including IPCU and secure)

- 12 were to CAMH inpatient wards
- 6 were not admitted to any hospital
- 4 were to pediatric wards

10 periods of care were in CAMH inpatient units in England (mostly specialist LD CAMH inpatient units).

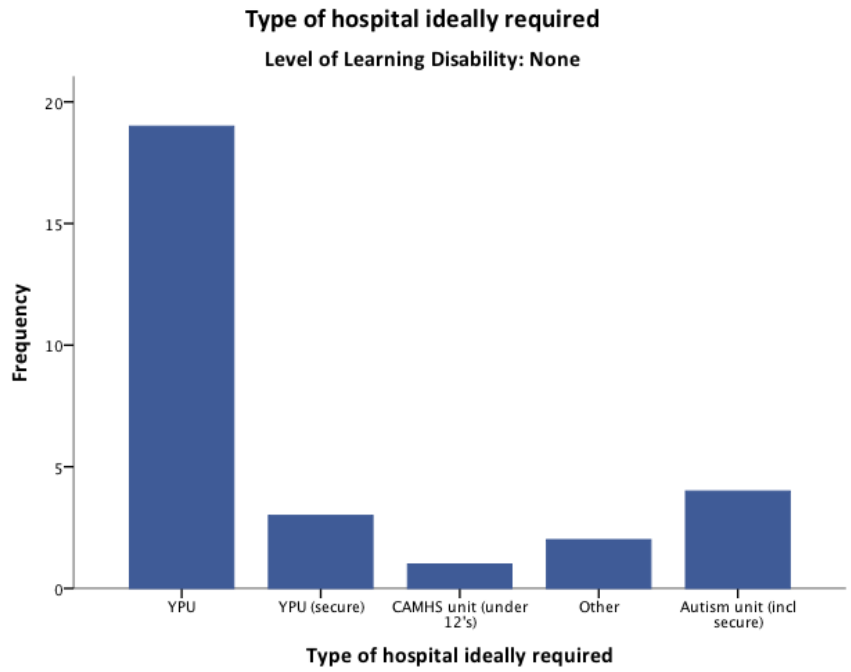
The following table gives more detail on these admissions, including information about those requiring secure or individualised LD CAMH admissions.

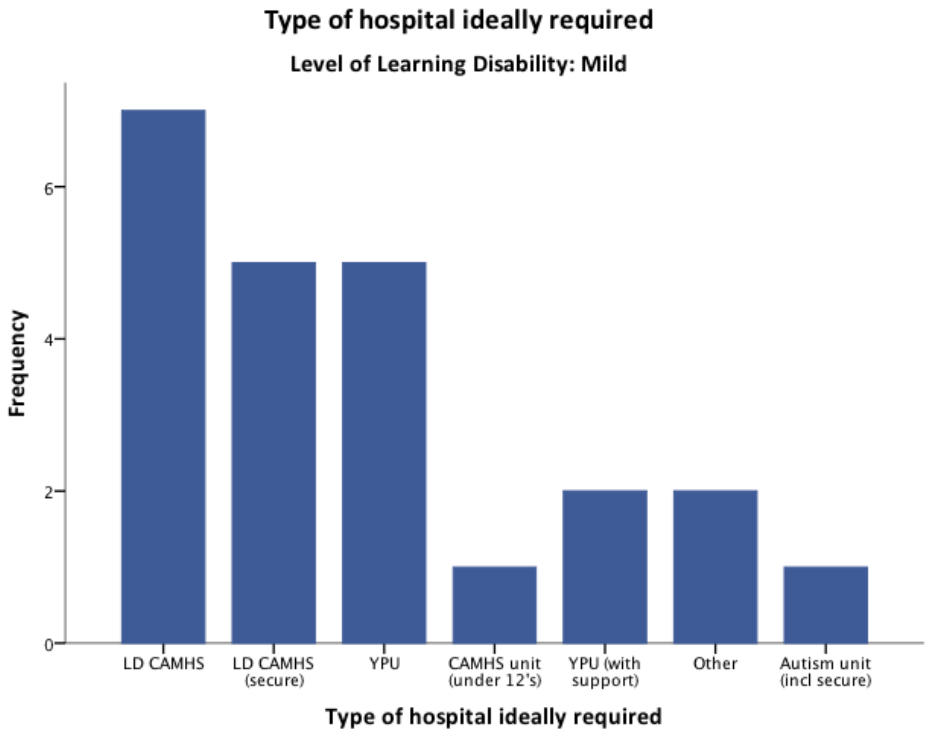
Mental health inpatient unit required → Mental health inpatient unit (or other) admitted to ↓	LD CAMHS	LD CAMHS (secure)	LD CAMHS (individual-ised)	Total LD CAMHS
Adult mental health (including IPCU & forensic)	6	15	0	21
Adult LD (including secure)	13	3	7	23
YPU	6	1	2	9
Paediatric	4	0	0	4
Non-hospital	2	1	0	3
Stayed at home	3	0	0	3

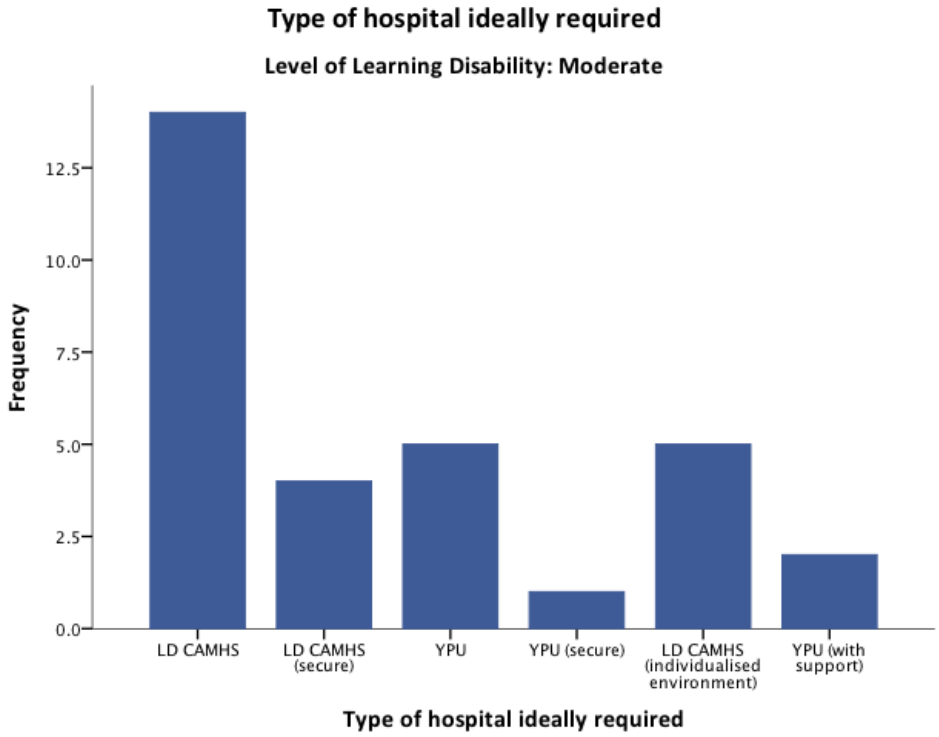
National Child Psychiatry Inpatient Unit	3	0	0	3
YPU (Secure, England)	0	1	0	1
LD CAMHS (including private, England)	5	3	1	9
Total number of periods of inpatient care	42	24	10	76
Total number of patients requiring this	29	9	7	45

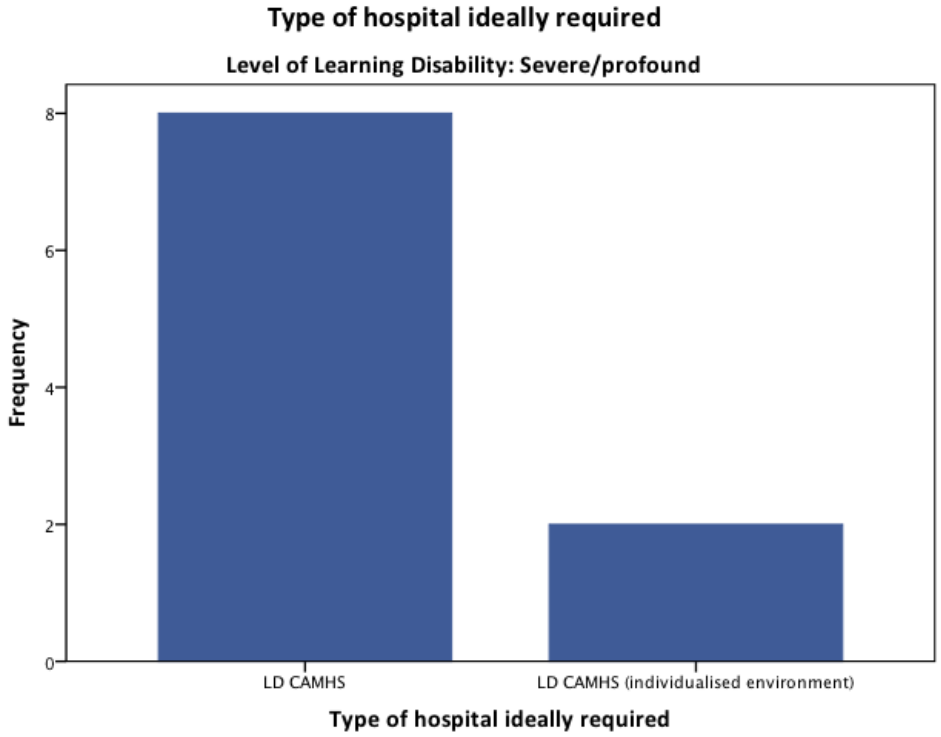
A4.19.2 Type of hospital ideally required by those with different levels of learning disability

Note that the y axis (frequency) has different scales in the following 4 different graphs.




Type of hospital ideally required
Level of Learning Disability: Mild
Frequency
6
4
2
0
LD CAMHS
LD CAMHS (secure)
YPU
CAMHS unit (under 12's)
YPU (with support)
Other
Autism unit (incl secure)
Type of hospital ideally required


Type of hospital ideally required
Level of Learning Disability: Moderate
Frequency
12.5
10.0
7.5
5.0
2.5
0.0
LD CAMHS
LD CAMHS (secure)
YPU
YPU (secure)
LD CAMHS (individualised environment)
YPU (with support)
Type of hospital ideally required



A4.19.3 Profiles of those requiring different types of specialist units

Numbers were too small to quote for all the different types of specialist units thought to be ideally required, so the main data given below pools data for those requiring learning disability-specific and those requiring non-learning disability-specific units. However, trends for patients requiring different types of units were as follows:

- **LD CAMH inpatient unit (non-secure)** had a range of levels of learning disability.
- **LD CAMH inpatient unit (secure)** – vast majority were male with mild learning disability, aged 16-17.

- **LD CAMH inpatient unit (individualised) –** required by some patients with moderate and severe/profound learning disability.
- **Adolescent (secure) mental health inpatient unit, not learning disability or autism spectrum disorder-specific** had autism spectrum disorder but no learning disability, but were not felt to require an autism spectrum disorder-specific provision.
- **Autism spectrum disorder-specific adolescent secure mental health inpatient unit** had autism spectrum disorder but no LD.

A4.19.4 Profiles of those requiring LD CAMH specialist inpatient unit compared with those requiring 'mainstream' YPU provision

Profile of patients requiring specialist LD CAMH inpatient provision - summary

Those requiring LD CAMH inpatient provision show the following characteristics:

- Greater degrees of learning disability, especially moderate and severe/profound learning disability
- 70% male
- Age group most likely to be admitted 16-17 years (21 patients), or 14-15 (15 patients), but significant number (11 patients) aged 13 or under
- Main reasons for requiring admission (most individuals had >1 reason):
    - Risk management 29 (73%)
    - Mental health assessment/stabilization 22 (55%)
    - Medication management10 (25%)
    - Home/care placement breakdown 6 (15%)
- High staff ratios required: 40% needing 1:1 care, 32% 2:1 care

A4.19.4 (i) Level of learning disability

The following chart summarises the numbers of each level of learning disability of those requiring the 2 main groups of mental health inpatient unit, i.e. learning disability specialist mental health inpatient units and non- learning disability specialist YPUs.

Type of mental health inpatient unit ideally required → **Level of learning disability of patient ↓**	**LD CAMHS** (includes secure or individualized environments)	**YPU** (includes secure adolescent and those requiring LD CAMHS support in YPU)
None	0	22
Mild	12	7
Moderate	23	8
Severe/profound	10	0

A4.19.4 (ii) Gender

70% of those requiring LD CAMH specialist inpatient admission were male, compared to 60% of those ideally requiring YPU.

A4.19.4 (iii) Age at first admission

Numbers of patients for each age group requiring either a specialist LD CAMH inpatient unit or non- learning disability specific YPU are given. There appears to be a trend towards those requiring specialist LD CAMH inpatient provision being younger than those requiring non-learning disability specific provision.

Type of mental health inpatient unit ideally required/→ **Age group of patient ↓**	**LD CAMHS** (includes secure or individualised environments)	**YPU** (includes secure adolescent and those requiring LD CAMHS support in YPU)
10 & 11	4	1
12 & 13	6	2
14 & 15	15	10
16 & 17	21	24

A4.19.4 (iv) Reason for admission

Numbers of patients for each reason for admission (% in brackets) requiring either a specialist LD CAMHS inpatient unit or non-LD specific YPU are given.

Type of mental health inpatient unit ideally required/→ **Reason for admission ↓**	**LD CAMHS** (includes secure or individualised environments)	**YPU** (includes secure adolescent and those requiring LD CAMHS support in YPU)
mental health assessment/stabilisation	22 (55%)	23 (68%)
Medication management	10 (25%)	5 (15%)
Home/care placement breakdown	6 (15%)	0
Risk management	29 (73%)	18 (53%)

A4.19.4 (v) Staff ratio required

Numbers of patients for each staff ratio (% in brackets) requiring either a specialist LD CAMHS or non-LD specific YPU are given.

Type of mental health inpatient unit ideally required/→ **Staff ratio required** ↓	**LD CAMHS** (includes secure or individualised environments)	**YPU** (includes secure adolescent unit and those requiring LD CAMHS support in YPU)
Standard ward level	<5	11 (46%)
1:1 staff: patient	10 (40%)	10 (42%)
2:1 staff: patient	8 (32%)	<5
3:1 staff: patient	<5	0

A4.20 <u>Clinicians' views on the potential advantages to their patients of specialist mental health inpatient provision in Scotland for children and young people with a learning disability</u>

Where clinicians indicated that their patient ideally required an LD CAMH specialist inpatient unit, they were asked during telephone interviews what they thought that patient would have gained from such a unit in Scotland. The same was asked for the very small number who they thought required a specialist ASD (non-LD unit). Many clinicians

independently gave similar answers, which are summarised in this section.

A4.20.1 Earlier, more effective treatment

A number of patients would have benefitted from an earlier, more planned specialist inpatient assessment, preventing escalation of difficulties over months or years. The child or young person could get 'back on track' quicker to benefit from education and community services and make developmental progress. Access to a Scottish specialist unit could have prevented long periods of illness and distress at home, or whilst being 'contained' with limited treatment on non-specialist wards. Patients with certain illnesses (e.g. bipolar disorder) could have had a less serious prognosis and course of illness with quicker treatment. Patients with learning disability and autism spectrum disorder struggle with transition, so admission straight to a specialist ward, rather than one or more move along the way would have been particularly helpful.

A4.20.2 A safer, more appropriate physical environment

A specialist unit would have had a safer and more appropriate physical environment, quieter and less over stimulating from a sensory perspective. Vulnerable children and young people would not be exposed to adult patients. Some with highly destructive behaviour would have required a particularly robust part of a unit, segregated from other young people, but with access to education and activities. A few of those with autism spectrum disorder and mild or no learning disability with forensic/secure needs would also have benefited from this type of environment. Some level of security would be helpful for the majority, due to either their vulnerability and lack of understanding of common dangers, or the risk they pose to others.

A4.20.3 Thorough assessment and treatment from a specialist multidisciplinary team

Thorough assessment and treatment from a specialist, well-functioning multidisciplinary team of professionals experienced in working with children and young people with learning disability and autism spectrum disorder and their families would have been a significant advantage for these patients. Professional groups indicated included nursing, psychiatry, clinical psychology, speech and language therapy, occupational therapy, pediatrics and teaching. Staff experienced and confident in working with this patient group would be able to more quickly and effectively assess and manage complex presentations, due to their ability to:

- assess mental state and role of any mental illness in their presentation
- assess communication level and needs and use a variety of appropriate forms of communication, engaging more effectively with young people and better understanding the role of challenging behaviour in those who cannot verbalise distress
- carry out functional analysis of behaviour, plan and implement behavioural interventions
- assess sensory processing issues and implement effective strategies
- manage aggression, self-injurious and destructive behaviours
- assess the need for psychotropic medication, understand medication effects, side-effects and dosages in this population

- safely monitor medication impact and side effects
- exclude and manage physical health problems, including epilepsy
- understand the impact of puberty in children and young people with learning disability.

Staff on a specialist unit would have a better understanding of patient needs from a developmental perspective. Assessment of level of learning disability and autism spectrum disorder assessment would be available where this was not already clear. Occupational therapy and nursing input would improve patients' functioning. Staff would also have more experience and expertise in attachment and family systems issues for children and young people with learning disability. Better and more effective relationships with families would be facilitated. Families would be able to be more confident in the care their children would receive.

A4 20.4 Other advantages

Specialist nursing staff would be able to provide a better structure to patients' days, with clear rules routines. There would be an age appropriate peer group and the type of structured and purposeful developmentally appropriate education and activity required for recovery. Young people would be less vulnerable in an age-appropriate setting.

A specialist unit would also be helpful in identifying patients' long term needs and facilitating more effective discharge planning to home, or alternative placement and education.

For some patients, where a short-term crisis admission to a local non-specialist ward was all that was required, consultation advice and support from a national specialist centre would have been helpful.

A5: Experiences from working with families of children and young people with LD and/or autism spectrum disorder requiring inpatient mental health care

Sophie Pilgrim, Director, Kindred.

A handful of children and young people with autism require inpatient CAMH care each year in Scotland. While it is fortunate that the numbers are low, a consequence is that the families feel extremely isolated in their experience. The lack of services for their children has a long term impact on wellbeing and cohesion of the family unit.

Lack of appropriate support clearly adds to the unavoidable distress of a child who is acutely unwell. Parents with other children are constantly concerned about the impact on siblings who inevitably witness very distressing scenes. Parents are shocked by the involvement of the police in admissions and by the scrambling for inpatient arrangements. The apparent lack of anticipation of the needs of this group of children in NHS provision leads families to feel frightened and isolated. They are given the impression that their child is uniquely difficult to manage and beyond the scope of existing services, and this then leads them to feel very uncertain about the future. Where they have the opportunity to meet families of children with similar needs they are greatly relieved and reassured. However, establishing longer term peer support is challenging because families may not have much in common other than their experiences of CAMHS.

CAMH staff are reluctant to explain the overall picture to parents and other relatives as they do not feel able to defend themselves by criticising lack of appropriate NHS provision. Families are therefore

often unaware of the extreme efforts of CAMH staff, evidenced by this research, to manage with insufficient resources. As a result, families feel bewildered and can misinterpret the motives of the staff. Because of the confused messages about ongoing support and assessment, parents inevitably resort to searching the internet and any other information sources for answers about treatment, care, inpatient facilities and even diagnosis. CAMH staff may brush aside parents' views. For some, these factors leads to a breakdown of trust and many parents attempt to make complaints through the NHS, the Mental Welfare Commission or their MSPs, only to find that the slow and time-consuming nature of the complaints process can add to the sense of frustration and exhaustion.

When the young person is moved from one facility to another, parents search for reassurance and support from the next CAMH team or care team. Moving to a facility (either inpatient or residential care) which has more appropriate provision, for example, autism spectrum disorder expertise, can dramatically reduce challenging behaviour. Once a child or young person is settled within a CAMH inpatient provision or residential care the family return to some semblance of normality. However, the families still have to manage being divided from their child and having to travel long distances, and continue to talk about the impact on their own physical and mental health. Events such as birthdays or Christmas have added significance in the circumstances, and present an opportunity for the family to regain trust in professionals providing support to their child or young person.

For the child or young person themselves, the experience of requiring admission to inpatient care is evidently frightening, stressful and out of their control. It is clear that the distress of admission is greatly

exacerbated by the lack of available acute facilities and appropriately trained staff. Family cohesion is threatened by the lack of appropriate care thus long term family support for the child or young person is jeopardised with huge cost implications for statutory services. When it comes to transition out of inpatient care, there are often significant questions over which statutory services will be picking up the bill (adult or child services, social work, health or education). As a result there is often a deficit in terms of information provided to the family who are left feeling confused and ill-informed about the options available for ongoing care. The lack of transparent planning with regard to transition adds to the anxiety of the family and certainly results in costly delays to discharge.

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