



Children & Young People's
Mental Health Coalition

Overshadowed

The mental health needs of children and young people with learning disabilities



Report by Paula Lavis, Christine Burke and Professor Richard Hastings on behalf of the Children and Young People's Mental Health Coalition

Acknowledgements

We would like to thank everyone who helped inform, gave advice and commented on the report. In particular we want to thank our Expert Reference Group who gave us valuable advice and feedback, all the young people, families and teachers who were involved in our focus groups, the organisations who agreed to take part and their coordinators who made it all happen.

We would also like to thank Andy Bell, Kadra Abdinasir, Emma Bailey and Alethea Joshi from Centre for Mental Health for copy editing and designing this report.

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Executive Summary

All children and young people deserve the best possible outcomes and start in life. Those with learning disabilities are likely to need additional support in various aspects of their lives including to enjoy good mental health. However, young people with learning disabilities continue to face challenges and inequalities that speak volumes about how they are regarded by society.

It is estimated that around 1.2 million people in England have a learning disability (Mencap, 2017). People with learning disabilities experience poorer health outcomes than the rest of the population, including with their mental health (FPLD, 2014). Children and young people with learning disabilities are **more than four times** more likely to develop a mental health problem than those without¹. This means that 14% or **one in seven** of all children and young people with mental health difficulties in the UK will also have a learning disability.

Studies suggest that it is the wider risk factors that these young people and families experience, rather than their learning disability, that contributes to poorer mental health. This report explores these factors combining insight from young people (aged 11 to 25), families, professionals and research. An expert reference group was also established to help inform the report and develop solutions.

This report was commissioned by Comic Relief to better understand the mental health needs of young people with learning disabilities. This report and its recommendations do not necessarily reflect the views of Comic Relief.

Key findings

Barriers to early intervention

This group of young people are at increased risk of developing mental health problems due to social and emotional factors, such as living in poverty, parental mental ill-health and negative life events, rather than their disability. This increased risk is apparent by at least the age of 3, indicating that with timely early intervention, their mental health could be improved.

Most of the young people and families we spoke to said they had not been offered a 'health check'. All those aged 14 years and over and on their GP's learning disability register are entitled to this check with their GP, which should cover both physical and mental health issues. Ideally, this health check could be offered to younger children as well, enabling support to be offered much earlier and avoiding the escalation of their needs during adolescence.

Poor access to mental health services

Children and young people with learning disabilities can face significant challenges accessing the right mental health provision at the right time.

- **Just over a quarter (27.9%)** of children and young people with a learning disability and a mental health problem **have had any contact with mental health services**.
- In our interviews with families, **nearly one in four (23%)** said they had to wait more than **6 months**, and many said they were still waiting to hear about their referral to specialist services.

A fragmented system

The families in the focus groups referred to a lack of join-up between different agencies which resulted in them being 'ping-ponged' around the system, with no one taking responsibility. Even if young people with learning disabilities do access mental health services, there is a serious lack of research and clinical evidence on assessment and psychological treatments, particularly for young people with severe learning disabilities.

The transition from child to adult services is difficult for many young people. It is likely that young people with mental health and learning disabilities find it even more difficult to make a good transition. They may also be transitioning from multiple services including mental health, social care, education and learning disability services.

¹ Emerson and Hatton (2007) reported data from a secondary analysis of the ONS surveys. The combined 1999 and 2004 children and young people's mental health surveys constituted a population representative sample of over 18,000 children between the ages of 5 and 16 years.

Lack of training and awareness

Young people and families highlighted concerns about the mental health workforce's training in learning disability, and the impact this has in diagnosing mental health problems. The same has also been raised about the lack of mental health training among learning disabilities specialists. It is often the case that young people's mental health needs are overlooked due to misattribution to their learning disabilities (National Guideline Alliance, 2016).

Professionals working in children and young people's mental health services need to have a better understanding of how people with learning disabilities experience mental ill-health. Amongst education professionals, training and awareness about the mental health needs of young people with learning disabilities also requires improvement.

Young people with learning disabilities are neither seen nor heard

Young people and families we spoke to as part of our focus groups reported that they did not feel listened to.

- **Around 65%** of young people in our focus groups told us that they had told someone about how they felt, but they did not feel confident that anyone would help them.

They felt that professionals did not believe them, and often saw learning disability support as their primary need rather than recognising their mental health needs. This is known as diagnostic overshadowing and has been confirmed by research highlighted in this report.

Loneliness and its impact

The young people we consulted reported feeling lonely. This may be because they have no or few friends outside of school, and little connection with their local community.

- **Nearly half** (46%) of young people felt that a buddy or friend would help them with their mental health difficulties.

Feelings of loneliness may exacerbate young people's mental health problems. Positive peer friendships and relationships are a known protective factor for mental health and can also reduce loneliness.

Young people and families worry about the future

Many young people and families who took part in focus groups expressed pessimism about the future. Young people reported that they wanted to get jobs and lead an independent life but felt that nobody was going to help them to achieve this.

Parents and carers looked towards the future care of their family members in adulthood with profound anxiety and fear. This was primarily related to fears about what will happen when the parent or carer is no longer around. Some parents and carers also shared concerns about preparing their child to make the transition to adult services.

Recommendations

Throughout this report, we make ten recommendations aimed at national and local agencies to help improve the mental health and wellbeing of children and young people with learning disabilities.

Our recommendations are in line with NICE Guidelines on *Mental health problems in people with learning disabilities: prevention, assessment and management* (2016) and *Learning disabilities: identifying and managing mental health problems: Quality standard* (2017).

National: Government

1. **The Department of Health and Social Care and Public Health England** should map out the provision of preventative mental health support for children and young people with learning disabilities. The forthcoming prevention green paper provides an opportunity to consider the needs of this group and develop an action plan to promote their mental health and wellbeing.

- 2. The Department of Health and Social Care** should fund research to strengthen and promote the use of evidence-based mental health interventions for young people with learning disabilities.

National: NHS

- 3. As part of the NHS Long Term Plan, NHS England** should:
 - Improve pathways to mental health support for children and young people with learning disabilities. This should be clearly identified as a priority for all Integrated Care Systems.
 - Consider the needs of young people with learning disabilities as they transition into adulthood, including as part of the development of 0-25 years mental health models.
- 4. NHS England** should strengthen guidance for specialist children and young people's mental health services to ensure that young people with learning disabilities are not turned away due to not meeting the eligibility criteria.
- 5. NHS England** should prohibit the use of an intelligence quotient (IQ) threshold in children and young people's mental health services.
- 6. Health Education England** should review the training offer available to professionals on the mental health needs of children and young people with learning disabilities and/or autism. This should be offered to all staff working with children and young people, including those in education and children's services.

Local: Strategic level

- 7. Integrated Care Systems** should lead the development of more coordinated care for children and young people who have a learning disability and need mental health support.
- 8. We echo the Care Quality Commission's** call for a shared local offer on mental health, to help local systems to work better together and avoid families feeling like they are 'ping-ponged' around the system.
- 9. Local leaders** should identify opportunities for young people with learning disabilities and their families to shape local strategy and co-design services.

Local: Service level

- 10. Children and young people's** mental health services should ensure families are supported and have the information they need to talk with their children about their emotional wellbeing, in light of the fact that friends and family are the first port of call when these young people are concerned about their mental health.
 - Families feel that they are left on their own to cope while waiting for a referral or treatment. Local commissioners should ensure there are other forms of support available in the community to avoid young people's needs escalating while they are waiting for their appointment.
 - Children and young people's mental health services should provide appropriate signposting to these services where available.

Introduction

Children and young people with learning disabilities face a multitude of inequalities in all aspects of their lives. Young people with learning disabilities tell us that they feel ignored, confused, lonely, angry and sad. They are not confident that someone will help them if they try to talk to them about their mental health. Parents and carers tell us that they have to battle to ensure that their children get any support. They are ‘ping ponged’ around the system, often with no one listening to them or taking responsibility for their care.

The needs of these young people come to the public’s attention when there is a scandal, such as the abuse experienced by people with learning disabilities in institutional settings such as Winterbourne View and Whorlton House. Opportunities to support their emotional health and wellbeing in a timely manner will, by that time in their life, have come and gone.

“My child is like a ping pong between mental health services. Can’t they have a parent liaison person instead of me keeping on chasing for support?”

Children and young people’s mental health is high on the political agenda but young people with learning disabilities are often sidelined or even excluded from mental health services.

“How dire does it need to be before support is offered?”

The situation is already dire for many young people with learning disabilities. One in seven young people with a mental health problem in the UK also has a learning disability, but only just over a quarter (27%) of children with both learning disabilities and mental health problems will have had any contact with mental health services in the preceding year. This is similar to the proportion of all young people referred to specialist mental health services (NHS Digital, 2018).

Early intervention, both in terms of promoting good mental health and addressing issues when they first emerge, is key to preventing mental health issues continuing into adulthood, potentially becoming more severe and enduring. The evidence base

around early intervention for young people with learning disabilities and mental health problems is limited, though growing, especially for those with severe and profound learning disabilities.

Our approach

We conducted a series of focus groups with young people aged 11-25, their parents and school-based professionals, to explore their experiences of mental health problems and the support they receive.

We considered this in the context of what existing qualitative research also says about the experiences of these groups.

We also undertook a series of literature searches to collate existing data on:

- The number of young people with both learning disabilities and mental health problems
- Facilitators and barriers to them and their families accessing support
- Policy, guidance and practice.

We also consulted with our Expert Reference Group (see Appendix 1) and other professionals across the Children and Young People’s Mental Health Coalition to collate views and solutions to problems raised in the report.

This report will review and summarise the evidence base about the mental health needs of young people with learning disabilities (including policy and practice), provide an overview of the themes that came out of our engagement work and outline a series of clear recommendations aimed at local and national decision-makers.

This report was made possible thanks to a generous grant from Comic Relief who are committed to the wellbeing of children and young people.

Background

Dame Christine Lenehan’s report, *These are our Children* (2017a) outlines the need to build, articulate and test a vision which is about:

- Valuing each young person and respecting their right to childhood

- Providing appropriate support at the right stage, at the right level, to help them access a full life in the community
- Understanding children as part of their family and providing support for the whole family
- Understanding that all children and young people, whatever their level of impairment, communicate and have a right to be heard.

These elements are essential for supporting all young people with mental health problems, but especially those who also have learning disabilities.

This list can be added to by incorporating the key principles that were identified in an inquiry convened in 2001 by the Foundation for People with Learning Disabilities, into meeting the needs of children and young people with learning disabilities and mental health problems. These principles included:

- Start with the needs of the child/young person and families
- Recognise that they are a young person first
- Recognise that each young person will have individual needs.

This inquiry was set up because of evidence that children and young people with learning disabilities and their families often failed to get adequate support. Eighteen years later, despite the Government's commitment to improve the children and young people's mental health system, little seems to have changed.

Definitions

What is a learning disability?

We have included some definitions to help clarify what is and what is not a learning disability, but we would like to add a caveat here as the situation is often complex. Young people may have a number of conditions or problems (co-morbidities), and each young person will have different and unique needs. The term learning disability does not pertain to any specific condition (or group of conditions) but a spectrum (see table 1). For instance, young people may have a learning disability, but also

autism, mental health problems and possibly other physical health issues. Some young people will have a range of complex needs, and meeting them can be challenging, but not impossible.

The Department of Health, in their report *Valuing People: a new strategy for learning disability for the 21st century* (Department of Health, 2001) uses the term 'learning disabilities' when the following three core criteria are present:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with
- A reduced ability to cope independently (impaired social functioning), which
- Started before adulthood, with a lasting effect on development.

The term learning disabilities is synonymous with the term 'intellectual disabilities' used commonly within the academic literature and in international policy. People may have learning disabilities from birth or develop them during infancy or childhood. They affect the person's development and are long-lasting. A person with learning disabilities needs additional support with learning while at school, and often with daily activities all through their life. Given that it can be more difficult to understand, learn and remember new things, they might have needs related to communication, being aware of risks and managing everyday tasks, and need support to live independently. There are many causes of learning disabilities and the specific cause is often unknown.

Many definitions of learning disabilities also specify that the person will have an IQ of less than 70, (e.g. the World Health Organization International Classification of Diseases (ICD-10) Classification of Mental and Behavioural Disorders, 2010). IQ is measured by intelligence tests, which allow a person's score to be compared with the range of scores achieved by large numbers of people on the same test. However, it must be remembered that an IQ score does not give any information about a person's social, medical, educational and personal needs, nor what help and support the person might need.

Table 1: Learning disability spectrum

| Level | Mild | Moderate | Severe and Profound |
|--------------------|---|--|---|
| Description | <p>Able to mix well with others.</p> <p>Able to cope with most everyday tasks.</p> <p>May need additional support for specific tasks (e.g. forms, managing their money etc).</p> <p>IQ likely to be around 50-70.</p> | <p>Will need more care and support depending on their individual needs.</p> <p>IQ likely to be around 35-50.</p> | <p>Will need more care and support with areas such as mobility, personal care and communication depending on individual needs.</p> <p>IQ for those with severe learning disabilities likely to be around 20-35, and those with profound learning disabilities under 20.</p> |

(based on information from BILD, 2011)

IQ is used as part of the assessment for learning disability but is not the sole criterion. To put the figures above in context, the average IQ is about 90-110.

People with learning disabilities will have varying levels of disability ranging from mild to severe or profound (see table 1 above). Whilst all children and young people with learning disabilities will meet the same overall definitional requirements, their needs will vary and so the support they need will vary as well.

‘Challenging behaviours’

Some young people with learning disabilities will develop behaviours that challenge. These are described by the Royal College of Psychiatrists as ‘behaviour of such intensity, frequency or duration as to threaten the quality of life and/or physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion’ (NICE, 2015).

Challenging behaviours can be hard for services to manage in the community. There are multiple reasons for challenging behaviour, and these behaviours are always functional – conveying a communicative message that needs to be understood (Hastings *et al.*, 2013). Challenging behaviours are clearly socially defined rather than constituting a medical problem. Challenging behaviour may be triggered by, occur alongside, or be made worse by a co-existing mental health problem (Hastings *et al.*, 2013). This report will not explore the support available to young people who present with challenging behaviours.

What is not a learning disability?

Autistic Spectrum and Neurodevelopmental Disorders

Autistic Spectrum Disorders (ASD) are defined by the National Autistic Society as a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them.

ASD is not the same as a learning disability, but about 50% of people with ASD may also have a learning disability (NICE, 2011), and will probably have quite complex needs. In this report, we will not be referring to ASD unless it is in the context of a cohort of children and young people who also have a learning disability.

Other neurodevelopmental disorders such as Attention Deficit Hyperactivity Disorder (ADHD) are also not classed as learning disability, but again there will be some young people who have both.

Specific Learning Difficulties and learning difficulties

There are Specific Learning Difficulties (SpLD) which affect one or more specific aspect of learning and include conditions such as dyslexia and dyscalculia. These conditions impact on the way in which people learn and process information and are not the same as learning disabilities because they not associated with lower IQs.

In UK education services, the general term “learning difficulties” is often used instead as a category of special educational needs and means then

essentially the same thing as “learning disability” as defined above.

What is mental health?

Mental health is defined as a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to contribute to her or his community (WHO, 2014).

What are mental health problems?

There are many terms used to describe this, but in this report we will generally refer to mental health problems that are included in systems such as ICD-10 (International Classification of Diseases). This includes common mental health problems such as depression and anxiety disorders, and less common problems such as bipolar disorder and schizophrenia. Mental health problems are clinically significant conditions that have reached a threshold of symptoms that are adversely affecting a person’s quality of life.

2. The mental health of children and young people with learning disabilities

It is estimated that around one in eight children and young people aged 5 to 19 experience a diagnosable mental health problem according to the latest NHS prevalence survey (NHS Digital, 2018). The study found that children and young people with a mental health problem were more likely to have recognised special educational needs (SEN), including those who may have learning disabilities (36%) compared to their peers without mental health problems (6%).

The latest study did not, however, provide a breakdown of the mental health needs of children and young people with learning disabilities in detail; therefore in this report, we have relied on secondary analysis of earlier studies. This includes the Office for National Statistics' (ONS) UK Child and Adolescent Mental Health Surveys conducted in 1999 and 2004 as these provide the most reliable information about the prevalence of mental health problems in children with learning disabilities.

Emerson and Hatton (2007) reported data from a secondary analysis of the 1999 and 2004 ONS surveys. The combined surveys constituted a population representative sample of over 18,000 children between the ages of 5 and 16 years. Children were identified for inclusion based on child benefit records, which at the time was a universal non-means-tested benefit with very high uptake across the UK. The ONS surveys did not include a clear ascertainment process for learning disability – no IQ test data or standardised adaptive skills measures were included. However, by combining various parent and teacher-reported information, Emerson and Hatton were able to identify a sub-sample of 641 children (or 3.5% of the total survey population) who were likely to have a learning disability.

The ONS surveys included an interview with a parental caregiver (usually the mother) about the young person and with the young person themselves, if they were able to participate and were 11 years of age or older, in order to ascertain whether they had a mental health problem.

Emerson and Hatton (2007) compared the prevalence of all mental health conditions in the sub-group of children with learning disabilities and the remaining group of children with no learning

disability. **Overall, children with learning disabilities were 4-5 times more likely to have a diagnosable psychiatric problem than children without learning disability (36% vs 8% in the overall prevalence of mental ill-health).** These group differences were apparent for almost all categories of psychiatric disorders, for example: any anxiety disorder (11.4% vs. 3.2%), hyperkinesis [ADHD] (8.3% vs. 0.9%), and conduct disorder (20.5% vs. 4.3%). Exceptions to a significant difference between the groups were depressive disorders (1.4% vs. 0.9%), and eating disorders (0.2% vs. 0.1%), although in both cases prevalence was still elevated in the learning disabilities group. Children and young people with learning disabilities were also more likely to have more than one mental health problem and thus more complex mental health needs.

These figures mean that **one in seven, or 14%, of all children with mental health problems in the UK also have a learning disability (Emerson & Hatton, 2007).** Thus, the mental health of children and young people with a learning disability is a mainstream mental health policy issue.

The ONS mental health surveys sampled children and adolescents between the ages of 5 and 16 years. Group differences in the prevalence of mental health problems between children with learning disabilities and those without are clearly established across these ages. An important question is then to ask when these mental health group differences might first emerge. Another UK cohort study of over 15,000 children, also sampled through child benefit records (the Millennium Cohort Study, or MCS) when children were 9 months of age, can help to answer this question. The MCS included a standardised measure of cognitive ability carried out with each included child at age 5 (third wave of MCS data collection). The prevalence of learning disability in UK 5-year-olds was 3.07%. Using a screening measure of parent-reported child behavioural and emotional problems, the children with learning disability were found to be 2-3 times more likely to have high levels of hyperactivity, conduct, and emotional problems (Totsika *et al.*, 2011). Similar group differences in levels of behavioural and emotional problems between children with and without learning disability were also found in the

MCS sample when the children were age 3 years (Emerson & Einfeld, 2010). Therefore, **increased risk for mental health problems is apparent for children with learning disabilities early in life, at least by the time children reach age 3 years – highlighting the need for early intervention and support.**

It might be tempting to conclude from the prevalence research that learning disability itself is somehow the reason for increased mental health problems in this group of children and young people. There are undoubtedly some contributing genetic risk factors that are associated with learning disability, such as the heightened risk of psychotic disorders in young people who have Prader Willi syndrome (e.g. Skokauskas *et al.*, 2012).

However, the vast majority of the evidence suggests that **the group differences in the mental health of children with learning disabilities compared to other children constitutes a mental health inequality** – that is, a group difference in health that does not have to exist. The reason for this conclusion is that the factors found to be associated with increased risk for mental health problems in children with learning disability are modifiable. Not only that, but most significant risk variables are the same as those associated with mental health problems in all children and young people – although children with learning disabilities may be more exposed to these risks (Emerson & Hatton, 2007).

In the Emerson and Hatton analysis of UK population based data, children with learning disabilities were 1.5 to 2 times more likely to be exposed to social and environmental risk factors: living in a single parent household (30% vs. 23%), living in income poverty (47% vs. 30%), two or more recent negative life events (37% vs. 24%), poor family functioning (27% vs. 18%), primary carer has no educational qualifications (38% vs. 20%), household with no adult in paid work (30% vs. 14%), child's mother screened positive for a mental health disorder (33% vs. 24%), and child's mother's physical health was less than "good" (20% vs. 6%). Children with learning disabilities were also more likely to be exposed to multiple (three or more) social and environmental risk factors (46% vs. 24%) (Emerson & Hatton, 2007). If these modifiable factors can be

addressed, this would have a large positive impact on reducing mental health problems for all children but especially for children with learning disabilities.

In addition to the same social and environmental risk factors affecting mental health outcomes for children with and without learning disabilities, there are other modifiable factors likely to affect the experience of mental health problems in children with learning disabilities.

1. First, the cognitive limitations and developmental delays experienced by children with learning disabilities may be associated with decreased ability to recognise and label emotions, including those that underlay mental health problems.
2. Second, children with learning disabilities may have limited communication skills and so reporting problems or asking for help may be more difficult. However, both emotion recognition and communication skills can be taught successfully to children with learning disabilities.
3. A third modifiable process is the tendency to mis-attribute problems to the child's learning disability rather than to an underlying mental health problem – a process called diagnostic overshadowing (Jopp & Keys, 2001). Increasing practitioners' and family carers' awareness of mental health problems in children with learning disabilities should reduce the impact of diagnostic overshadowing.
4. Children with learning disabilities also have difficulties forming and sustaining relationships, and may have fewer friends than non-disabled children (Solish *et al.*, 2010) which may exacerbate feelings of loneliness and mental health problems.
5. Finally, in the preschool years, both reduced closeness and increased conflict in maternal-child relationships have been shown to predict behavioural and emotional problems in children with learning disabilities at 5 years to a greater extent than those without learning disabilities (Totsika *et al.*, 2014).

Children and young people with learning disabilities' access to mental health services

Despite the increased risks they face, children and young people with learning disabilities can face significant delays in receiving the help they need to address their poor mental health.

Studies by Emerson and Hatton (2007) and Toms *et al.* (2015) have examined parental reports of contact with mental health services for their children in the past year based on the 2004 ONS child and adolescent mental health surveys. Their analysis indicates that **only 27.9% of children with learning disability who also had a diagnosable psychiatric disorder (based on a clinical interview) had any contact with mental health services in the preceding year**, similar to the proportion of children without learning disability who had mental health problems and had received mental health services support (23.5%). These UK population-based data did not suggest an inequality in access to mental health services but did suggest that only a minority of all children with significant mental health problems received mental health support. However, details of treatment offered and delivered, and more recent population-based data, were not available.

A significant treatment-related inequality does, however, exist when it comes to the availability of evidence for treating mental health problems in children with learning disability. The National Institute of Health and Care Excellence (NICE, 2016) clinical guideline on mental health problems in children and adults with learning disabilities included comprehensive reviews of pharmacological and psychological treatments. It found that evidence for pharmacological approaches could be drawn directly from research on children with mental health problems – although there was also some evidence testing pharmacological treatments for ADHD in children with learning disabilities (NICE, 2016).

However, psychological treatments require some adaptation to be suitable for children with learning disabilities. There were 14 randomised controlled trials (RCTs) which suggested that adapted parent

training interventions can have a positive impact on the mental health problems of children with learning disabilities, with study quality rated between Very Low and Moderate (NICE, 2016). However, there was only one other controlled trial (not randomised) of a psychological treatment for mental health problems in children or adolescents with learning disabilities included in the NICE guideline after comprehensive international searches. Holstead and Dalton (2013) compared cognitive behavioural therapy with individualised behavioural interventions in the treatment of trauma/post-traumatic stress disorder (PTSD) symptoms in adolescents with a learning disability. The quality of this research study was graded as Very Low. Therefore, in effect, **there is currently no evidence for psychological treatments delivered directly to children with learning disabilities – representing an inequality in availability of treatment evidence**. Research on psychological treatments for mental health problems in children with learning disabilities is needed urgently (NICE, 2016). It is also important to point out that NICE Guidance is just guidance and practitioners can bypass any recommendations given based on the limited evidence.

Children with severe learning disabilities are even more marginalised. They are more likely to be prescribed psycho-active medications in the absence of a diagnosis of mental health problems (Vedi & Bernard, 2012). In addition, there are no assessment or measurement tools for mental health problems in children with learning disabilities which have evidence of psychometrically robust properties for those with a severe learning disability (see systematic review by Flynn *et al.*, 2017) In a further systematic review of pharmacological or psychological treatments for mental health problems, there was only one intervention study (on vocal and motor tics in an adolescent with Tourette's syndrome) with evidence reported specifically for children and adolescents with severe learning disabilities (Vereenooghe *et al.*, 2017). Thus, **research and clinical evidence on the assessment and treatment of mental health problems in children with severe learning disabilities is a priority for the immediate future**.

The current context: policy and practice

There are a number of current policy initiatives that are relevant to children and young people with learning disabilities and mental health problems. These include:

- *NHS Long Term Plan* (2019a)
- Transforming Care Programme (2015)
- *Future in Mind* (2015)
- Special Educational Needs and Disabilities (SEND) reforms (2014).

The treatment of people with learning disabilities is increasingly in the spotlight, including their access to and treatment in mental health services. *Future in Mind* (2015) sought to radically overhaul child and adolescent mental health services (CAMHS) to better meet the needs of children and young people aged 0 to 25 and promote a whole-system approach. The report recommended a strengthening of the links between children's mental health and learning disabilities services, and services for children and young people with special educational needs and disabilities (SEND) in particular. While progress is being made in some areas to achieve change, there continues to be significant variation between local areas (CQC, 2018).

Furthermore, the additional funding allocated for CAMHS to fund the transformation programme (£1.4bn) has not been protected and the National Audit Office has recently concluded that NHS England cannot be certain all the additional funding to date was spent as intended (NAO, 2018). A recent report by the Children's Commissioner suggests that less attention is given to spending on early help and preventative services. Local areas spent less than £14 per head in the last year on low level mental health support, again with wide variations between areas (Children's Commissioner for England, 2019b).

This suggests that CAMHS may be struggling to meet the needs of the general population and potentially more so for children and young people who also have a learning disability.

The Five Year Forward View for Mental Health (2016) includes little information about learning disabilities, and defers to the Transforming Care Programme (2015). The programme does not set out a specific vision for all young people, only those

from a very specific cohort (young people who are in inpatient settings). Children and young people with both learning disabilities and mental health problems are not a clear priority within either of these important policies.

There is a drive to prevent admissions to hospitals, but there are still about 240 young people under 18 with a learning disability in inpatient units (NHS Digital, 2019b) – equivalent to 11% of the overall inpatient population. Many of the young people are in these settings due to mental ill-health. Care and Treatment Reviews (CTR) have been developed to help prevent admission where possible and find alternatives, and agree discharge plans (ADASS *et al.*, 2015). There have been concerns raised about the effective use of CTR (Public Accounts Committee, 2017) and subsequently changes were introduced in March 2017 (NHS England, 2017) to recognise the specific needs of children and young people, including their learning, which also resulted in a name change to Care, Education and Treatment Reviews (CETRs). Findings from an evaluation of these changes shows promising results though there is still room for further improvement – for example, informing families about CETRs and sharing information about the support available to them as part of the review (Clark, 2018).

The reforms to Special Educational Needs and Disabilities (SEND) policies now include social, emotional and mental health as an area of need as part of the SEND code of practice produced by the Department for Education. It now also covers young adults up to 25 years old, and therefore provides an opportunity to help young people make the transition to adult life. It encourages joint working by placing a duty on local authorities and their partner commissioning bodies to improve services for children and young people who have special educational needs or disabilities, including those who have an Education, Health and Care Plan. While this is positive, there is currently no equivalent requirement for children and young people's mental health services to have a similar offer in place.

Dame Christine Lenehan (2017) was commissioned to undertake a review of provision for children and young people with complex needs who are placed in inpatient services, often for long periods of time. Her findings include that there is no cross-government ownership of the issue, which reflects

the fragmented policy framework discussed above. She also found that there is a lack of strategic vision for children; a lack of accountability and coherence within the system; a domination of classifications, diagnoses and labels which effectively rule out support; and a strong professional agreement for a model of support, one which isn't actually commissioned.

Lessons from Dame Christine's review include issues about the commissioning footprint, patchy support for parents, austerity biting across all statutory and non-statutory services, and disagreements about workforce. With regards to tier 4 services (highly specialist such as inpatient units) Dame Christine highlighted a lack of provision in the right place; a financial system which incentivises crisis interventions, but disincentivises prevention; and a short-sightedness about change. Dame Christine is also undertaking a review of Residential Special Schools that was commissioned by DfE, which is still in progress.

The NHS Long Term Plan sets out several commitments to help improve the lives of all those with learning disabilities and/or autism. This includes tackling the root causes of the health inequalities faced by this group, including poor mental health outcomes, intervening earlier and ensuring that agencies work more effectively together, including improving awareness and understanding the specific needs of this population (NHS England, 2019). Furthermore, in response to the BBC Panorama investigation about Whorlton House, the Department of Health and Social Care has also committed to establishing a working group to develop a new model of care for those with learning disabilities and autism (Department of Health and Social Care, 2019).

Many of the issues raised above are relevant to all children and young people with mental health problems, but are likely to be worse for those with learning disabilities because they cut across a number of policy areas, and to some extent, none of them fully tackle the issues we know exist for this specific group of young people.

SUMMARY

- Children and young people with learning disability in the UK are 4-5 times more likely to have a diagnosable psychiatric problem than children without learning disability
- Children and young people with learning disability are more likely to have more than one mental health problem
- One in seven, or 14%, of all children and young people with mental health problems in the UK also have a learning disability
- The increased risk for mental health problems in children and young people with learning disabilities is apparent at least by the time they reach 3 years of age
- Less than a third (27.9%) of children with learning disability who also had a diagnosable psychiatric disorder had any contact with mental health services in the preceding year. This is similar to the overall population of young people (25.2%) with mental health needs (NHS, 2019)
- There are significant inequalities regarding access to effective mental health treatment for this group
- There is a lack of evidence-based psychological intervention for children with learning disabilities who also have mental health problems
- There are serious gaps in research and clinical evidence on the assessment and psychological interventions for children with severe learning disabilities.

2: Young people's experiences in practice: key themes

This section covers the wide range of practice-based issues identified in the literature that cut across the whole health, social care and education system, and include commissioning as well as practice.

Problems accessing help

One of the key issues that came out of our focus groups and from the literature was problems accessing help when needed. Lengthy waiting times were a key issue for young people with learning disabilities and mental health problems. Many children and young people are 'ping-ponged' around the system from service to service, with none of these services talking to each other or taking responsibility. These young people and families can be in contact with their GP, paediatricians, CAMHS, social care and education among other services. Although there may be documents outlining what interventions are on offer, these appear to fail in practice.

One possible explanation for such gaps in support is the different terminology used by different professional groups. For instance, a young person with learning disabilities is likely to be under the care of a community paediatrician, and they may use the term 'learning difficulty' or 'neurodevelopmental delay'. This becomes an issue when professionals communicate with each other about a specific case and can have an impact on access to support. GPs, for instance, have a learning disability register, and the young person may not be placed on that register if their diagnosis is labelled as learning difficulty. The consequences for this would be that the young person would not be offered the annual health check that is now being offered for young people 14 years and over.

Commissioning of services for children and young people with learning disabilities

Connected to problems accessing help is the commissioning of services for this group of children and young people. As is the case for children and young people generally, the commissioning landscape is quite fragmented, but is potentially

worse for children and young people with both learning disabilities and mental health problems.

Clinical commissioning groups (CCGs) commission community-based NHS services, including mental health and learning disability services; and the majority also commission primary care services. There is likely to be a separate commissioner and budget line for both mental health services and learning disability services within CCGs. We should stress that there will be variation in how CCGs manage this. Some will work with local authority colleagues to jointly commission these services and there have been some discussions about all-age neurodevelopmental services.

Local authorities will commission a range of services for this group of children and young people. There is a duty on CCGs and local authorities to put joint commissioning arrangements in place for education, health and care provision for young people with special educational needs and/or a disability (Children and Families Act 2014). This will of course include some children and young people with learning disabilities, but not all.

NHS England commissions specialist services such as children and young people's inpatient beds for this age group. There have been some moves to change the way that these services are commissioned, but currently there are only a few pilot new care models.

More generally, the commissioning structures within the NHS are in a state of flux, with the development of Integrated Care Systems (ICS) and NHS England and NHS Improvement's proposal to reduce the number of CCGs to typically one per ICS (NHS England, 2019).

The need for evidence-based approaches

The NICE guideline on learning disabilities and mental health highlighted the lack of evidence base regarding mental health assessment and the treatment for children and young people with severe to profound learning disabilities (NICE, 2016). There are examples of emerging good practice, but these are yet to be evaluated. Therefore, we do not know if they make a difference for young people with

learning disabilities, particularly in the long term. This has huge implications for practice as it will mean that commissioners and practitioners will not have high quality evidence to guide them.

The case for early intervention

There is a strong argument for early intervention, given the high prevalence of mental health problems in young people with learning disabilities. It is often social and environmental issues that these young people face (such as poverty, loneliness and bullying) that impact on their mental health, rather than the learning disability itself (Institute of Health Equity, 2018). Therefore, a more targeted approach is needed for those most at risk. We need a public health approach to tackle the risk factors or social determinants of mental health problems that these young people and their families face.

Emerging mental health problems can be identified at a very young age, even in pre-school children. As with any child or young person, there needs to be a suite of interventions available that cover universal level services aimed at every child, including health visitor checks during the very early years, support for families and in primary care services, as well as targeted and specialist services including speech and language therapy, mental health services, and school-based counselling services.

Early intervention is only possible if young people's needs are identified early or they can tell someone about their problems and know that appropriate action will be taken.

The role of primary care

Primary care services play a crucial role in the health and wellbeing of young people with learning disabilities. The young people and families we spoke to reported mixed experiences of primary care provision, particularly those delivered by GPs.

Concerns regarding GPs' knowledge of learning disabilities and mental health emerged in the qualitative research from young people and families' views. At the focus groups conducted to inform the NICE guideline on learning disabilities, people with learning disabilities consistently shared that they were not listened to, and GPs were singled out for criticism. However, they also stated that

good support was provided by GPs and mental health professionals who knew them well and could therefore understand any early signs.

A recent campaign by Mencap has been raising awareness about the fact that people can sign up to be on their GP's learning disability register, which entitles them to a longer appointment, to make health care more accessible and to have a 'health check'. The health check is for people aged 14 and over, and the Quality Standard for the NICE guideline specifies including a mental health assessment in the health check. Data from NHS Digital shows that more people are receiving health checks (NHS Digital, 2019c), including children and young people. Further evidence is needed to understand whether these checks are having a positive impact on the health of people with learning disabilities.

The Royal College of GPs has produced a toolkit aimed at GPs and practice nurses to help with the health check for people with learning disabilities, (RCGP, 2017) including a section on mental health and behavioural issues. Mencap (2017) has also produced easy-read leaflets about the health check and what to expect.

Children and young people's mental health services

The difficulties children and young people face in accessing mental health services are known and well-documented (e.g. in *Future in Mind*, 2015).

There have been particular concerns regarding access to inpatient units for children and young people with serious mental health issues. Work is under way by NHS England to improve the availability of these beds as some areas have few or no local beds. NHS England's plan is to increase capacity (the number of beds) in the short-term while they improve community-based services, thereby reducing the needs for as many beds in the longer term (NHS England, 2016).

A report recently published by the Children's Commissioner for England reveals that too many children and young people are admitted to secure hospitals unnecessarily when they should be helped in their community. Some of these young people were held in secure settings for several months and even years. Around one in seven young people

in these settings have only a learning disability, suggesting that they may be inappropriately held in these settings due to gaps in provision (Children's Commissioner for England, 2019a).

The paper also highlighted concerns about the use of physical restraint and seclusion to manage the needs of these young people. According to the analysis, 75 children with a learning disability and/or autism in hospital were recorded as having been restrained in December 2018 (Children's Commissioner for England, 2019a). Furthermore, findings from an interim review by the Care Quality Commission on the use of restraint, prolonged seclusion and segregation for people with a mental health problem, a learning disability and/or autism found that 39 children and young people were cared for in segregation in these settings at the end of 2018 (Care Quality Commission, 2019).

There are service standards for specialist child and adolescent mental health services - namely Quality Network for Community CAMHS (QNCC) and Quality Network for Inpatient CAMHS (QNIC) – to ensure patients receive high quality services. There is an annual review of how well services who are members of QNCC or QNIC meet these standards, and this process involves self-review and peer review, including interview with CAMHS staff and young people. The latest QNCC report suggests that most services are meeting standards which relate specifically to learning disabilities. For example, 81% of services met the standard around young people and their parents/carers being able to access support appropriate to their disabilities (The Royal College of Psychiatrists, 2017). However, based on the views of many of the parents and carers we spoke to, it seems unlikely they would agree with this conclusion.

The Royal College of Psychiatrists (2016) have set out what a good psychiatric service for young people with learning disabilities should look like, and states that the acceptability of the service by young people and their families is paramount.

This College Report is intended to help leaders shape their service and sets out the components of a model service, which are:

- Diagnosis and assessment
- Counselling services to help the individual and their family cope with disability and the associated difficulties

- Family work
- Specialist individual therapies
- Pharmacological treatment
- Liaison and joint working with other agencies
- Emergency response
- Advice to the courts (expert opinion).

The academic elements of the service include:

- Continuing professional development and training
- Teaching for other agencies as well as the service, this should include undergraduate and postgraduate
- Research and audit.

Since the publication of that report (RCPsych, 2016), and in response to the Lenehan Review (2017a), there has been a move to develop a Joint Statement about the roles and responsibilities of GPs, developmental paediatricians and child and adolescent psychiatrists (RCGP, RCPCH and RCPsych, 2018). It sets out that this group of young people requires access to health services based on joint working, collaborative practice and good information sharing. Young people should be able to access clinicians who have the right skills to assess, diagnose and intervene depending on the child's age, developmental status, and physical and mental health co-morbidities.

Out of area provision

Despite the Winterbourne View Concordat (Department of Health, 2012) which sets out a plan of action to transform services for people with learning disabilities or autism and mental health problems, around 250 children and young people are held in Assessment and Treatment Units (ATUs) (JCHR, 2019). They are often placed in inpatient provision, some for many years, miles from their homes.

Dame Christine Lenehan refers to these hospital placements as being used for the 'warehousing' of children. This is contrary to the intention of an Assessment and Treatment Unit (ATU), which is for short term use. Government policy is to move away from hospital to community provision, but this is not always happening for young people with learning disabilities and mental health problems.

There are also many children and young people with learning disabilities who are living miles from home in residential special schools. These schools generally provide placements for young people with the most complex needs, but provision is patchy, leading to many out-of-area placements often miles from their home. These young people may be displaced from their families and home communities for years, only returning home in adulthood. The Challenging Behaviour Foundation and Mencap's (2016) resource *Keeping in Touch with Home* looks at how children should be supported to stay in touch with their families when they are inpatients.

Data from Learning Disability Services Monthly statistics (NHS Digital, 2019b) suggests that whilst only a small proportion of the people being cared for in hospital are under the age of 18 (11%), this figure slightly increased over the year 2016-17. Around a third (32%) of admissions for both children and adults were due to mental health problems; 27% were for issues related to learning disabilities, and just under a fifth (19%) because of challenging behaviours. Many young people are placed in mental health units miles away from their home. According to the Children's Commissioner for England, 95 children were placed in wards more than 50km (31 miles) away from their home (Children's Commissioner for England, 2019a).

There is concern that while the Government is committed to closing NHS Assessment and Treatment Units, these are being replaced with private hospital placements. It was estimated that in 2015/16, £477.4 million was spent on keeping 2,500 people with learning disabilities in hospital (Brown *et al.*, 2017). Of these beds, 52% were provided by the private sector. The percentage of beds in the private sector has risen considerably since 2006, and the value of the inpatient healthcare market to the independent sector is considered to be in the region of £284 million (James *et al.*, 2016). However, this increase in private provision isn't linked to an improvement in outcomes for patients. According to the Centre for Disability Research (Brown *et al.*, 2017) patients detained in private provision were 30% more likely to experience an assault and 60% more likely to be restrained than inpatients in NHS units.

Improving transitions

The transition from child to adult services is difficult for many young people and is often described as a 'cliff-edge' of support. It is likely that young people with mental ill-health and learning disabilities find it even more difficult to make a good transition. They may be transitioning from mental health, social care and learning disability services. However, there is a lack of high-quality research into the impact of transition to adulthood on young people with learning disabilities (Cvejic, 2018).

The Track study (Singh *et al.*, 2010) found that young people struggle to meet the eligibility criteria for adult learning disability, adult social care or adult mental health services. There is a real risk that these vulnerable young people will fall through the 'care net' and not receive any support, despite having significant needs. In addition, adult mental health services often lack provision for those with learning disabilities and have to depend on voluntary sector organisations for information and support (Singh, *et al.*, 2010, quoting Lamb, 2008).

Poor transitions between child and adult mental health services is unique to the UK. Indeed, the Milestone study, an ongoing European-wide study, has identified the lack of tailored care pathways and a lack of join up between services as two significant practical barriers to the continuity of care for young people transitioning (Signorini, 2018).

We know what a good transition should look like and what should happen in theory, but it isn't always being implemented on the ground for this group of young people. For instance, young people with an education, health and care plan, or a care and support plan, should be offered a review by local authorities, but it is unclear whether these are happening and whether they are helping with transitional planning.

There is variation across the country regarding transitional arrangements. Some young people with learning disabilities will be covered by the SEND framework, which covers young people up to 25. We know that some areas have a transitions social care team for 14-25 year olds and this plugs the gap between child and adult disability social work teams.

A shift towards 0-25 models of care may prove effective for this group of young people. The iThrive model, for example, is a person-centred framework with an emphasis on prevention and early help. It is currently offered to 47% of the 0-18 population and is often delivered up to the age of 25 (NHS England, 2019). The NHS Long Term Plan has committed to developing a comprehensive mental health offer for young people aged 0 to 25 (NHS England, 2019a).

NICE have produced a guideline on the transition from child to adult services which provides some generic recommendations, but it is not specific to mental health or learning disabilities.

Supporting the whole family

When any child has a mental health problem, support from their family is important; however, providing this support can put stress on the whole family. Studies have found that the mental health of parents who have children with learning disabilities is influenced by the severity of their child's mental health problem more than the degree of their learning disability (NICE, 2016). Siblings of children with learning disabilities may also be at an increased risk of mental health problems. Good and timely support for children and young people with learning disabilities can help support the wellbeing of the entire family. Unfortunately, we know that parents/carers do not always receive the support they need when their child has mental health problems (Association for Young People's Health, 2016).

Mental health support in educational settings

It is estimated that in schools in 2017, there were 10,969 children with profound and multiple learning disabilities; 32,680 with severe learning disabilities, 119,909 with autistic spectrum disorder and 3,020 with multi-sensory impairments (Department for Education, 2018a). It is thought that the number of school children with complex needs has increased by nearly 50% since 2004 (Council for Disabled Children, 2017).

Children and young people with special educational needs (SEND) – which includes learning disabilities – are far more likely to be excluded on a fixed term basis or permanently (Timpson, 2019). According to

the latest available data, children and young people with identified Special Educational Needs (SEN) accounted for 46.7% of all permanent exclusions and 44.9% of fixed period exclusions (Department for Education, 2018b).

Young people with identified SEN but without an Education, Health and Care Plan (EHCP) were more likely to be permanently excluded compared to those with a plan, though the latter were still 2.8 times more likely to be excluded on a fixed term basis (Timpson, 2019). According to the Timpson review, this may be due to requirements in the Department for Education's exclusion guidance which prevent the exclusion of those young people with an EHCP (ibid).

Many children with learning disabilities will be in mainstream schools, but some will be in special schools or placed in residential special schools. Around 6,000 children and young people are placed in residential special schools and colleges in England (Lenehan, 2017b). An estimated 5,200 children with complex needs live away from home in these schools, with over 1,100 in full-time 52-week placements. Around two-thirds of these placements are in the private sector, and more than three-quarters of children were placed more than 20 miles from their family home (Council for Disabled Children, 2017). Being so far from home can have an impact on young people's relationships with their family and friends, and on their mental health. This may also help explain why so many young people with learning disabilities feel lonely and do not have a best friend (Lemos and Crane, 2012).

There is increasing focus on the role of education in promoting mental health and wellbeing. However, the majority of school-based interventions or prevention approaches are not aimed at young people with learning disabilities.

The recent green paper on children and young people's mental health (DHSC and DfE, 2018) seeks to improve the identification and provision of early help in education settings through the development of Mental Health Support Teams (MHSTs) and a Designated Senior Lead for mental health in schools. Children and young people with learning disabilities will also benefit from these initiatives, but only if there is a focus on the specific needs and experiences of this group.

At a policy level, it is important that the needs of this group aren't overlooked. At a practice level, we need to ensure that resources are developed or adapted to meet the needs of this group and are evaluated to ensure that they work. For instance, The Friends for Life programme is an evidence-based approach to promoting mental health in schools, both as a universal and targeted prevention programme (Burke, *et al.*, 2017). It was developed in Australia, but is used internationally and endorsed by the World Health Organisation. However, it may not be suitable for children with learning disabilities. The Mental Health Foundation developed an adapted version for use with children with learning disabilities called Special Friends (Mental Health Foundation, 2016).

Zippy's Friends, which is another internationally renowned programme to improve children and young people's mental health, has been adapted for children with special educational needs. Importantly, it has been independently evaluated in a pilot study and found to have a positive impact (University of Birmingham, 2015).

A whole school approach to mental health and wellbeing can help by ensuring that mental health is integral to all aspects of school life, and its policies and processes. To be effectively implemented, it needs to be led by the head and senior staff and supported by the governors. Public Health England and the Children and Young People's Mental Health Coalition developed a framework to help schools implement a whole school approach to supporting mental health and wellbeing (CYPMHC and PHE, 2015). While it is aimed at any type of school, it is just a framework so will need adapting to fit local needs, and reasonable adjustments need to be made for young people with learning disabilities.

Workforce and training

NICE guidance states that 'health, social care, [and] education services should train all staff who may come into contact with people with learning disabilities' so they have a good understanding of mental health issues in this group. It also recommends that health and social care staff who deliver interventions for this group should be competent, receive supervision, deliver manualised interventions, and monitor their practice.

This guidance chimes with what we hear from young people and families, who feel that many practitioners (including GPs and CAMHS professionals) do not have a good enough understanding of learning disabilities. We were told that practitioners focus on the learning disability rather than looking at the wider needs of the young person. They may not have an understanding of how mental health problems present in people with learning disabilities – which can be different to young people without learning disabilities.

There are existing training materials for teachers or other non-mental health professionals. MindEd, the eLearning platform, is freely available and includes modules on mental health and learning disabilities. Disability Matters is also a freely available eLearning platform focusing on disabilities.

There are a number of policy interventions under way which aim to improve training:

- A major element of the CAMHS transformation programme is the children and young people Improving Access to Psychological Therapies programme (CYP IAPT). This programme involves training up existing CAMHS staff in psychological therapies as part of the CYP IAPT Autism Spectrum Disorder and Learning Disabilities course (University College London, 2018)
- Health Education England (HEE), an arm's length body responsible for developing the NHS workforce, has developed Generic Service Interventions Pathway, a competency framework to support the development of the learning disabilities workforce (Health Education England, 2015). This document details the skills and competencies needed by staff operating across a range of health settings, including the need to identify and respond to the mental health needs of people with learning disabilities (*ibid*).
- An NHS workforce implementation plan is currently being produced by NHS Improvement, HEE and NHS England to address current and future workforce challenges as part of the NHS Long Term Plan. This is due to be published later in 2019 (NHS England, 2019a).

3: What young people, their families and professionals told us

We spoke to stakeholders to find out more about their experiences through a series of focus groups and surveys. We heard from:

- 59 people with learning disabilities between the ages of 11 and 25
- 13 parents and carers, including the families of children with more severe learning disabilities
- 10 school-based professionals, including teachers, Special Educational Needs Co-ordinators (SENCOs) and outreach teachers.

A full list of the groups we consulted is included in Appendix 2.

The results of the consultation exercise and surveys have been analysed and presented below. It should be noted that while these findings are not representative of the wider population of young people with learning disabilities, they closely align to the body of qualitative research that highlight the unmet mental health needs of young people with learning disabilities.

Young people, families and school-based staff expressed their dissatisfaction in the systems, pathways, referral processes, quality of support, and outcomes for young people with learning disabilities. They were all concerned about the lack of support, training and understanding about the mental health needs of young people with learning disabilities. Early intervention and prevention services in particular were not consistently available or accessed by young people. The overall feeling from all those we spoke to is that this group of young people are at risk of falling through the cracks of poor services.

The main themes from the consultation were:

- **Young people** felt that they were not believed or listened to. The majority had asked for help but felt they would not be able to find the right support to meet their needs. They did not feel confident that those they sought help from understood them or were able to support them.

Several issues were identified that affected the wellbeing of young people with learning disabilities. The young people we spoke to said that they often felt lonely because they spent a lot of time on their own and they did not have friends outside school. Young people also worried about the future, particularly about their access to employment. They wanted to get jobs but felt that nobody was going to help them to secure this.

- **Parents and carers** felt they had to fight to access support for their child. Parents felt that early intervention was crucial to the development of their child. However, they identified several barriers to accessing support and there was no one point of contact that could help them navigate through the system. Parents and carers highlighted the need for a coordinator to help them navigate the system and manage the care their child receives, including support from multiple services.

Parents and carers also felt that services did not understand or address their needs, much like the young people. Similarly, they were also concerned about the future. However, unlike the young people, parents highlighted the difficulties faced when making the transition from child to adult services.

- **School-based staff** felt that there was a long way to go before high-quality, timely support was offered to families. If this support was readily available to young people, professionals felt that it would help avoid the need for costly interventions in the future. A key barrier to support identified by school-based staff was the lack of funding available for support services, including early interventions. The gaps in training and awareness were also raised as barriers to support for young people, and professionals we consulted felt that this would make a significant difference.

The views and experiences of young people with learning disabilities

The core components of the focus groups were:

- A discussion around ‘what is mental health?’ We used a spectrum of mental health ranging from healthy to unwell.
- A conversational style was used to encourage a discussion on key themes.

Young people recognising their feelings and emotions

As part of our discussion about mental health, we asked young people if they have ever felt any of a range of emotions for at least a month or longer (see figure 1 below).

‘When someone annoys you and disturbs you then you get angry or upset’

‘What is the point of telling anyone? They don’t take any notice’

Around a third of young people reported feeling lonely (32%) and confused (36%). Some of the young people spoke of feeling depressed during the focus groups and that they had a hard life and were lonely.

Anger was another significant feeling expressed by young people (30%) and this often related to feelings of frustration or feeling misunderstood.

‘I get angry at football and don’t know how someone can help me’

‘I get angry because they push me, and I punch the wall. I then just want to sleep.’

A common theme in all the discussions with young people was that they were not listened to and people either spoke over them or for them.

‘They ignore me and I am lonely and I think of my grandad and feel sad’

Seeking support to help manage their feelings and emotions

Children and young people with learning disabilities may struggle to approach services and individuals about their mental health problems for a range of reasons, including communication difficulties or past negative experiences.

Over two thirds (65%) of young people in our focus groups told us that they had told someone about how they felt, but they did not feel confident that anyone would help them.

‘If I tell someone nothing will change, it’s not going away, [I] don’t feel anyone cares. Hold it in like a bottle’

Figure 1: Young people’s experience of negative feelings and emotions lasting a month or longer

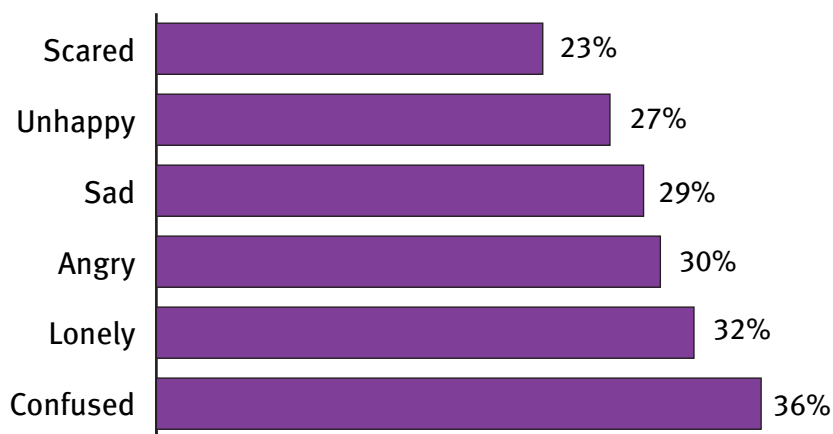
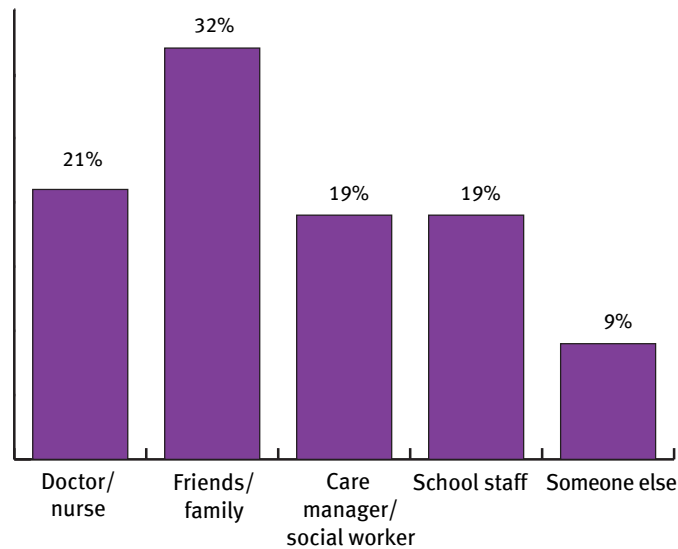


Figure 2: Where young people turned to for support



In some cases, young people may also be unaware of who to turn to for help. We asked young people whether they were confident they knew who to approach if they felt sad.

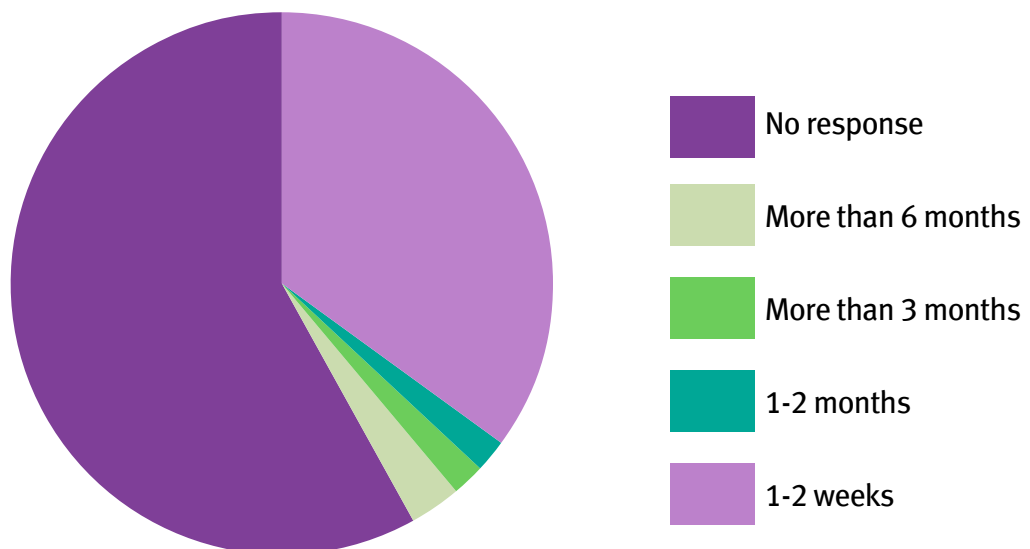
Of these, 32% of young people spoke primarily to their family about their feelings (see figure 2 above). Around one in five (21%) spoke to their GP; often with support from their parent or carer. A similar proportion of young people sought help from a professional at school or from either their care manager or social worker.

When young people did seek help, they were not always confident that people would help them with their mental health needs. 18% of respondents felt this way compared to 12% who did believe they would get good support.

Waiting times for support

The majority of respondents were unable to answer this question, but over a third (35%) said they received some form of support within 1 to 2 weeks. However, this was often a response to a referral and not to the wait for treatment.

Figure 3: The length of time it took young people to receive help



The same proportion of young people (2%) said they waited 1 to 2 months or more than 3 months. A further 3% of respondents said they waited more than 6 months to hear back from services or receive support.

This is in line with the findings in previous research (FPLD, 2010) where people with learning disabilities experienced lengthy waiting times. This often fuelled their feelings about being ignored and not listened to.

The type of support received by young people

Two thirds (66%) of young people reported that they did receive help once they told someone.

As part of our discussions with young people, we reflected on the types of interventions they received. Young people were often referred for counselling services, including provision based in schools and colleges. Some of the young people were prescribed medication to help manage their needs and others were given social prescriptions such as taking part in community activities or clubs.

School staff also featured highly in the discussion, as well as family members who advised and supported them.

The results present a mixed picture about young people's experiences of these services. Around a third (32%) of young people said they felt better once they accessed support.

'feel this is a mixed bag'

'met nice people but then never saw them again'

A slightly higher proportion (35%) of young people said they did not feel better and highlighted the lack of consistency in the support offered to them.

'No, waste of time – never saw the same person twice'

Alternative forms of support

Young people were asked about alternative forms of support that they feel might better meet their needs:

- 46% of young people said they would like a buddy or volunteer to support them
- 21% said they would like to receive counselling
- 7% wanted something else
- 2% of young people felt that medication would help them manage their needs.

'a walk in the park and listen to music/meditation when I am depressed, or anxious. It helps me to keep positive energy'

'a book which I keep my feeling in a diary helps me'

'more time to myself to think and to do what I like'

Nearly half (46%) of young people felt that a buddy or friend would be able to help them. They wanted to speak to others who had similar experiences.

'someone to listen and talk to whenever I need'

'being listened to and having your ideas heard'

Young people also wanted their teachers to learn how to listen, understand and help them. They expressed the same about parents and carers being supported to learn how to help them.

Annual health checks for young people with learning disabilities

Annual health checks provide a crucial opportunity to detect underlying health problems facing people with learning disabilities. Around 67% of respondents said they did not get an annual health check, whereas 30% did and 3% did not respond.

However, there are caveats that should be noted. Many of the young people were unclear as to whether they had a health action plan, or indeed if they received a formal health check. This number may be low due to the high number of school pupils taking part in the focus group. Despite this, these findings correlate with the feedback from parents and carers (see later in chapter).

Young people's worries about employment and the future

Many of the older young people raised the importance of employment to their mental health. They felt that work opportunities would allow them to utilise their skills and meet people.

'going to work will keep me mental healthy, all we do here is work experience'

'work is important otherwise we sit around getting bored and lonely'

'help us find jobs'

While the young people we spoke to expressed a strong appetite to work, they felt that they were not

provided with enough support into employment from services. For some, this negatively impacted on their confidence.

Results from interviews with families

We held interviews with 13 parents and carers to ensure that young people with the most severe learning disabilities, who could not speak to us directly, still had a voice in this research. Although we only interviewed a small group of parents and carers, the information they provided was rich and insightful.

Parents and carers expressed feeling that there was little support offered to them and their child. They did not feel that their own mental health needs were supported or recognised.

Identifying the mental health needs of young people with learning disabilities

The needs of children and young people are often first detected by those closest to them, such as their parents or family member. We asked parents about where the needs of their child were first highlighted.

Table 1: The identification of your child's mental health need

| | |
|-----------------------|-----|
| Myself (parent/carer) | 69% |
| School | 19% |
| Other | 13% |

The majority (69%) of parents and carers said they identified emerging mental health problems in their child and had to convince professionals of this. For example, one mother we spoke to said that she was concerned about her child's behaviour and asked for support from school staff.

'The teacher/SENCO observed my son in school and concurred with myself that there was an issue. We both separately consulted the doctor.'

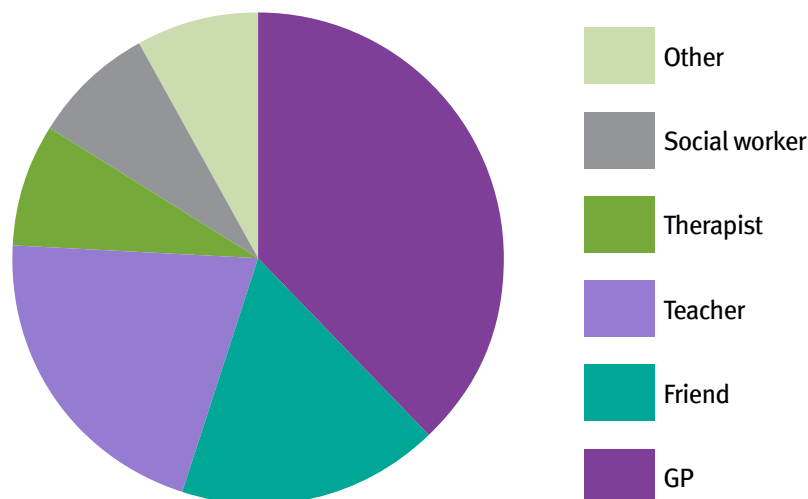
Nearly one in five (19%) families reported that their child's school identified their mental health need.

Many families raised the importance of having a well-trained named professional to improve the identification of mental ill-health amongst young people with learning disabilities.

Turning to others for advice and support

The GP was the first port of call for 38% of families, with 21% approaching teachers. The feeling for most families was that the GP should be able to offer advice, information and support. If young people's needs were deemed serious or enduring, they were referred on to other specialist services. Parents and carers were grateful for the additional information and signposting available to them while they waited for help from other services. GPs often also prescribed young people medication, such as antidepressants, during the process.

Figure 4: Where parents and carers turned to for support



We asked parents and carers about what advice and support would have helped them. They told us:

'More general information on what to look for as my son is autistic and I was therefore more aware of what to look out for.'

'It would be great to have a help line and you know something could happen straight away.'

'An immediate crisis response, not left to the police to intervene, and something is done to support rather than [being] sectioned and moved away. If they get there early enough it would cost them less money.'

Young people were subsequently seen by various professionals, including GPs, social workers, psychiatrists, psychologists, therapists, nurses and education professionals. However, parents found help from these professionals to be inconsistent or delayed, and were largely critical of the help they were offered.

Staff in school were another source of support for parents and carers, much like young people. 21% had sought support from teachers.

'I informed his secondary school of his issues and sat with his head of year to discuss a plan of action'

'My daughter is at college where there is access to a counsellor, and this has been very successful'

Parents also really valued support from their peers, particularly where their friends had children with similar needs.

Support for young people and families during waiting times

Over three quarters of parents (77%) said their child was not offered any other support while they endured long waiting times for mental health support.

'I was not going to complain in case they did not see us'

15% of respondents said they were signposted to other services and support in the community for their child while they waited for an assessment from CAMHS.

Appointments in health settings were generally scheduled at times that were convenient for the

parents and carers (54%) who responded to our survey. However, 23% of respondents were given inconvenient appointment times which they struggled to attend due to work or caring responsibilities.

Annual health checks

As noted earlier in the chapter, most young people who engaged in our project said they did not undergo an annual health check. All but one of all the families responded stating that their son/daughter had not been offered a health check.

The future: low expectations, high hopes

Many of the parents and carers we spoke to looked towards the future care of their child with anxiety and fear. This centred around concerns about what would happen when the parent/carer is no longer around. The fear was that their family member would not be loved and cared for like they would at home.

Some carers identified difficulties in getting support to help their child make the transition to adult services.

'We have tried to get them on board since he's been 16 and a half, asking why we had no input from the young adult team... he is 19 soon and we have heard nothing.'

It is unclear whether this family's view is based on any solid evidence of local services or is just due to low expectations.

'My child is like a ping pong between mental health services. Can't they have a parent liaison person instead of me keep on chasing for support?'

'early support by qualified professionals who understand both learning disabilities and mental health, maybe a named person we can contact [would be helpful]. Also offer some help to families like family therapy'.

The views and experiences of professionals in schools

We interviewed 10 school-based professionals, aiming to speak to a wide variety of professionals. All those we spoke to felt strongly that the mental health services available to young people with learning disabilities needed improvement.

The effectiveness of mental health services for children and young people with learning disabilities

Early intervention was seen as very important by school professionals.

Staff in schools raised concerns about the gap between demand and capacity in CAMHS. They felt that funding pressures are a significant factor and have meant that services have had to raise their thresholds and revise their eligibility criteria in order to meet local need. This made it difficult for this group of young people to receive any input or treatment.

'Dire – how dire does it need to be before support is offered?'

'Fund it properly – don't wait for a tragedy and then act on it'

Professionals in schools suggested that there should be a balance between funding for specialist services and lower level support to ensure that school outreach services, advocacy, access to support for families, access to counselling, key workers and pastoral care can also be made available.

School staff also felt that the support offered was sometimes too short and that CAMHS and learning disabilities services were only responsive to young people in crisis.

The pathways to support for young people with learning disabilities

Access to support is often hindered by confusing referral pathways that lead to a delay in making referrals and result in lengthy waiting times for young people.

'We don't have access to any advice as professionals'

School professionals we spoke to suggested that referrals to CAMHS had been the main pathway for reaching support, but as mentioned above this service continues to be under pressure. The GP was the other main point for referral for school staff. Some schools offer counselling and behavioural support, and young people get direct access to school outreach teams.

Furthermore, we were told that there are CAMHS teams that still operate an IQ threshold, despite guidance by the Royal College of Psychiatrists suggesting that services take a more holistic approach to assessing young people with learning disabilities (Royal College of Psychiatrists, 2016). Many families have no support from CAMHS when behaviours that challenge first become apparent. Their first encounter with mental health services may be when they are sectioned under the Mental Health Act, 1983.

'we need to work jointly with mental health and social care services as it seems to take too long for the wheels to start turning because we are all overstretched'

'Families and young people cannot just cope with talking therapies. We should be able to recognise issues and intervene quickly.'

What works for young people with learning disabilities and mental health needs in education?

School staff told us about the value of having provision based in school settings for young people with learning disabilities. It was noted that some schools have their own counsellors and outreach who provide young people with effective support and use strategies to support their mental health. Learning mentors and a designated member of staff were also identified as helpful approaches.

'I think there are a range of committed professionals attempting to bridge and fill the gaps in mental health services.'

'In my experience young people with LD have plenty to say about their mental health. They are receptive and open if the correct means of communication is used.'

'We find that schools are too ready to exclude and when we intervene the solution is at times so simple to manage.'

Support for parents and carers through schools has also been proven to be effective, for example, through outreach teams who have been upskilled in this area.

Respondents felt awareness about mental health has improved, including among parents and carers. This was also true for staff wellbeing in school settings. The Mental Health Foundation's Peer Education project was reported to have been instrumental in raising awareness on mental health to young people and teachers in some of the schools consulted.

The barriers to support

Overall, professionals in schools felt that learning disability and CAMHS services are not aligned, and there are relatively few examples of good CAMHS/ learning disability support. This lack of alignment is compounded by gaps in national guidance on areas critical for good support of young people with learning disabilities, such as the lack of focus on person-centred care or Positive Behaviour Support in CAMHS inpatient service specifications.

'It's difficult to differentiate mental health difficulties from the young person's usual behaviour sometimes – you have to know them really well'

Our conversations with schools-based professionals indicate a great need for an improvement in the skills and understanding of learning disability and challenging behaviour among CAMHS staff. Diagnostic overshadowing and behaviours are not understood or addressed. Similarly, professionals working in learning disability services are not always able to spot the signs of mental ill-health and respond to young people's needs.

School staff also felt that the lack of evidence-based interventions for this group makes it difficult to consider examples of good practice developed for young people with learning disabilities across the whole spectrum, including children with severe learning disabilities and challenging behaviour.

Conclusion and recommendations

Young people with learning disabilities experience unacceptable inequalities in health, including their mental health. The risk factors associated with poor mental health outcomes for this group of young people are known and can be addressed with timely and effective interventions.

Many of the issues identified in our focus groups and interviews reinforce findings from qualitative research about the mental health needs of young people with learning disabilities and their families (Griffith *et al.*, 2013; Griffith & Hastings, 2013; NICE, 2016). Young people with learning disabilities and their families do not always have confidence in the system to meet their mental health needs and they are often ignored and misunderstood.

Children, young people and their families often do not know what support is available to them and what they are entitled to. There is also great variation across the country with regards to what mental health services young people have access to. While pathways to care for young people with learning disabilities do exist in some areas, they are not always effectively implemented.

Our recommendations identify the first steps that can be taken, nationally and locally, to close the gap and ensure that no one's mental health is overshadowed as a result of a learning disability.

Recommendations

Our recommendations are in line with NICE Guidelines on *Mental health problems in people with learning disabilities: prevention, assessment and management* (2016) and *Learning disabilities: identifying and managing mental health problems: Quality standard* (2017).

National: Government

1. **The Department of Health and Social Care and Public Health England** should map out the provision of preventative mental health support for children and young people with learning disabilities. The forthcoming prevention green paper provides an opportunity to consider the needs of this group and develop an action plan to promote their mental health and wellbeing.

2. **The Department of Health and Social Care** should fund research to strengthen and promote the use of evidence-based mental health interventions for young people with learning disabilities.

National: NHS

3. As part of the NHS Long Term Plan, **NHS England** should:
- Improve pathways to mental health support for children and young people with learning disabilities. This should be clearly identified as a priority for all Integrated Care Systems.
 - Consider the needs of young people with learning disabilities as they transition into adulthood, including as part of the development of 0-25 years mental health models.
4. **NHS England** should strengthen guidance for specialist children and young people's mental health services to ensure that young people with learning disabilities are not turned away due to not meeting the eligibility criteria.
5. **NHS England** should prohibit the use of an intelligence quotient (IQ) threshold in children and young people's mental health services.
6. **Health Education England** should review the training offer available to professionals on the mental health needs of children and young people with learning disabilities and/or autism. This should be offered to all staff working with children and young people, including those in education and children's services.

Local: Strategic level

7. Integrated Care Systems should lead the development of more coordinated care for children and young people who have a learning disability and need mental health support.
8. We echo the Care Quality Commission's call for a shared local offer on mental health, to help local systems to work better together and avoid families feeling like they are 'ping-ponged' around the system.

9. Local leaders should identify opportunities for young people with learning disabilities and their families to shape local strategy and co-design services.

Local: Service level

10. Children and young people's mental health services should ensure families are supported and have the information they need to talk with their children about their emotional wellbeing, in light of the fact that friends and family are the first port of call when these young people are concerned about their mental health.
 - Families feel that they are left on their own to cope while waiting for a referral or treatment. Local commissioners should ensure there are other forms of support available in the community to avoid young people's needs escalating while they are waiting for their appointment.
 - Children and young people's mental health services should provide appropriate signposting to these services where available.

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Appendix 1: Expert Reference Group

Professor Dame Sue Bailey

Former Chair of the Children and Young People's Mental Health Coalition and current Chair of Trustees at Centre for Mental Health

Paula Lavis

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Chair, Faculty of Social Sciences Research Forum
Monash Warwick Professor, Centre for Developmental Psychiatry and Psychology, Monash University

Matthew Dodd

Head of Policy and Public Affairs, NCB

Dr Camilla Rosan

Programme Lead for Families, Children and Young People / Perinatal and Infant Clinical Psychologist, Mental Health Foundation

Dr Mark Lovell CAIDPN, NHS

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Child and Adolescent Intellectual Disability Psychiatry Network - Vice-chair
Royal College of Psychiatrists Faculty of Psychiatry of Intellectual Disability- Co-opted member
Association for Child and Adolescent Mental Health- Board Member (Lead for CPD and Training)

Dr Karen Bretherton

Consultant Psychiatrist for Children with Learning Disabilities, NHS Leicester

Dr Tim Devanny

Transforming Care Workforce Specialist (North), Health Education England

Kirsten Lamb

Clinical Lead for Learning Disability, Herts Valleys CCG

Dr Jill Cadwgan

Consultant Paediatrician - Neurodisability, Guy's and St Thomas' NHS Foundation Trust

Dr Pru Allington-Smith

Consultant Psychiatrist Child LD, Coventry and Warwickshire Partnership NHS Trust

Dr Max Davie

Assistant Officer for Health Promotion, Royal College of Paediatrics and Child Health
Consultant Community Paediatrician, Mary Sheridan Centre

Appendix 2: Groups involved in our consultation work

The Focus Groups

We consulted with ten focus groups of people with learning disabilities. In total we spoke to 59 young people with learning disabilities and poor mental health. The groups of people we spoke to are described below:

Forest Academy, East London

A mainstream school that has an ethos of inclusion. We spoke to two groups of young people with mental health needs and learning disabilities aged between 16-18.

Skillnet Group, Dover, Kent

The Skillnet Group supports people with learning disabilities to speak up, make choices and become powerful and influential. We spoke to two groups of young people above the age of 21.

Little Heath School, Redbridge

A special school that primarily supports children and young people with more complex needs and or autism. We spoke to 3 groups of young people aged 11 to 20, as well as 2 groups of families.

Generate, Wandsworth

An advocacy organization that also runs youth groups and supports the voice of people with learning disabilities with more moderate needs. We spoke to 2 groups of young people aged 11 to 16.

Redbridge College in Romford

An adult education college that has a route to employment program to support young people into work. We spoke to 3 groups of young people aged 19 to 25.

Selworthy School in Taunton

Selworthy is a co-educational special school for children and young people with learning disabilities aged 4 to 19.

The Redbridge Outreach Team

A group of teachers that support young people with learning disabilities in mainstream schools.

West Sussex Parent Carer Forum

The forum helps parent/carers of children and young people aged 0-25 with additional needs and disabilities to improve and make positive changes to the lives of their families and others.

Mindfulness UK

A training and support organization on mindfulness with compassion which has links to parents.

Challenging Behaviour Foundation UK

The charity for people with severe learning disabilities whose behaviour challenges.

Appendix 3: Data from the Focus Groups

The Consultation with children and young people, their families and school-based professionals, plus the methodology and results from the consultation, are presented in Section 4 of the Report. The information in this Appendix is presented to provide the full results, additional information and tables excluded from the main document.

Demographic information gathered from the focus groups and questionnaires

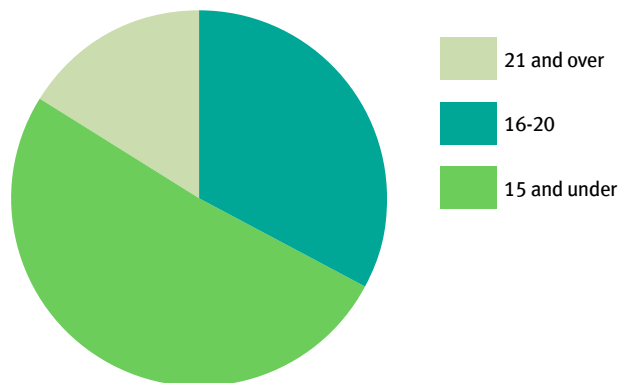
We spoke to 59 people with learning disabilities, 13 parents and 10 school-based staff. The information here is supplementary to that in section 4.

a. Age and gender

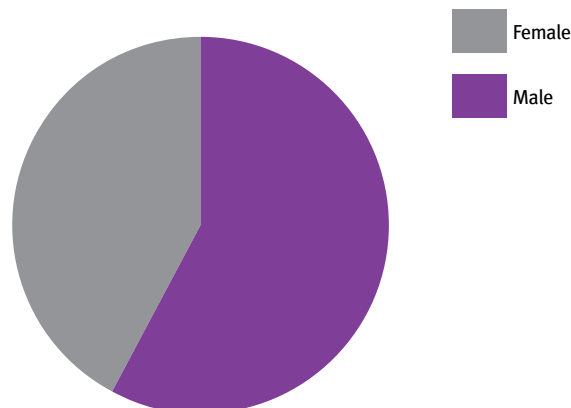
All participants were asked to declare their age (ranging from 11 to 25 years) and gender (see graphs below).

We did not ask about sexual orientation because of our experience from previous consultations which indicated that a lot of time was required to explain what we were asking. There was confusion about what each category meant.

Age



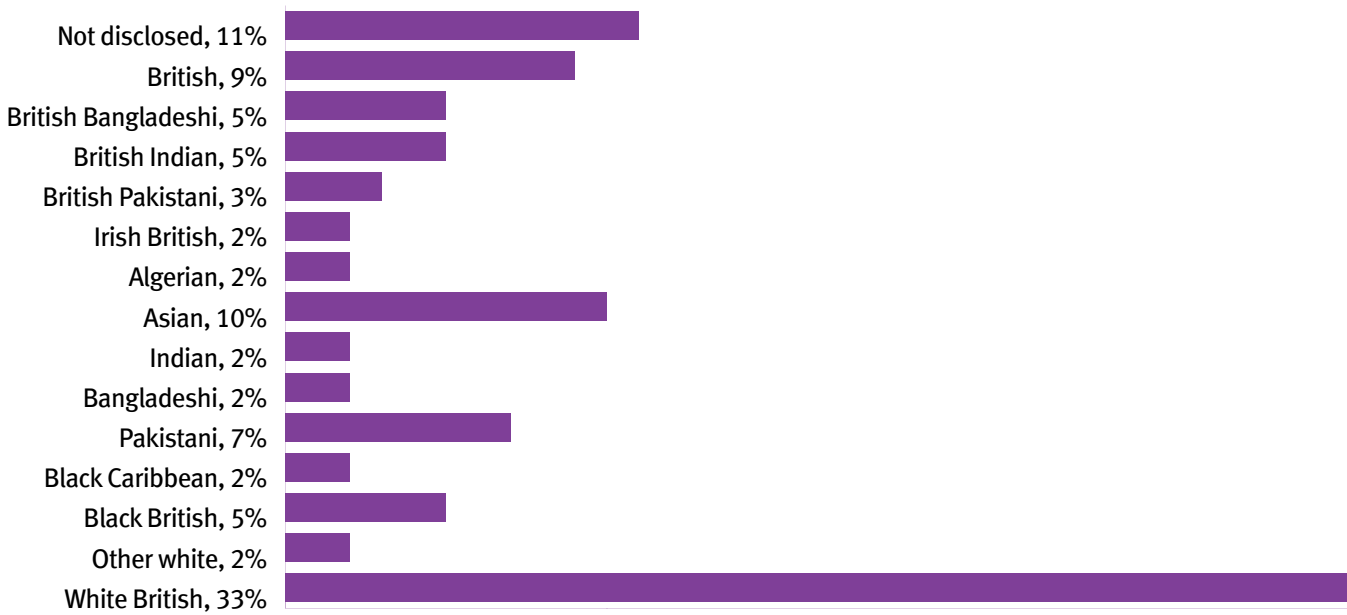
Gender



b. Ethnic origin

The demography of the three areas of consultation, according to the local census information is predominantly white/British, however we used the categories as described by the young people which allowed for a split of India, Asian, British Bangladeshi, Bangladeshi, British Indian. We might have a different split if we used traditional ethnographic categories.

This echoes the Census data recorded in 2011 for the South East region of the UK. This data indicates that 90.7% of the South East population is made up of White/White British, followed by 1.6% of Black/African/Caribbean/Black British, 5.2% being Asian/Asian British, 1.9% being of mixed/multiple ethnic groups and 0.6% of other ethnic groups.



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Published June 2019

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