Feeling Down

Improving the mental health of people with learning disabilities.

Christine-Koulla Burke

foundation for people with learning disabilities

Acknowledgements

Foreword

I am very pleased to see this timely report looking at the way in which the mental health needs of people with learning disabilities are currently being met. The strapline 'No health without mental health' applies equally to people with learning disabilities as to the general population.

We know that the majority of people who have mental health problems including anxiety and depression do not receive such prompt and comprehensive care as they do for physical health conditions, and timely access to mental health services is even worse for people with learning disabilities. The 2012 Health and Social Care Act introduced a commitment to parity of esteem for physical and mental health and this must be introduced for the whole population.

Much has been written about disability discrimination and inadequate disability awareness training for staff working in the NHS from the perspective of people's physical health. This report and the accompanying resources provide a wake-up call to policy makers, commissioners, regulators, professional bodies and providers.

It does not claim to be an in depth scientific study but has been co-produced with self-advocates and this gives the report an authenticity which is sometimes lacking in policy papers.

The accompanying guide for people with learning disabilities will be a wonderful addition to the tools already available to support health action plans which by and large neglect mental health.

I am looking forward to further publications from the Foundation, in particular to the planned guide for families in partnership with the Challenging Behaviour Foundation and the Royal College of Psychiatrists.

Baroness Sheila Hollins
Emeritus Professor of Psychiatry of Disability at St George's, University of London

Foreword from reference group

In spite of welcome initiatives such as the national campaign 'Time to Change', aimed at reducing stigma for people with mental health problems, it is still the case that people with learning disabilities have more difficulty accessing mental health services than other groups in society, and the quality of care they receive is still of a poorer standard. False assumptions by clinicians and managers about what is appropriate often goes unchallenged and people with learning disabilities can be denied access to services or excluded from certain treatments. This is not to say specialist services are the answer.

The recent Winterbourne scandal, as well as revealing horrendous abuse, highlighted the failure of current systems in which people are hospitalised due to a lack of appropriate local services and outdated commissioning strategies. Service provision varies greatly by location and the best model for delivering mental health services is still up for debate. What is agreed is that services should be person-centred, afford the necessary support and embrace the principles of choice, rights and inclusion as set out in the Valuing People White Paper in 2001.

This resource from the Foundation for People with Learning Disabilities is designed to help promote positive mental health by offering information, case studies and real-life experiences of people with learning disabilities and their carers and their strategies for enhancing their mental wellbeing. This report builds on the excellent Count Us In report, first published just over ten years ago. During this time the Foundation has worked with people like Peter Cronin, Liam Peyton and Maggie Brennan from the Tuesday Group (a mental health promotion group for people with learning disabilities) to build on the findings of the survey and establish what information should be included in the guide for people with learning disabilities.

The resources developed by this project serve as a testament to all those people with learning disabilities and their carers who have given up their time and energy to ensure the findings reflect their input. They are not just guides to good mental health but practical manuals offering ideas that people can adopt to help them manage and cope with their mental health problems.

Eddie Chaplin
Estia Centre
South London and Maudsley NHS
Foundation Trust

On behalf of the reference group

Contents

Glossary

The definition of learning disabilities utilised in England is:

- A significantly reduced ability to understand new or complex information, and to learn new skills (impaired intelligence), with;

- A reduced ability to cope independently (impaired social functioning);

- Onset before adulthood, with a lasting effect on development.

(Valuing People, Department of Health. 2001)

Executive summary

The Foundation for People with Learning Disabilities was commissioned to write a report about the mental health of people with learning disabilities as well as offer information to people with learning disabilities and their families to support their access to mental health services.

The aim of the report is to raise awareness among policy makers, commissioners, health and social care services and anyone supporting or working with people with learning disabilities, and to develop a picture of the customer journey to receiving support and make recommendations for change.

Background

It has long been recognised that there are inequalities in the way people with learning disabilities are supported by health and social services.

Valuing People in 2001 emphasised the need to consider how we support people to lead a good life with the same rights and choices afforded to other citizens. Both specialist and mainstream services need to provide person-centred support which is of a high standard.

There have been many initiatives working to reduce stigma in mental health, yet people with learning disabilities and their families still have great difficulty in accessing mental health services compared with other groups in society and still have to ask to be taken seriously. They have to explain that **their mental health is unrelated to their learning disability and just like the general population, they are at risk of experiencing mental health problems**. There have also been many calls for mainstream mental health services to be improved and be more inclusive, particularly for people with a learning disability.

Many people with learning disabilities can and do achieve a full and rewarding life, experiencing physical, mental and social wellbeing. However, there is evidence to suggest that there are still many barriers to them gaining the necessary support to lead a healthy life, especially when they have a dual diagnosis such as a learning disability and a mental health problem.

A summary of research evidence, compiled by the Public Health Observatory for Learning Disability (October 2012) cites the following prevalence rates:

- 3% for schizophrenia (three times greater than for the general population), with higher rates for people of South Asian origin.
- The same as the general population for anxiety and depression (though higher in people with Down's syndrome).

At least one in four people experiences a mental health problem at some point in their life (Singleton et al, 2001), yet studies using psychiatric evaluation in people with learning disabilities report prevalence rates of between 20.1% and 40.9% (Taylor et al, 2004; Cooper et al, 2007).

Methodology

We worked with an established reference group of people with learning disabilities who also experienced mental ill health.

A literature search was carried out into the mental health needs of people with learning disabilities, both children and adults, in order to inform our work.

A national survey was conducted to gather qualitative and quantitative information on the current experiences of people with learning disabilities, their families, friends and staff when accessing support for their mental wellbeing.

Key messages

People with learning disabilities should have the same rights and choices as everyone else.

People with learning disabilities said that:

- people did not see them – they just saw their learning disability

- the information that was provided was not accessible and in a format that they could understand

- they were not believed, listened to or supported when they felt down

- they wanted to have more control around their mental health

- a diary and information to explain what was happening to them would make it easier to talk to staff and tell the GP how they were feeling.

Family members and friends said that:

- access to support, getting the GP to believe them or refer them to a specialist, was the biggest barrier to their son/daughter's mental health and was extremely hard

- that the long wait was detrimental to their son/daughter's wellbeing

- psychological support was valuable once received.

Professionals said that:

- not enough was being done to support the mental health needs of people with learning disabilities

- support from GPs was crucial in accessing mental health support but difficult to obtain

- mental health services needed to improve and make reasonable adjustments to ensure access

- support during treatment and aftercare was crucial in supporting the mental health needs of people with learning disabilities

- there was a need for better and more joint work between mental health services.

Recommendations

The following recommendations are drawn from reflection and discussion of our findings and an understanding of the new and sometimes confusing organisational framework in which responsibility for a particularly vulnerable group could fall between the gaps.

1. Commissioners should ensure that service providers demonstrate compliance with the Equality Act and the Mental Capacity Act through regular audits to be shared with the local Health and Wellbeing Boards and Clinical Commissioning Groups (CCGs).

2. Each CCG should appoint a specialist learning disabilities clinical lead to advise and act as champion for the needs of people with learning disabilities, as well as maintain a link with the NHS England learning disability clinical lead.

3. Professional bodies responsible for education and training should introduce compulsory modules on learning disability for all health professionals including psychiatrists, GPs and psychotherapists in training posts. Practitioners should be required to gain experience in working with people with learning disabilities, regardless of their chosen speciality, with teaching being partly delivered by people with learning disabilities.

4. General practices should ensure they have identified all people with learning disabilities on their register and offer appropriate health checks (which include mental health) and health action plans through regular audits to be shared with the local Health and Wellbeing Boards and CCGs.

5. NHS England should audit the roll-out of inclusive national mental health programmes such as Improving Access to Psychological Therapies (IAPT), dementia screening and information prescriptions, checking that they are delivering inclusive services.

6. Service providers should implement the Michael inquiry recommendations in mental health trusts as well as in acute hospitals and primary care.

7. Directors of social services should require health and social care commissioners to ensure that all individuals receive personalised care and support in appropriate community settings as soon as possible. (The Winterbourne action plan stated that detailed personal plans for the return of all out of borough placements should be drawn up and presented to district and borough councils for approval by June 2014. Councils are to report to NHS England on progress by July.)

8. NHS England, working in conjunction with local commissioners, should prepare detailed plans setting out how specialist learning disability services are to provide prompt and effective liaison and facilitation services, with special emphasis on delivering communication support and identifying appropriate adjustments, to support people with learning disabilities or autism to fully access a service.

9. The Care Quality Commission (CQC) should require the chief inspectors of hospitals, of primary care and of social services to include questions about reasonable adjustments and barriers to the provision of inclusive services in all of their inspections (on the basis that people with learning disabilities should have access to all services, not just specialist services).

Background

Aims of this report

The Foundation for People with Learning Disabilities (the Foundation) was commissioned to write a report about the mental health of people with learning disabilities as well as offer information to people with learning disabilities and their families to support their access to mental health services.

The aim of the report is to raise awareness among policy makers, commissioners, health and social care services and anyone supporting or working with people with learning disabilities, and to develop a picture of the customer journey to receiving support and make recommendations for change.

How this report is organised

The report is organised in three parts:

1. The context of the mental health needs of people with learning disabilities, with a supporting literature review.

2. Findings from a survey, interviews and focus groups, reflecting the views of people with learning disabilities, their families and friends, and professionals.

3. Some recommendations for improving the mental health of people with learning disabilities.

This report does not set out to specify which types of services are most appropriate but to draw attention to the fact that access to mental health services, assessment and treatment for this group of people needs to be improved. Neither is it an in-depth study; rather it provides a snapshot of some people's experiences of current mental health services and their perspectives regarding what would help them to improve their wellbeing. It includes a number of case studies based on real-life experiences and some general conclusions and recommendations.

Context

'Health is a state of complete physical, mental and social wellbeing and not merely the absence of disease and infirmity.' (WHO)

It has long been recognised that there are inequalities in the way people with learning disabilities are supported by health and social services.

Valuing People in 2001 emphasised the need to consider how we support people to lead a good life with the same rights and choices afforded to other citizens. Both specialist and mainstream services need to provide person-centred support which is of a high standard.

There have been many initiatives working to reduce stigma in mental health, yet people with learning disabilities and their families still have great difficulty in accessing mental health services compared with other groups in society and still have to ask to be taken seriously. They have to explain that their mental health is unrelated to their learning disability and just like the general population, they are at risk of experiencing mental health problems. There have also been many calls for mainstream mental health services to be improved and be more inclusive, particularly for people with a learning disability.

Many people with learning disabilities can and do achieve a full and rewarding life, experiencing physical, mental and social wellbeing. However, there is evidence to suggest that there are still many barriers to them gaining the necessary support to lead a healthy life, especially when they have a dual diagnosis such as a learning disability and a mental health problem.

Prevalence of mental health problems

It is recognised that people with learning disabilities can develop poor mental health in the same way as any other person in the wider population, and there is some evidence that the prevalence is higher in this group (Cooper et al, 2007).

At least one in four people experiences a mental health problem at some point in their life (Singleton et al, 2001), yet studies using psychiatric evaluation in people with learning disabilities report prevalence rates of between 20.1% and 40.9% (Taylor et al, 2004; Cooper et al, 2007). A summary of research evidence, compiled by the Public Health Observatory for Learning Disability (October 2012) cites the following prevalence rates:

- 3% for schizophrenia (three times greater than for the general population), with higher rates for people of South Asian origin.
- The same as the general population for anxiety and depression (though higher in people with Down's syndrome).

For children and young people, Emerson and Hatton (2007) report a prevalence rate of 36% for a diagnosable psychiatric disorder, compared with 8% for those who do not have a learning disability. These young people were also 33 times more likely to be on the autistic spectrum and were much more likely than others to have emotional and conduct disorders.

Risk factors for mental health

People with learning disabilities have an increased risk of developing poor mental health, due to social, economic, psychological and emotional factors as well as some biomedical factors. Having a learning disability can often mean that the individual has fewer psychological and material resources to deal with adversity (Jahoda et al, 2006) and is more likely to experience social exclusion, poverty and abuse (Gravell, 2012). Risk-averse service cultures contribute to restrictive environments which mean fewer opportunities for these individuals to build a sense of self-efficacy and develop problem-solving skills (Dagnan and Jahoda, 2006), and a lack of meaningful activity can increase vulnerability for mental health difficulties such as depression (Stancliffe et al, 2011).

The Foundation in its UK-wide inquiry *Count Us In* (2002) found that young people often encounter discrimination in that they are not given opportunities: to get a job, move out of the family home, socialise, or have relationships. This may cause them to develop low expectations of themselves, in addition to being lonely, bullied and discriminated against. Evidence in a joint project by the Foundation and Lemos and Crane

(Gravell, 2012) shows that people with learning disabilities living independently in the community experience a disturbing range of harassment, abuse and related crime with alarming frequency. The loneliness of some people with learning disabilities – one in four people interviewed for the research said they didn't have any friends – is putting them at particular risk.

There are many barriers to the early identification and diagnosis of mental health issues in people with learning disabilities. The Count Us In inquiry (the Foundation, 2002) identified the following factors:

- Diagnostic overshadowing where presented symptoms are considered as challenging behaviours or part of the learning disability.

- Parents' and professionals' lack of knowledge about the range of mental health problems people experience, and about whom to go to for advice.

- Not being listened to.

- Referrals passed from service to service, particularly if the person has mild/moderate learning needs.

- Communication and language – it can be difficult to communicate or articulate the symptoms of mental health.

Challenging behaviour

A major barrier in recognising the symptoms of mental health in people with learning disabilities has been the readiness to label people as 'challenging'. The term 'challenging behaviour' was introduced with the intention of highlighting that many of the 'aggressive' problems people with learning disabilities experience are caused as much by the way in which they are supported as by their own characteristics (Emerson, 2007). Over the years, there has been a drift towards using it as a label for people. Mental health issues may become apparent because of a change in behaviour, especially if the person has not shown this type of behaviour in the past and may struggle to express their distress using words. However, it is important to take into consideration that there could be physical causes for the behaviours, or that they are serving as a means to communicate a need or emotion.

James

James has a diagnosis of a severe learning disability and autistic spectrum disorder. He was 60 years old when his 85-year-old father, with whom he was living, died.

A decision was made by the care manager that James would be placed in a local residential care home as he was deemed to lack capacity to make this decision for himself. (This preceded the Mental Capacity Act).

James was taken to the home where he knew no one, on the day that his father passed away. There were no other family members in the area, and only two distant cousins who had no contact with him.

The care manager and the new staff did not allow James to attend the funeral as it was felt it would upset him and he might become aggressive. In his first week at the home, he refused to eat and drink and stayed in his room. When asked what the problem was he became aggressive, lashing out at staff and other residents who came near him. When staff tried to get him to do things, he would try and hit them and throw things at them. A locum psychiatrist was called to the home.

James was given psychotropic medication to calm him down. The calming effects of the medication enabled James to go to the day centre where he had been going up until his father died. At the day centre, his key worker, who had returned from holiday, found James in a poor state (listless, not talking, his appearance dishevelled) and was shocked. This was understandable as he had suffered a double bereavement: not only the loss of his father but also his home and all his familiar routines.

She contacted the social worker and insisted a meeting be held to look into James's situation. She also contacted the local GP who knew James and his father. They went to see the GP who assessed him to be severely depressed, with additional anxiety.

James was able to tell the support worker and the GP that he was scared and felt bad. A best interests meeting was held and an emergency care plan was developed. His medication was changed to an antidepressant and he was monitored carefully by his GP. He began receiving grief therapy and was allowed to go back home with support paid for by social and health services.

Physical health

People with learning disabilities have increased health needs compared with the wider population. Physical health and mental health have a direct impact on each another. Factors that can create risks for people with learning disabilities (Hardy et al, 2011) include:

- development of physical health problems due to self-neglect, for example, poor dental hygiene and poor health care

- overuse of medication and the absence of other interventions, such as psychological therapies

- less choice and fewer opportunities to express their views and opinions

- higher frequency of epilepsy than in the population as a whole.

People with learning disabilities die younger than other people (Heslop et al, 2013). The Independent Inquiry into Access to Healthcare for People with Learning Disabilities (Michael, 2008) followed the Mencap report Death by Indifference (2007). The report concluded that there are inherent risks in the care system that result in high levels of health needs not being met. The inquiry found that people with learning disabilities appear to receive less effective care and that there are many shortcomings in the way treatment is delivered, with avoidable suffering caused by untreated ill health.

Dr Dominic Slowie, in his work (2007) prior to becoming National Clinical Director for Learning Disability NHS England, found that annual health checks in primary care were beneficial particularly if they led to an action plan that specified the reasonable adjustments required for that individual. There is evidence that fewer than 50% of people with learning disabilities actually get a health check and many of the checks carried out did not include mental health. He recommends a standardised system for health checks to be routinely undertaken by GPs.

The NHS is undergoing major change and for this reason Dr Slowie recommends the introduction of safeguards that take into account the needs of people with learning disabilities. This is particularly important in view of the Winterbourne scandal. Commissioning for people with learning disabilities can be high cost but it is extremely important. His report recommends that a specialist clinical lead is appointed in each CCG to advise and advocate on behalf of people with learning disabilities. CCGs would therefore be able to establish which specialist and mainstream services need to be commissioned for people with learning disabilities.

Interventions

Positive behaviour support (PBS)

PBS is one of the preferred options when working with people with learning disabilities who exhibit behaviours described as challenging. It is a holistic approach that considers all the factors that impact on a person's behaviour, suggests strategies to deal with it and teaches new skills. It can be used to address problem behaviours that range from aggression, tantrums and destruction of property to social withdrawal.

The increase in support for this approach is due to its success in helping understand behaviour and finding alternative ways for the person to communicate. It is rooted in person-centred values, aiming to enhance community presence, increasing personal skills and competence and placing emphasis on respect for the individual being supported. (British Psychological Society, 2004; Royal College of Psychiatrists, British Psychological Association and Royal College of Speech and Language Therapists, 2007).

The Department of Health review: Winterbourne View Hospital, Interim Report (2012) stressed the importance of staff training in positive behaviour approaches.

Cognitive behaviour therapy (CBT)

CBT is increasingly being used with people with a learning disability (Hassiotis et al, 2012). Brown and Marshall (2006) describe how learning disability nurses are in a good position to provide this, but report that there is a lack of leadership regarding how it should be adapted to influence clinicians' practice. Dagnan and Jahoda (2006) state that although CBT is beginning to be used with people with learning disabilities, clinicians need to extend their skills in this area. They have used CBT with people with social phobia with success, prompting calls for more work to be done with different types of anxiety. The IAPT programme has been established to ensure that evidence-based psychological therapies (primarily CBT) are available to anyone experiencing common mental health problems. In 2009, the Department of Health published advice on making the IAPT programme accessible to people with learning disabilities. The IAPT taskforce identified some of the barriers people with learning disabilities face in accessing this service and has produced good practice guidance regarding how IAPT services can make 'reasonable adjustments' in line with their equalities responsibilities for this group of people.

Research carried out by the Foundation in partnership with Kings College to be published in 2014, suggests that IAPT services have a long way to go to offering adequate support to people with learning disabilities. Some of the problems arise when GPs and other primary care professionals fail to recognise symptoms of depression or anxiety, or to accept that people with learning disabilities can be treated with psychological therapies. Furthermore, some specialist mental health services lack confidence in working with people with learning disabilities and this may prevent them from referring them to psychological therapies services. The Do Once and Share care pathway (Department of Health, 2007) for children and adolescents with learning disabilities who have mental health problems advises practitioners to consider the full range of interventions that they would normally apply, with adaptations according to the communication needs and cognitive development of the young person.

Psychotherapy and counselling

There is growing evidence of the effectiveness of psychotherapy and counselling for people with learning disabilities (Hollins, 2003). In a retrospective case notes review of anonymised data relating to 100 sequential patient episodes, Parkes et al (2007) found that a total of 81 people out of 100 with a range of intellectual disabilities from mild to severe were assessed as suitable for therapy; 66 were eligible for individual, art or group therapy.

Common reasons for referral were: trauma/abuse, bereavement, depression and challenging behaviour. Many people had more than one cause for referral and/or co-morbid psychiatric diagnoses. Indicators of success included: increased daily living skills, improved confidence, self-esteem and behaviour, and finding employment. This study confirms findings from other studies that psychotherapy is possible in people with mild to severe intellectual disability with clinically recorded outcomes ranging from reductions in problem behaviours to getting a job.

The effectiveness of counselling for grief and bereavement has been extensively researched and reported. It is important that all people, including those with learning disabilities, are able to access support to understand death and loss. Bereavement counselling for people with intellectual disabilities should be made available as well as individual and group work with bereaved individuals as this may be helpful, particularly if nonverbal approaches, such as the use of counselling picture books, are available. (Hollins, 2004).

Access to services and support

Until fairly recently, services for children with mental health problems and services for children with learning disabilities have been developed independently of each other. This segregation has led to a lack of professionals who are experienced and confident enough to work with children who have both a learning disability and a mental health problem. The Treasury made the area a priority Public Service Agreement Target in 2005 and has attracted funding to explore ways of addressing this. In addition, the Disability Discrimination Act 1995 has been amended to place a duty on all public sector authorities to promote disability equality. Similarly, until recently there was reluctance from mainstream services to provide mental health support for adults with learning disabilities.

The quality of practice for mental health care in general needs to be improved for people with learning disabilities. The challenge for the NHS is to know how well they are doing. The CQC along with Health Quality Checkers would go some way to bringing a different perspective as to what is acceptable care. The Green Light Tool Kit (Turner and Bates, 2013) gives services the opportunity to review their own quality and share and replicate good practice. The Reasonably Adjusted Report (Turner, 2012) described the reasonable adjustments that mental health services were already putting in place for people with learning disabilities and people with autism. The sharing of good practice and reasonable adjustments will offer ideas of positive practice that others can replicate.

Hall et al (2006) demonstrated that a local service called the Mental Health Service for People with Learning Disabilities (MHSPLD) can be effective in supporting and treating this group. It is a service development in keeping with UK government policy that promotes cross-agency working and access to mainstream mental health services for people with intellectual disabilities. Community and inpatient groups were compared across three time points using a range of clinical outcome measures that assessed psychiatric symptoms, risk, needs and level of functioning. Inpatients and community groups had similar mental health problems, but inpatients had higher unmet needs and lower functioning, and were at greater risk. There were significant improvements across the range of outcome measures in both groups.

Hall et al (2006) conclude that working with mainstream mental health services and across health and social service boundaries delivers effective mental health care for people with intellectual

disabilities. Hemmings (2008) describes a continuing lack of evidence regarding community treatment services for this service user group. Few studies have been published, while even fewer have reported outcomes in any detail.

Hemmings (2008) states that an evidence base is urgently needed for these community-based services. Research should utilise the opinions of service users and their carers as well as professionals and focus on those people with intellectual disabilities and more severe mental health problems. It may be more fruitful to examine the components of community-based services rather than use the terminology of specific models such as assertive community treatment.

The No Health without Mental Health strategy (Department of Health, 2011) set out a vision for improving mental health and wellbeing in England and outlines how emphasis on early intervention and prevention will help tackle the underlying causes of mental ill health. It stipulates how the government will work with the NHS, local government and the third sector to help people recover and challenge stigma.

The strategy made several references to people with learning disabilities. In particular it highlighted the importance of ensuring mainstream mental health services were inclusive of people with learning disabilities and autism and that staff in these services had appropriate skills and could provide reasonable adjustments to meet their individual needs.

The strategy also mentioned the need for early intervention to prevent later problems for children with special educational needs and disabilities, including those who have underlying or associated mental health problems.

Liam

Liam is in his forties and lives in an urban area. He has a learning disability and experiences anxiety on a regular basis, and has done so for the past 15 years. He demonstrates his anxiety through shaking and pacing up and down. At these times he also loses his appetite, has trouble sleeping and scratches himself, which can lead to bleeding. Below are examples Liam gives of situations that give rise to his anxiety:

'Like if I work from 4 to 6pm I get anxious. When it comes to 6pm it gets crowded on the train.'

'Staff coming in late and not letting me know.'

'Lifts and escalators get me worried.'

When he first sought help for his anxiety Liam saw a psychologist who developed a care plan for him to follow. The sessions included developing problem-solving skills to help him to manage his own anxiety.

Liam found this help useful. For his anxiety he also takes medication and this is reviewed every six months. At home when he experiences episodes of anxiety he talks to staff that are on duty. Currently Liam sees a counsellor on a regular basis and has developed a number of self-help strategies which include using a stress ball and practising deep breathing. He also attends a group to talk about mental health, and yoga and pottery classes.

Liam put these skills together to manage a situation when he felt anxious and stressed in an underground station. To calm himself down he let five or six trains go by, and used his stress ball and deep breathing exercises while his support worker talked about different topics to distract him.

Liam is not currently receiving mental health services. This is due in part to the strategies he has developed that have helped him to have more control when he is anxious.

Methodology and results

We established a reference group of people with learning disabilities who also experienced mental ill health. The group helped us to keep focused on the issues surrounding barriers, what worked well and what was needed to support people's mental health and wellbeing. A literature search was carried out into the mental health needs of people with learning disabilities, both children and adults, in order to inform our work and identify resources that may be useful to individuals, families and staff alike.

A national survey was conducted to gather qualitative and quantitative information on the current experiences of people with learning disabilities, their families, friends and staff when accessing support for their mental wellbeing. This included an easy read survey for people with learning disabilities. We used Survey Monkey, an online resource, which was sent out via three online forums, including a provider's forum, along with the easy read questionnaire.

The questions were designed with the reference group. We selected people with learning disabilities for interview from our existing networks. All other interviews were self-identified via the questionnaire. The interviews with people with learning disabilities were face to face and lasted as long as the person required. The interviews with families were primarily over the telephone and lasted not more than 45 minutes.

Case studies from these interviews were written to provide a vignette of people's experiences.

Findings from the survey

Key messages

People with learning disabilities should have the same rights and choices as everyone else.

People with learning disabilities said that:

- people did not see them – they just saw their learning disability

- the information that was provided was not accessible and in a format that they could understand

- they were not believed, listened to or supported when they felt down

- they wanted to have more control around their mental health

- a diary and information to explain what was happening to them would make it easier to talk to staff and tell the GP how they were feeling.

Family members and friends said that:

- access to support, getting the GP to believe them or refer them to a specialist, was the biggest barrier to their son/daughter's mental health and was extremely hard

- that the long wait was detrimental to their son/daughter's wellbeing

- psychological support was valuable once received.

Professionals said that:

- not enough was being done to support the mental health needs of people with learning disabilities

- support from GPs was crucial in accessing mental health support but difficult to obtain

- mental health services needed to improve and make reasonable adjustments to ensure access

- support during treatment and aftercare was crucial in supporting the mental health needs of people with learning disabilities

- there was a need for better and more joint work between mental health services.

'Sometimes I feel anxious and get angry. I don't know what to do.'

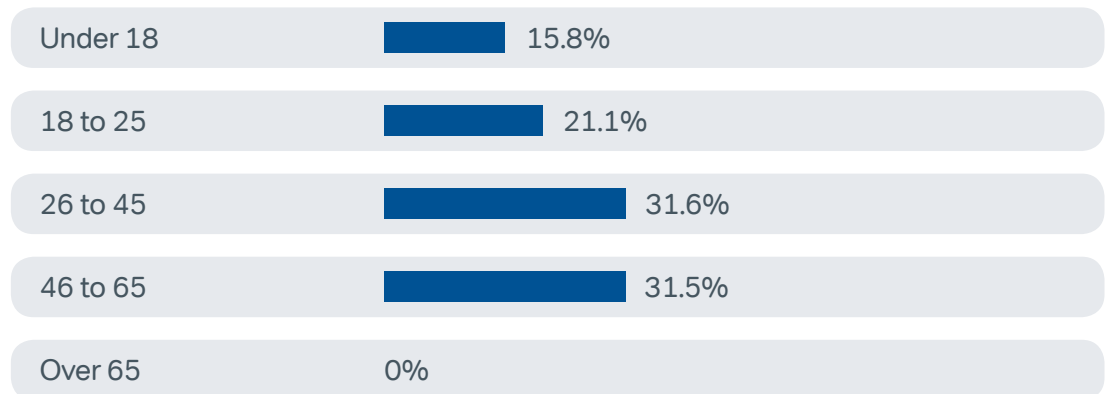**'I am upset because staff say forget it when I tell them I am sad.'**

Who took part?

There were a total of 197 responses to the survey, 23 of which were from people with learning disabilities who responded to the easy read questionnaire.

A total of 25 people were interviewed: 10 people with learning disabilities, 10 families and 5 professionals.
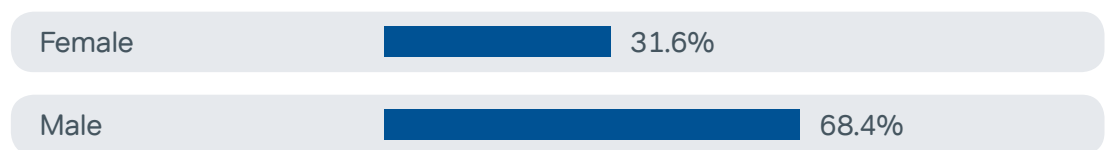
The majority of the people with learning disabilities who responded to the easy read questionnaire were aged between 16 and 25.

The graph below shows the age, gender and ethnicity of the person as indicated by family members and friends who completed the survey:
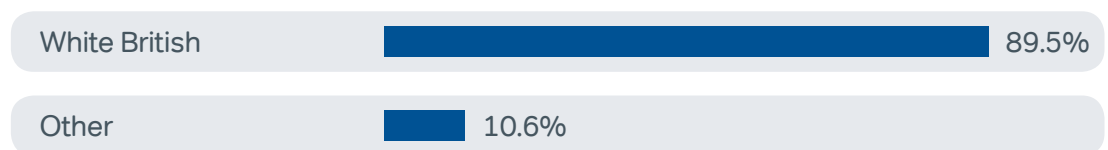
Age:

Under 18	15.8%
18 to 25	21.1%
26 to 45	31.6%
46 to 65	31.5%
Over 65	0%

Gender:

Female	31.6%
Male	68.4%

Ethnic origin:

White British	89.5%
Other	10.6%

The survey and interviews focused on the perceptions and experiences of people with learning disabilities, their families, friends and professionals. There were some interesting differences of opinion between respondents in the main areas targeted by the survey, which were:

A. Referral processes and pathways of support.

B. Quality of service, including treatment and aftercare.

C. Reasonable adjustments.

A. Referrals and pathways of support

The most common point of referral to mental health services is through the community learning disability team/specialist team (respondents; n=35). — **78%**

69% of families (n=34) went to their GP for support; however, the smallest number of referrals had come from GPs (7.1%) (n=34). — **69%** / **7.1%**
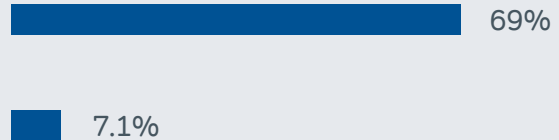
> **'There is still a barrier as most doctors are too judgemental and often don't get to know enough about a person. They only see the learning disability.'**

Percentage of the sample (n=62) who agreed that the referral processes to mental health services were not working well. — **72%**

Families (n=25) that reported they were either referred to the mainstream adult mental health team or prescribed medication. — **80%**
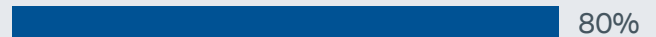
Families (n=25) who found that it took up to six months to see a specialist once referred. — **47.4%**

People (n=25) who reported that no other support was offered while they were on the waiting list. — **85%**

At interview, families felt that the long wait was detrimental to their son/daughter's wellbeing. However, once they reached specialist support they felt that this was of a very high quality.

Health professionals (n=62) who reported that people with learning disabilities presenting with mental health issues are not taken seriously and treated in a timely manner. — **78%**

'There is no agreed commissioning arrangement which clearly signposts people into the most appropriate mental health'.

'There appears to be reluctance for mental health services to get involved with people with learning disabilities and it is difficult to access services if you have learning disabilities.'

'Often people's IQ is used to say which service they should access. I feel it should be based upon which service is most skilled.'

Families (n=25) who reported that they were not offered any support whilst waiting. **85%**

Families (n=62) who reported that people with learning disabilities did not know or could not easily access mental health services. **61%**

Families (n=35) who reported that their experience of accessing mental health services was difficult. **63%**

Professionals described the most common reasons for referral as challenging behaviour, anxiety and depression. However, these were not the only reasons, and people also presented with more than one problem.

What are the most common things that people with learning disabilities are presenting with when they see you or are referred to you?

Underlying physical health problems (11) 31.4%

Physical pain (3) 8.6%

Sleep deprivation (7) 20%

Behaviour that put them at personal risk (25) 71.4%

Depression (23) 65.7%

Anxiety (26) 74.3%

Loneliness (12) 34.3%

Anger management (18) 51.5%

Challenging behaviour (27) 71.1%

A change in mood or behaviour (21) 60%

Grief (12) 34.3%

(N=62)

B. Quality of service

Families were asked whether the service provided to their family member made a positive difference to their mental health.

85% of families (n=20) felt that once they reached a mental health professional they were satisfied with the quality of support. This was also the case within interviews.

85%

'My son is now able to be himself. He is such a gentleman and all it took was for the psychologist to work with him and develop a support plan.'

'Once we got a specialist we felt supported and understood.'

Families felt that access was the biggest barrier to their son/daughter's mental health. Also getting the GP to believe them or refer them to a specialist.

Treatment and aftercare

77% of respondents, which included families and professionals (n=62), felt that the treatment offered to people with learning disabilities was not sufficient to meet their mental health needs.
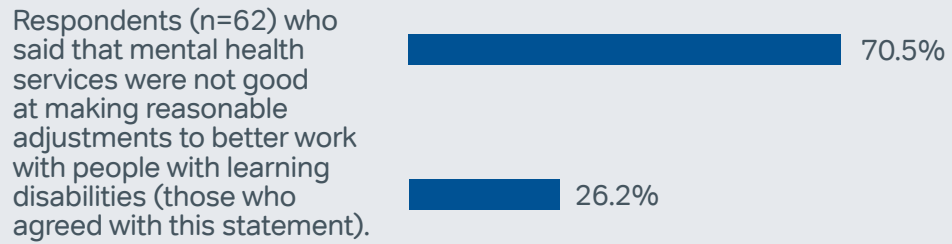
77%

85% (n=62) felt that treatment and services did not last long enough to ensure positive changes were made.

85%

86% (n=62) felt there was no good aftercare or support when they left mental health services.
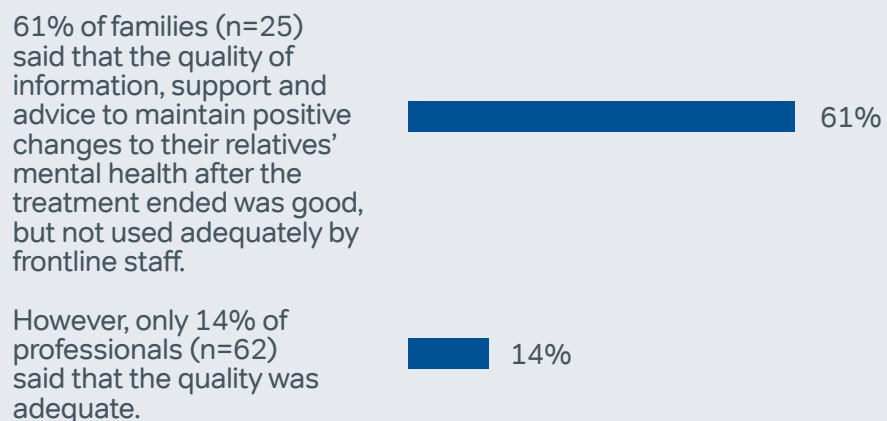
86%

C. Reasonable adjustments

Respondents (n=62) who said that mental health services were not good at making reasonable adjustments to better work with people with learning disabilities (those who agreed with this statement).

70.5%

26.2%

'We really struggle to support our service users into mental health services and we work in the same NHS trust.

Those (n=62) who felt that the information offered was not accessible to people with learning disabilities.

67%

Respondents (n=62) who reported that joint working between community/specialist teams and mental health services was not effective.

87.9%

Those (n=62) who reported that talking therapies were not readily available and designed in a way that was effective for working with people with learning disabilities.

88.3%

Differences of opinion between families and professionals

There were some differences of opinion between families and professionals on a number of issues:

61% of families (n=25) said that the quality of information, support and advice to maintain positive changes to their relatives' mental health after the treatment ended was good, but not used adequately by frontline staff.

61%

However, only 14% of professionals (n=62) said that the quality was adequate.

14%

63% of families (n=62) agreed that the treatments offered were of sufficient length and depth to support their family members.

63%

However, only 15% of professionals (n=62) agreed with this statement and felt that greater training for practitioners was needed to enable understanding of the mental health needs of people with learning disabilities.

15%

75% of families (n=21) agreed that the people who treated their family member offered them, as a family, information and advice about how to best support their family member.

75%

While only 15% of professionals (n=62) thought that information offered and aftercare were adequate.

15%

Differences of opinion between people with learning disabilities and their families

We also found some interesting differences of opinion between people with learning disabilities and their families:

Families (n=21) who responded that the people who treated their family member treated them with respect as a person, not just someone with a learning disability or mental health issue.

90%
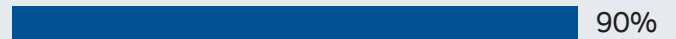
However, all respondents with learning disabilities (n=23) felt they were not respected or listened to. They felt angry that people just told them to go away and forget it. They did not feel that their mental health needs were taken seriously.
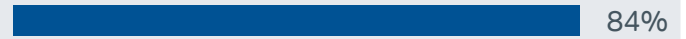
100%
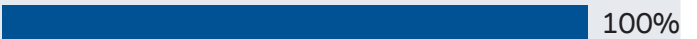
'We need to give more training to practitioners about learning disabilities to enable better understanding.'

'Information should be more easy read – in basic language/pictures.'

84% of families (n=21) agreed that the people who treated their family member had knowledge and understanding about learning disability issues.

84%

However, 95% of people with learning disabilities (n=23) felt strongly that those that treated them did not understand them and were not good at supporting them.

95%

Families (n=35) who said that the information that was provided to their family member was accessible and in a format that they could understand.

80%

However, all people with learning disabilities (n=23) said that nothing was written for them in easy read. They would have liked to have had a family member or friend with them to help them to understand things. They felt that the information and advice was not accessible to them or person-centred.

100%
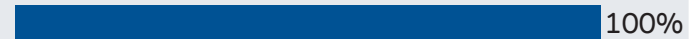
Ethnicity

The majority of respondents to the questionnaire were white British, with only 10.6% from a different ethnic group (n=19).

10.6%

88% of families (n=21) agreed that the people who treated their family member offered help in a way that respected their ethnic background and religious beliefs.

88%

'Mental health services should adopt inclusive policies to ensure patients have equal access to services not made on an ad hoc case by case basis.'

'Need more joint work between mental health teams and services.'

'Green Light working in practice. Ensure that services are commissioned to work jointly (learning disabilities and adult mental health) and supported by data quality feedback.'

Peter

Peter is in his forties and now lives in his own home and gets daily outreach support. He is an only child and lived with his mum and dad until they died. Then he and his wife moved into a group home where he received 24-hour support. Peter has experienced depression and anxiety since childhood and says his mum was very good at helping him to calm down.

'I spoke to my mum and always felt better; she helped me to do breathing and relaxation.'

His anxiety increased when his parents died. When he moved into a group home he initially felt extremely anxious and depressed. His symptoms were shortness of breath, sweating, pacing up and down, inability to sit still, being fidgety, dizzy, tearful and emotional. Peter sometimes found coping with his anxiety and depression within supported living more difficult. Examples he gave included:

'The staff were not good at supporting me, there were many rules and it did not feel like home however much they said this is your home.'

'Staff would say calm down but it didn't help.'

Just over a year ago Peter's wife died. At first he was prescribed diazepam (Valium), which is often prescribed for a couple of weeks after a bereavement. This made him feel sleepy and tired. Peter does not remember being told anything about the medication or having the side effects explained – he was just asked to take it.

Shortly after this Peter moved to an independent flat supported by outreach staff. Peter takes different medication now that he says helps him to calm down. He also finds counselling helpful, so much so that he continues to this day to pay for it himself.

'When I am anxious I need to tell someone what the problem is.'

'Feeling anxious makes you concentrate [on what's worrying you], you block out everything else. You can't think of anything else, only about the thing that worries you. It is too much for your mind.'

Elsa

Elsa is the mother of 53-year-old Dee who has had a history of depression since 1998. Dee lives in a supported living flat in a block with other tenants who have a learning disability. Support is available around the clock. Her mother lives a mile away. Dee does a number of day activities, has a long-term boyfriend and a circle of support.

In 1998 Dee experienced her first episode of depression. It was hard during this time to identify that she was experiencing depression because she complained of stomach problems rather than of feeling low. After her mother realised something was wrong she went to the local Mencap and asked what she should do. The Mencap family support worker referred Dee to a care manager who saw her quickly and referred her to the learning disabilities psychiatrist. She was diagnosed with depression and given antidepressants.

Over the years Dee has managed her depression through medication and support from psychiatrists and psychologists. There have been times when she has responded well to the medication and times when her depression has got worse. At one time she was admitted to a specialist assessment and treatment unit because of her suicidal thoughts.

This was helpful and after a short period of therapy she was discharged to her own flat. She currently has a good support group around her who know her well and how to help her when she is depressed.

Elsa's advice to others

Monitor in a diary or calendar your son/daughter's mood swings. Look out for the behaviours or symptoms they display when they are depressed or anxious. In Dee's case she complains of a bad stomach and bad head. She cannot say she is feeling low, so it is important to record these symptoms.

Elsa found the picture book 'Sonya's feeling sad' (Hollins, Banks and Webb, 2011) and other similar books from **'Books Beyond Words'** very helpful as they helped with Dee's perception of her mental health problems. She recommends these books as they use pictures to communicate and make it possible to convey difficult subjects.

Discussion

It appears from our literature search and the survey findings that significant improvements are needed to support the wellbeing of people with learning disabilities. Research, policy and guidance, however good relating to mental health and learning disability, still need to effect change and develop good practice. Despite the evidence on prevalence, it appears that little is being done to promote mental health to people with learning disabilities, their families and frontline staff. Early signs of common mental health problems are not readily spotted and are sometimes described as challenging behaviour. Very few people with learning disabilities known to services appear to get an annual health check in primary care and there is little evidence as to whether mental health issues are considered if a check is carried out. A system to ensure these are undertaken and supported is needed as is a champion within each CCG for people with learning disabilities. This would enable CCGs to consider the commissioning of both specialist and mainstream services for people with learning disabilities.

Mainstream mental health services need to be inclusive for people with learning disabilities. They need to develop appropriate skills and to know how to make adjustments to meet people's individual requirements. Improvement in the development of diagnostic services and pathways to care and support alone will not create the necessary changes to good practice. Greater awareness must be promoted among health and social care professionals on the issues relating to presentation and diagnosis, and a requirement for adjustments in meeting individual needs must be established.

We found in the literature review that people with learning disabilities experience high levels of mental health problems. Prevalence of anxiety and depression in people with learning disabilities is at least the same as in the general population. This suggests a real need for people with learning disabilities to be able to access mental health services. However, there is a long-held belief among medical professionals that people with learning disabilities will not benefit from accessing psychological (or talking) therapies. Some services use criteria preventing anyone with an IQ lower than 70 from accessing these services as they are deemed unable to use them effectively.

Furthermore, the literature and our study reveal that people with learning disabilities often feel that they are not listened to when they complain of feeling unhappy or experiencing mental health issues. Their symptoms are assumed to be part of their learning disability and ignored. Our research shows that it is still a challenge for the NHS to know how well they are doing in meeting the mental health needs of people with learning disabilities. Reasonable adjustments are still not widely evident.

The quality of practice for mental health services, both specialist and mainstream, needs to be improved. It is evident in many of the interviews and case studies in this report that lack of recognition of the impact of grief on people with learning disabilities has led to expensive interventions. These can be avoided if support is planned whenever a person with learning disabilities experiences loss. This is not to suggest that an intervention from specialist support is always needed but it should be made available if support from family, friends or care workers is not enough.

People with learning disabilities and their families have made it clear in the interviews and survey that it is hard to access mental health support and services. They report that they are

unfamiliar with how mental health services are delivered and find it difficult to navigate them. People with learning disabilities are therefore less likely to seek help for mental health problems, and when they do, their symptoms are often attributed to their learning disability (diagnostic overshadowing) or classed as challenging behaviour. The mental health needs of people with mild to moderate learning disability frequently go unmet, due to the fact that their symptoms are not recognised, understood or supported by frontline staff. Making access and information easier to read, in plain English, would make it easier for everyone in the wider public to access services too.

In addition, people often tell us that they get a poor deal from services. There are often disagreements about whether they should be treated by mental health services or by specialist learning disability mental health services. People with mild learning disabilities are at particular risk of falling between the two stools, with both services often denying that they meet eligibility criteria.

Both people with learning disabilities and their families expressed a need for support with visiting the GP. They felt that GPs were the first port of call and yet the biggest obstacle to gaining a referral to a mental health professional.

There were some discrepancies in opinion between families and people with learning disabilities in the survey around the quality of support. We explored this issue with them and found that it may be due to the difference in the way they experience their journey to gaining support. Families describe it as a battle and feel relief and gratitude once they get support. This could explain why they describe services as good, once they get them. People with learning disabilities, on the other hand, experience their journey as being ignored and not believed, and say that once support is offered it is not followed through by support staff where they live. Hence the support is not immediately evident.

Members of the reference group discussed their journeys to gain support with their mental health.

'I can manage my anxiety by controlling my breathing; I don't have to get angry.'

'My counsellor lets me cry when I want to and talk when I want to. She listens and helps me to think things through.'

'The psychologist was great. He helped with developing ground rules of how to support our son. People needed to follow these to make sure of his wellbeing.'

'I sometimes need space to get rid of the cloud that is over my head.'

People with learning disabilities said that having a diary and information that would help them explain what was happening to them would make it easier to talk to staff and tell the GP how they were feeling. They said they needed help to be taken seriously by their staff who were there to support them. They wanted them to understand that some feelings do not just 'go away' and that for some things they are not the right people to support them.

Professionals felt that there was a great need for improvement in mental health services; 85% felt that access, treatment, information and aftercare were not adequate to meet the needs of people with learning disabilities. They reported that reasonable adjustment was not readily made and there was a need for improvement in all aspects of the pathway to gaining mental health support, both specialist and mainstream. Access does not end when a session finishes. Aftercare and homework, with support to remember the skills that are taught by support staff, are needed. Outreach to where people live is crucial if we are to ensure that people are supported positively with their mental health. There are many reasonable adjustments that need to be made, including consideration of the length of the sessions and the number offered. Commissioners need to be aware of the requirement for frontline support staff to follow advice, support plans and treatment and ensure that this happens.

'People need help with their therapy, once they get it. They need help with homework between sessions. The counsellor/therapist should give written information, individualised as the person may forget.'

'Due to the high incidence of mental health difficulties in people with learning disabilities, professionals should routinely screen for these needs emerging so that preventative/early intervention measures can be put in place. This should be by those who are qualified to do so and in the most regular contact with the person.'

'There is a need for awareness in universal services about mental health, its impact on people with a learning disability and how to recognise presenting symptoms.'

'We need to remember and raise awareness that we are treating mental health issues, not learning disability.'

'It is crucial to raise awareness for ALL those with moderate and severe learning disabilities as well as people who are described as challenging.'

'Staff need to be skilled in communicating and adapting their practice to meeting the needs of a person with a learning disability.'

Roy

Roy's parents went to their GP as they felt that he was not the same as their other children. They found that the GP knew nothing about learning disabilities and offered them little support or advice. Over the years Roy's behaviour deteriorated and he became violent and what people called 'challenging'. He was moved from home to home as services did not seem to be able to help him.

'We kept asking for mental health support for him from the beginning and got nowhere.'

'The homes were all private and only seemed interested in the money. They were paid to have a one-to-one for my son but they were not visible. Where were they when he got into trouble or got anxious and angry?'

They described support staff as having no training, poor wages and poor English. There was no information on how to recognise the symptoms of mental health, or how to get support for it. It took ten years of pushing and shouting from Roy's parents for him to eventually see a psychologist.

'He was brilliant. He gave good advice and developed a support plan for Roy. However, this was ignored and he was kicked out of his home. None of the staff were aware of the psychologist's guidelines on how to work with our son.'

'He was moved ten times because they could not manage his behaviour. The information was there, it had all the ground rules for good support. All they needed to do was to follow them.'

Roy moved into his current home where staff listened to the family and used the information from the psychologist and the support plan offered by his father.

'They listened to the psychologist who has been amazing. I can now die happy.'

Recommendations

The following recommendations are drawn from reflection and discussion of our findings and an understanding of the new and sometimes confusing organisational framework in which responsibility for a particularly vulnerable group could fall between the gaps.

1. Commissioners should ensure that service providers demonstrate compliance with the Equality Act and the Mental Capacity Act through regular audits to be shared with the local Health and Wellbeing Boards and CCGs.

2. Each CCG should appoint a specialist learning disabilities clinical lead to advise and act as champion for the needs of people with learning disabilities, as well as maintain a link with the NHS England learning disability clinical lead.

3. Professional bodies responsible for education and training should introduce compulsory modules on learning disability for all health professionals including psychiatrists, GPs and psychotherapists in training posts. Practitioners should be required to gain experience in working with people with learning disabilities, regardless of their chosen speciality, with teaching being partly delivered by people with learning disabilities.

4. General practices should ensure they have identified all people with learning disabilities on their register and offer appropriate health checks (which include mental health) and health action plans through regular audits to be shared with the local Health and Wellbeing Boards and CCGs.

5. NHS England should audit the roll-out of inclusive national mental health programmes such as IAPT, dementia screening and information prescriptions, checking that they are delivering inclusive services.

6. Service providers should implement the Michael inquiry recommendations in mental health trusts as well as in acute hospitals and primary care.

7. Directors of social services should require health and social care commissioners to ensure that all individuals receive personalised care and support in appropriate community settings as soon as possible. (The Winterbourne action plan stated that detailed personal plans for the return of all out of borough placements should be drawn up and presented to district and borough councils for approval by June 2014. Councils are to report to NHS England on progress by July.)

8. NHS England, working in conjunction with local commissioners, should prepare detailed plans setting out how specialist learning disability services are to provide prompt and effective liaison and facilitation services, with special emphasis on delivering communication support and identifying appropriate adjustments, to support people with learning disabilities or autism to fully access a service.

9. The CQC should require the chief inspectors of hospitals, of primary care and of social services to include questions about reasonable adjustments and barriers to the provision of inclusive services in all of their inspections (on the basis that people with learning disabilities should have access to all services, not just specialist services).

Developing guidance

As a result of this research the reference group recommended the development of materials that would support people with learning disabilities and families in accessing mental health services. These were developed because there is more to access for people with learning disabilities than just getting professional support with their mental health. There is a need for awareness to recognise the symptoms and plan the support required for them to maintain wellbeing after they receive support.

A guide for people with learning disabilities

The guide for people with learning disabilities was developed because most people interviewed and all the members of the reference group felt that it was important for them to have control over their lives. The consensus was that materials were needed to help them understand about mental health and wellbeing, but most importantly, so they had something that would help them with their visits to their family GP. This guide is to be launched at the same time as this report and covers:

- What is mental health?

- Looking after your mental wellbeing

- What to do if you need help with your mental health

- A diary for visiting your GP

These resources are available from the Foundation for People with Learning Disabilities website: www.learningdisabilities.org.uk/mentalhealth

A guide for families

Families were clear about what information they would need in order to best support their relative. They also wanted to be able to initiate timely support that would ensure their relative's wellbeing instead of having to resort to crisis management.

The guide for families will be written in partnership with the Challenging Behaviour Foundation and the Royal College of Psychiatrists, bringing together materials already available and learning from the new research. It will include useful resources and organisations that may be able to help.

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