

Themed Review

# Better health and care for all

Health and care services for people with learning disabilities





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## Foreword

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The last thirty years has seen big changes in health and social care to support people with learning disabilities. This includes a move from long-stay hospitals to supporting more people to live well in the community. But it is not easy – and we still have a long way to go if this is to be a reality for everyone with learning disabilities across the country.

We know that people with learning disabilities still experience poorer health outcomes and are more disadvantaged than others. This is why we have made reducing health inequalities and improving quality of care for people with learning disabilities one of the top priorities in the NHS Long Term Plan. This means not just the development of specialist services, but also reasonable adjustments embedded across the wider NHS to facilitate access to care, digital flagging to ensure people with learning disabilities are more visible particularly when evaluating and planning for services. This includes a commitment to understanding best practice and increasing the uptake of Annual Health Checks. The research in this review confirms that annual checks by a GP can make a real difference in identifying health problems and getting the right treatment. This leads to better outcomes and fewer emergency hospital admissions. This is just one of the areas where NIHR research can help decision-makers.

I am delighted to support this first collection of NIHR research on health and care services for people with learning disabilities. It includes research on mainstream and specialist services for people with learning disabilities, as well as large real-world trials of interventions in community and residential settings to support people and reduce behaviour that challenges. I am particularly pleased to see the ways in which people with learning disability have helped to shape this research. Evidence can give us insights into the services and support needed for every individual to have the best chance of living a full and happy life. It also shows us areas where more research is needed to shape services of the future.

”

**Dr Jean O'Hara**  
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**Former National Clinical Director for Learning Disabilities, NHS England**

## Abbreviations used in this review

**CAMHS** - Child and Adolescent Mental Health Services

**CBT** - Cognitive Behaviour Therapy

**CIPOLD** - Confidential Inquiry into premature deaths of people with learning disabilities

**CQC** - Care Quality Commission

**GP** - General Practitioner

**IAPT** - Improving Access to Psychological Therapies

**IQ** - Intelligence Quotient

**LD-DES** - Learning Disability-Directly Enhanced Service

**NICE** - The National Institute for Health and Care Excellence

**NIHR** - National Institute for Health Research

**NHSE** - National Health Service England

**QOF** - Quality and Outcomes Framework

**PBS** - Positive Behaviour Support

**RCT** - Randomised controlled trial

## Executive summary

This review brings together NIHR-funded research for and about health and social care services for people with learning disabilities. Work is needed to improve care for these people, who experience poorer health and die earlier than the general population. Many of these deaths could be prevented by public health interventions or better access to high quality care. This review features 23 recent studies with important findings for those who commission, deliver, work in and use these services. These range from qualitative research on user experience to randomised trials of complex new services. Many of these studies involved people with learning disability and family carers in the research and in delivering some of the interventions.

### Identifying health risks

People with learning disabilities are more likely than other people of the same age to be admitted to hospital as emergencies. NIHR research shows that the rate is five times higher than in the general population for conditions such as respiratory or urinary infections, which could be avoided by better primary care. There is good evidence that annual health checks by GPs introduced in 2008 can improve health and health care of people with learning disabilities. NIHR studies show health checks result in better identification of health risks like diabetes and heart disease, and hearing and vision problems as well as specific issues, such as thyroid and gastrointestinal disorders. Use of emergency hospital services also tends to be lower, particularly for preventable conditions. We know annual health checks work, but only just over half of

people with learning disabilities get them. Increasing uptake is now a priority in policy and for services.

### Keeping well and safe in the community

We know that people with learning disability experience poorer physical and mental health than the general population. One reason may be general services not making adjustments to improve access to services. This may be more marked for those from minority ethnic or disadvantaged groups. NIHR studies have developed and tested a number of treatments and services which have been specially tailored for people with learning disability. These include early studies to adapt weight loss interventions, and programmes to prevent and to manage diabetes. These were all welcomed and practical, but too small to show how effective they were. Two studies of services to improve mental wellbeing show that learning disability services can deliver adapted interventions for low mood and anxiety. This included a trial comparing activity-based support with guided self-help, where both showed improvements but no real differences between the approaches. Cognitive behavioural approaches to reduce anger and aggression show mixed results with a recent large NIHR trial showing no effect on the main outcome but some improvement in coping skills. More evidence is needed for effectiveness in community learning disability services. Overall, these various studies show that adapting programmes for people with learning disabilities may work best when their care staff or family are involved.

### Staying well and safe in hospital

Following national inquiries into avoidable deaths in general hospitals, a number of measures were put into place. One study found continuing problems

with a lack of systems for hospitals to identify people with learning disability and knowledge among staff on what adjustments to make.

Learning disability nurses were found to make valued contributions to care, and further research may demonstrate their impact on experience and outcomes. This study, together with a number of others, identified lack of confidence among general hospital staff in caring for people with learning disabilities during their hospital stay and highlighted areas for improvement in patient care and discharge arrangements. Particular NIHR studies are addressing issues, such as training staff to communicate with children with severe learning disabilities. We do not yet know the impact of recent standards to improve care.

### Services supporting positive behaviour

One in five adults with learning disability have behaviour that is challenging. A person-centred approach known as positive behavioural support is recognised as best practice. This was shown to be effective in small studies when delivered by specialist staff in NHS or residential care. NIHR has funded three large trials to test this further. When scaled up in real-world community learning disability services, a large trial showed little effect, although few staff delivered the intervention as planned. A second study showed that people with behaviour that challenges can successfully deliver training to residential care staff, but there were no marked differences in staff empathy. A third trial used a positive behavioural support-informed approach to work with staff to make quality improvements in residential settings. This resulted in a reduction in behaviour that challenges by two thirds. All studies underlined the importance of involving a range of

support staff and family carers in understanding behaviour that challenges and using behavioural support approaches. This is important given that a further study found that only one third of people in community group homes received consistently good support to stay active. Those who received most support were the least disabled.

### Future directions

The research funded by NIHR in the past decade has helped to drive forward research on topics that people with learning disabilities have told us are important. People with learning disabilities have been involved in designing interventions and taking an active part in research studies. We know much more than we did, but there are still gaps. We need more research on services where many people spend their adult lives, including supported group homes and residential settings. We need to know more about effective approaches to self-management for people to improve physical and mental wellbeing, including peer support and tailored interventions. There are gaps at all points in the life course, from research on services for children to those for older adults and at the end of life.





## About this review

This review is focused on National Institute for Health Research (NIHR) research into learning disability health and social care services conducted throughout the UK. The NIHR is the largest government funder of health and care research. It has supported a number of relevant high-quality studies on the organisation and quality of learning disability services. The review highlights NIHR studies of interest published from 2010 that have added to our knowledge, rather than being an exhaustive review of all available research in this area. We focus on research where there are peer reviewed outputs in the public domain.

We hope that this research will be of interest to people with learning disabilities, their family, professional carers and those delivering and planning specialist services, and universal services accessed by people with learning disabilities. This review should also be useful for commissioners as well as frontline staff working in mainstream organisations – from general practices to hospitals to community therapy or mental health services and social care – who will be commissioning and providing general care to local populations. We hope that this research provides insights into how services can best meet the needs of all, including those with learning disabilities. We are also producing an accessible version of our review.

This review looks primarily at studies of health and social care services targeted at people with lived experience of learning disabilities and their families. It excludes studies specifically concerned with autism because these may relate to separate pathways and services. Although there is a small

number of studies on services for children, most are on services for adults. The NIHR has funded many studies on the effectiveness of individual interventions, from drugs to psychological therapies, but the focus of this review is on services for people with learning disabilities. These interventions are only included where the study is also about how this works in the context of health and social care services.

The review is structured as follows:

1. Understanding learning disability and services
2. Identifying health risks
3. Keeping well in the community
4. Staying well and safe in hospital
5. Services supporting positive behaviour
6. Conducting research together
7. Conclusions and future directions

In this review, we have included some personal views of people with lived experience around the issues the research is about. This input was secured by commissioning community organisations to conduct three sets of focus groups, two with people with learning disability and one with family carers of people with learning disability. We highlight studies that show examples of good practice in involving people with lived experience of learning disabilities in doing research.

## Understanding learning disability and services

### What is a learning disability?

NICE refers to the formal diagnostic criteria for learning disability that people with learning disabilities (also called intellectual disabilities) have lower intellectual ability (an IQ of less than 70). The disabilities are 'global, causing significant difficulties in managing a wide range of everyday health tasks and self-care, and starting in childhood' (1). Most definitions include not only lower intellectual ability, but associated limitations in adaptive skills, that together manifest during childhood or adolescence (essentially before age 18 years). More detail is provided in the definitions used for the Learning Disabilities Observatory (2). Learning difficulties, as used in education services, may also refer to conditions that are not related to overall cognitive ability, such as dyspraxia, and are not included in this review.

### The health of people with a learning disability

Learning disabilities affect approximately 1-2% of the population. In 2015, it is estimated that there were at least 1,087,100 people with learning disabilities, of which 900,000 were adults in England. Rates are difficult to determine as not all people with learning disabilities are registered with services and as few as 252,446 patients were recorded as having learning disabilities in GP records (2).

People with learning disabilities experience many inequalities in health and social care as well as in education, employment, standard of living, justice, political participation and identity (3), all of which are fundamental to the human rights of people in the UK.

People with learning disabilities live with lifelong conditions which vary in nature and complexity. Mental health problems in people with learning disabilities are even more prevalent than in the rest of the population. Access to both specialist community learning disability services and mainstream mental health services is increasing, but with wide local variation (2). People with learning disabilities are more likely to be on major psychotropic medications in the long term. Often they are not prescribed for a psychiatric condition but to control behaviours that are described as challenging (4). There is also the problem of diagnostic overshadowing (5). This happens when clinicians overlook symptoms of mental health or physical health problems in this client group and attribute them to being part of 'having a learning disability' (6). Some people with learning disabilities are at higher risk from conditions associated with their disability such as dementia (e.g. people with Down's syndrome) which may be misdiagnosed or diagnosed late (7). Preventable conditions such as aspiration pneumonia can have serious adverse health effects but can be misdiagnosed or missed.

Throughout their lifespan, people with learning disabilities are proportionately more likely to experience physical health problems (such as obesity). Although overall life expectancy has improved in recent decades, people with learning disabilities are still at risk of dying earlier than their non-disabled peers. People with learning disabilities in England die much younger than the general population: 13 to 20

years younger for men with learning disabilities; 20 to 26 years younger for women with learning disabilities (8). Often early death arises from conditions that are amenable to effective treatments. But people with learning disabilities are less likely to receive them than other people.

As adults, people with learning disabilities have particular housing and support needs. Two-thirds live with family carers who themselves may be caring for older family members and have support needs as they themselves age. Some people with learning disabilities are cared for by their elderly parents, and those needs may change as the family ages. These factors create vulnerability to breakdown of support for the person with learning disabilities. (9)

NICE has produced several guidelines and associated Quality Standards for learning disability services. This provides an important context for services. NICE also identifies a shortage of high quality research to inform these guidelines, for instance around models of specialist community health services or supported living models for those with behaviour that challenges (1). This review should go some way to addressing these gaps.

### Health and Social Care Services

People with learning disabilities have the right to enjoy the 'highest attainable standard of health' without discrimination (10). In the UK, health services are required by law to make changes in order to support access by people with a learning disability and/or autism. This includes making reasonable adjustments where necessary, in line with the Equality Act (2010) (11), with access to specialist multi-disciplinary community-based health and social care expertise as appropriate (12).

People with learning disabilities access universal health services, including community health services such as pharmacy, sexual health and contraception, and primary care dental and general practice (GP) services. People with learning disabilities may need “reasonable adjustments” to access these services. Social care services include the services of social workers who undertake assessments and care planning, as well as providing information and advice, support with benefits, access to housing and other services.

Specialist learning disability health services aim to support adults with learning disability, including those with profound and complex needs, to access suitable general care for physical health problems such as epilepsy, swallowing, or incontinence, or provide this within their services. Health professionals within the community learning disability services also provide specialist assessments and treatment for communication disorders, mental health problems, cognitive decline and behaviours that challenge. In many teams, care is integrated with social workers working alongside their health colleagues. Staff in these services are trained specifically to work with people with learning disabilities in community settings. There is currently a small number of specialist assessment and treatment in-patient units, including those in the independent sector. In-patient care for mental ill-health, e.g. psychosis, mania or severe depressive illness, may be provided within general psychiatric in-patient settings.

Health services for children with learning disabilities are primarily provided via children’s physical and mental health services. Children under five are usually referred to child development teams, typically staffed by speech and language

therapists, occupational therapists, psychologists, paediatricians, nursing health care professionals, and social workers. Children over five can be referred to the child and adolescent mental health services (CAMHS). Special schools have input from speech and language therapists, psychologists, nurses, and psychiatrists. Social services must provide support, such as parenting programmes, to those family carers eligible under the Care Act 2014.

Following the preventable deaths of six patients in general hospitals highlighted in Mencap’s report *Death by Indifference* (13), an independent inquiry was published in 2008 (14) into health care for people with learning disabilities. It set out key principles for all NHS hospitals in England. Hospitals should identify people with learning disabilities and, by law, make reasonable adjustments (11) so care is safe and effective, and involve family and other carers in their hospital care.

The independent Inquiry: Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD published in 2013) (8) reviewed the deaths of 247 people with learning disabilities over the period 2010–2012. The report found many failings in access to and provision of care. It highlighted the continuing need to identify people with learning disabilities in healthcare settings, and to record, implement and audit the provision of ‘reasonable adjustments’ to avoid them experiencing serious disadvantage. The recommendations included better inter-agency working, training staff in the application of the Mental Capacity Act, proactive use of GP health checks and annual health action plans, support for access to screening and diagnostic services, changes to advanced care planning and how people’s care is managed at end of life in an emergency.

Following this report, the Learning Disability Mortality Review (LeDeR) programme was established in England. This report identified that ‘the difference in age at death between people with learning disabilities (aged four years and over) whose deaths were notified to LeDeR, and the general population of England and Wales (all ages, 2010 data) is 22.8 years for males and 29.3 years for females.’ (LeDeR 2017, p18) (15). In its most recent report with data to 2018, (16) it continues to show the gaps in service access and provision, diagnostic overshadowing, and associated early mortality for people with learning disabilities. Recent government response to improve care in the light of these findings includes an important commitment to mandatory training for all health and care staff in contact with people with learning disabilities.

An overview in England of inspections of services in 2019 identified concerns in the provision of learning disability services (17).

### Better Integration of services

In England, various joint health and social care commissioning arrangements have been used with the aim of achieving better integration between services and personalisation of care for people with learning disabilities. The National Health Service Act (2006) (18) allows health bodies and health related local authority services to pool money and integrate resources and management structures. This supports partnership working. This is intended to achieve service improvements through the joining up of existing services or the development of new initiatives, improving operational efficiency, and increasing the options for people with learning disabilities and their families to exercise their right

to choose and maintain control across health and social care (19). Conversely, constraints on social care funding may lead to disintegration as social care withdraws from joint arrangements.

### Policy Context

Responsibility for health and social care is devolved to the four countries of the UK. Policy in the White Paper *Valuing People* in 2001 (20), followed by *Valuing People Now* in 2009 (21) focussed on increasing and improving services for people with learning disabilities to lead full and independent lives as part of their local communities. This requires that services are built round the individual needs of the person and respects their choices. This includes how they access and use mainstream services and live in community settings of their choice. It includes people buying personal support services through the use of direct payments from the local authority, which may be managed by the person with a learning disability and their families or by a professional carer.

Since the *Valuing People Now* strategy ended in 2012, the principles underpinning *Valuing People* and *Valuing People Now* continue to inform support and services for people with a learning disability, and in England, are part of the NHS Long Term plan.

The legal and statutory frameworks to protect the rights of people with learning disabilities for England, Scotland, Wales and Northern Ireland are summarised in Appendix A.

### NHS long term plan

The NHS Long term plan in England (2019) (22) highlights learning disabilities and autism as one of the five top clinical priorities. The plan contains further aspirations for improving the general health of people with learning disabilities. It includes a raised target for people aged 14 years and above so that at least 75% have an annual GP health check, a digital flag in electronic medical notes, and further development of the programme to stop over-medication with psychotropic drugs and increase employment opportunities.

### Building the right support for people with a learning disability who display behaviour that challenges

Following the abuse scandal at the privately-run hospital Winterbourne View in 2011, the Department of Health’s Transforming Care programme committed to transforming services for people with learning disabilities and behaviour that challenges. The programme aimed to ensure that care is based on the needs and wishes of individuals and their families and provided by general and specialist services in the community.

A report by the National Audit Office (23) in 2015 found that the complexity and challenge in meeting the commitments of the Transforming Care programme had been underestimated and progress was slow. The programme was reconfigured and a national plan ‘Building the Right Support’ (24) and a service model for commissioners were published in 2015 outlining the range of support that should be available to people with learning disabilities



and behaviour that challenges. This also applies to people with autism. Building the Right Support had a target to reduce the number of inpatient beds for people with a learning disability and/or autism by 35-50% by March 2019. This deadline was not met and has been extended. There is now a commitment to achieve the 50% reduction by March 2024.

The abuses at Winterbourne View, Muckamore Abbey in Northern Ireland in 2018, and at Whorlton Hall, have highlighted how some of the most vulnerable people with learning disabilities can be abused in institutional settings, which fall far short of quality and safety standards. People in these services were cared for by staff with little training, inadequate supervision and poor leadership. Further, there is growing recognition of the serious shortfalls in workforce of health and social care services for people with learning disabilities (25).

## Conclusions

Government policy aims to drive up the quality and integration of health and care services used by people with learning disabilities and their family carers to improve their health and well-being. Approaches include personalisation and the use of personal budgets and direct payments to offer more person-centred care tailored to the needs of the person and their family. Health and care services are intended to be provided as far as possible out of specialist settings and services, with an emphasis on living well and with personal choice in the community. This is against a backdrop of serious scandals about abuse and poor care, and reports showing that inequalities in access to services and rates of ill health and early death continue to be greater than for the general population. Recent assessments confirm there is still much work to be done. The research funded by NIHR can inform the decision-making about these services.

## Identifying health risks

People with learning disabilities are much more likely to have poorer health and die earlier than the general population. They are also at greater risk of being admitted as emergencies to hospital, yet many of these admissions are preventable. These are called ambulatory care-sensitive conditions, and include seizures, dehydration, constipation, and respiratory infections. Some of these conditions and deaths could be prevented by these adults getting the assessment, treatment and services they need earlier. This has been known for many years, as suggested in an early 2003 NIHR-funded review by Albortz (26) and 2013 confidential inquiry (8). The confidential inquiry makes several recommendations including “standardisation of annual health checks and a clear pathway between annual health checks and health action plans.”

In England, a GP Quality and Outcomes (QOF) payment is made to GPs to incentivise them to keep a register of all patients with learning disabilities (27). In Wales, a primary care health check was introduced in 2006. Since 2008 a directed enhanced service (LD-DES) incentivises GPs in England to offer adults with learning disabilities annual health checks; this has been extended to those aged 14. According to national NHSE figures to 2017-18, only 55% are having health checks, with only about half of practices reporting results. The NHS Long Term Plan (22) has an aspiration to increase uptake for people with a learning disability, so that at least 75% of those eligible have a health check each year, and to improve the reach and completeness of registers, so

research into the use of health checks is very timely.

Three important NIHR studies have looked into the implementation and effect of health checks in primary care in improving the health of people with learning disabilities.

### Evidence on health needs:

An early NIHR review (26) helped to establish what was known about health services for people with learning disability. This 2003 study found 82 studies of different kinds, 27 of which were reasonable quality. Most focused on identifying unmet need and the quality of general practice services. Available evidence suggested that GP services were used less than expected and there were missed opportunities for preventive health screening, advice and treatment. In many other important areas, from access to specialist outpatient clinics to vision and hearing services, there was little or no research. This review helped to make the case for health checks in general practice and identified an agenda for further research in other areas.

<https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/081210023/#/>

An English study in 2012 (**Study 1**) showed that the LD-DES GP incentive scheme was associated with more health checks being recorded, and increased identification of important general health problems such as diabetes and coronary heart disease. The health checks were also more likely to pick up problems that are more prevalent in people with learning disabilities, such as hearing and visual impairment, and refer them to appropriate services. Although the NHS is required by law to make

reasonable adjustments to the way in which services are provided in order to promote equality of access, qualitative research highlighted some difficulties that professionals experienced in communicating effectively with their patients. There was evidence of GPs making some helpful adjustments, such as home visits. While largely welcoming the scheme, GPs identified many barriers to its implementation, including insufficient training of staff, poor engagement with community learning disability services, and many further recommendations were made to improve the scheme.

A study (**Study 2**) looked at how effective health checks have been clinically. This study showed that, while diabetes and epilepsy were being picked up by health checks as often for people with learning disabilities as in the general adult population, health checks in people with learning disabilities more often identified other specific problems such as thyroid and gastrointestinal disorders. The study also looked at the costs and effect on healthcare use of those who had an annual health check and those who did not. The study found that in both groups there was an increase in healthcare use and costs in subsequent years from when they were introduced. People with learning disabilities who did not have an annual health check had a significant increase in unplanned health care use (such as hospitalisation). Those who had a check made greater use of planned services like GP phone consultations and outpatient appointments to deal with problems which had been identified. The average cost of the check was estimated at £142.57, which may be because more than half were delivered by GPs (28).

We now have the ability to link large-scale data to track the experience and outcomes of those with learning disability across settings and compare

them with the general population. In a national 2017 study (**Study 3**) of more than 21,000 adults with learning disabilities and matched population controls identified from primary care, it was found that people with learning disabilities had more long-term conditions, higher risk of early death and more emergency hospital admissions, with more of these being deemed potentially preventable. The study found that adults with learning disabilities were five times more likely to be admitted for conditions, such as urinary tract and respiratory infections, where more effective treatment given by primary care health workers like GPs could have prevented the admission to hospital. While there was no association between the introduction of health checks and overall emergency admissions to hospital, there was evidence they were associated with a reduction in potentially preventable hospital admissions both at an individual and practice level. Patients with learning disabilities had a 70% higher rate of GP consultations, but they were less likely to have long consultations or with the same GP over time. Health information recorded on the patient record varied greatly around the time of the health check. The study suggests GP services could make more adjustments such as improving access to longer consultations and continuity of care for these patients, as well as better standardisation of health checks. These steps make health checks more effective in addressing health problems that might otherwise result in emergency hospital admission.

“ I received a letter from my surgery asking me to go for a Health Check. I didn't fully understand the letter because it was not in Easy Read. I rang the receptionist at the surgery and she was very good at explaining to me what it was all about. I asked my support worker to come along with me. I've known my GP for years so I wasn't too worried about seeing him. He was very kind to me when I lost my mother. On the day of the Health Check we were seen on time. This was good. I entered my GP's room. He was polite and friendly. I introduced my support worker to him. He asked me what he could do for me and I told him that I'd come for the Health Check. I was surprised he needed to ask me this because this was a Health Check appointment and not a normal visit to see my GP. I asked him if I could have the Cardiff Health Check but he didn't reply to this. The Health Check started and he took my blood pressure. He weighed me. He didn't say anything so I can only guess that he thought I was a lean, mean, fighting machine! I've been seeing him a lot over the last year about my shoulder. He gave me some treatment for this. We spent most of the time talking about my shoulder. The whole appointment lasted between 10 and 15 minutes

I like my GP and he has been good to me in the past but I don't think he knows what a proper Health Check is.

Gareth, a man with learning disability.

## Conclusions

There is good evidence that annual health checks can improve health and health care of people with learning disabilities. This evidence underpins NICE guidance on the effectiveness of these checks. Health checks have increased the recording and assessment of important common conditions, such as diabetes and heart disease, as well as problems such as hearing and vision impairment in people with learning disabilities. Health checks also help GPs to identify specific issues, such as thyroid or gastrointestinal problems. Use of emergency hospital services also tends to be lower, particularly for those conditions which may be preventable by better primary care or access to specialists by out-patient appointment. A range of strategies, including advocacy from professionals or family has been identified to ensure that people get the best out of the annual health check. This is important to address health problems that might otherwise result in emergency hospital admissions and poor health in the longer term.

### Prompts for reflection

- How complete are GP learning disability registers, and how well do the GP and Local Authority registers match? How well are they used for planning?
- How can health checks inform the health action plan agreed with the person's GP that are used for planning care throughout the year by professionals?
- How can more people with learning disabilities be supported by those who know them well to attend, engage with, and benefit from, annual GP health checks?
- How well do our practices do in carrying out health checks including those who might not usually access primary care, and what is the quality of health checks for people with learning disability?
- What more can we do to train and support practice staff to carry out health checks well?
- Can health checks be delivered by other providers or in other novel ways that reduce the burden on primary care (e.g. the third sector, or, for children, in collaboration with schools)?



## Keeping well in the community

Although the life expectancy of people with learning disabilities has improved over recent decades, they continue to have a shorter life expectancy and increased risk of early death compared to the general population (29). People with learning disabilities vary as much as the general population in their lifestyle habits including their diet. However, studies show that people with a learning disability are more likely to be overweight, and a Dutch study has shown there is a greater risk of developing diabetes, a diet- and weight-related long term condition (30). GPs can play an important role in discussing weight gain with their patients and their options for referral to lifestyle change programmes. With sufficient training and resources other staff such as support workers, health and care navigators and community nurses could provide support for people to access healthy living programmes such as smoking cessation and weight loss programmes, and gyms. The role of social care staff includes considering the support needs of people to promote well-being, including opportunities to be active.

A review (**Study 4**) has mapped the evidence on how community services can be made more accessible for people with learning disabilities. This review updates many aspects of the seminal NIHR-funded review by Albortz in 2003 (26). The quality of evidence was no better than in the original review. Most studies were focussed on GP services, with a smaller number on referral to mental health services for mood disorders, optical, sexual health and dental clinics. Important

factors for accessing health services for adults with learning disabilities were: consistency of care and support; staff training; communication skills and time to communicate; and provision of accessible information. Innovations such as extended hours of GP services are not increasing access for people with learning disabilities. Consistency in seeing the same GP has advantages in reducing anxiety for the person with learning disabilities and enables the clinician to develop a rounded view of their patient's health needs in the context of their support and living arrangements and building important bridges to other services.

I have been going to the same High Street optician for many years. I used to go with my carer but they know me now and I can go without her. I ask them to write notes for me in my diary. I can give these to my carer to make sure I understand... When I went for the eye test itself I struggled to see the letters. I could see the high ones, but not the lower ones. The person doing the test said 'guess', but I don't like getting it wrong so won't guess. I said no.

Person with a learning disability.

I always went to the same dentist for years. I went to see him on the bus with my carer. No one told me the dentist was closing. One day we went there and he wasn't there. I didn't see a dentist for years. Now I'm on a waiting list to see a new dentist.

Annabel, person with a learning disability.

### Swallowing problems

Dysphagia or problems in swallowing is common amongst people with learning disabilities. While under 1% of the general population die from aspiration pneumonia, the rate is 3% in deaths of people with learning disabilities. Complications arising from dysphagia are a common reason for emergency hospital admission and for respiratory infections in people with learning disabilities. Many of these complications are preventable with identification of dysphagia and good support such as at mealtimes both at home and when in hospital. A cohort of adults with learning disabilities and difficulties swallowing was studied (**Study 5**) with the aim of finding out which adults with learning disabilities who receive mealtime support are at an increased risk of respiratory infections and emergency hospitalisation related to eating, drinking and swallowing problems. The study found those who had a history of respiratory infection, epilepsy, or difficulty swallowing were at risk of respiratory infections a year later. Adults with greater mealtime support needs, particularly those who need total

support at mealtimes, and those with epilepsy were at greater risk of emergency hospitalisation. The study has helped to identify those who may require closer monitoring at mealtimes, and that GP health checks should include an inquiry into mealtime support, particularly because of the link to preventable respiratory infections.

## Epilepsy

People with more severe learning disabilities are much more likely to have epilepsy than the general population. Having epileptic seizures can be both disabling and life threatening, with a condition known as Sudden Unexpected Death in Epilepsy. Some people have seizures that are resistant to anti-epilepsy medication, which can cause great concern to themselves and their families. A study (**Study 6**) aimed to skill learning disability nurses to a common standard to promote effective management of these patients' seizures. Services managed by learning disability nurses trained to this standard were compared to services where nurses were not trained at this level. There was no clinical difference in the severity of seizures between the groups, although there was limited evidence that seizures were rated as less severe in those with mild or moderate epilepsy in the services where nurses were trained in the epilepsy competences. This may suggest the framework enables learning disability nurses to better manage those with less severe seizures that do not respond to usual medications. The services varied greatly in how they were delivered, and the experience of family carers did not differ overall between the groups. There is scope to improve how learning disability nurses deliver care for this group and how they engage with families to provide consistent high-quality care.

## Healthy weight and lifestyles

Three NIHR studies have designed and tested the feasibility of future trials of weight management and lifestyle interventions tailored for adults with learning disabilities.

One study (**Study 7**) identified people with learning disability at risk of diabetes and piloted an education programme to reduce risks. From 675 people who were tested, they found 1 in 100 had type 2 diabetes, which had not been diagnosed and five in 100 had high blood sugar levels making them at risk of diabetes. This was lower than expected, and the authors suggest it may reflect the success of health checks by GPs in identifying people with diabetes. However, more than two thirds of those screened were overweight or obese. The study also developed and piloted a group education programme tailored to the specific needs of people with learning disabilities (and their carers), including making more use of visual resources. The educational sessions were piloted twice. Then, in the feasibility phase, five people attended the group course with good attendance for four of them. Improvements were seen in measures at three months, but numbers are too small to say how effective it was. Given the greater chances of people with learning disabilities developing diabetes, this research will be useful to inform how the National Diabetes Prevention Programme could be delivered and adapted: <https://www.england.nhs.uk/diabetes/diabetes-prevention/>

Another study (**Study 8**) developed the first Type 2 diabetes self-management programme in the UK for people with mild to moderate learning disabilities living in the community. They tailored a proven programme with a good track record for the general population with the assistance of specialist learning

disability experts. Recognising the diverse living arrangements for people with learning disabilities and the people they live with, the sessions involved their supporters in helping them set personal goals and supporting them in these activities in and outside the home-based diabetes nurse sessions. This was an early trial of a tailored supported self-management programme delivered at home involving 82 people with learning disabilities and diabetes. It was found to be acceptable and feasible, and people who started it were likely to complete it. Although the study was not big enough to test definitively the impact on health, early findings suggest a more sustained programme of support with more than the two hours of intervention may be needed to achieve sufficient and lasting changes in lifestyle for people with learning disabilities.



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**Lou:** “I have always tried to keep a healthy weight but at the moment our provider has changed, we’ve been quite short-staffed so...we all end up eating together and it’s like a takeaway and stuff. They’ll say, oh, we’re having a takeaway because we’re short staffed tonight. Some people might like that and other people don’t. But what I get so cross about is because some of the people have one-to-ones in the day, they get a proper meal whereas the people whose tea calls are, like scattered, don’t – and I think that is bad. How I do my meals – I like to batch cook, freeze them and take them out and eat them. When I first went to (residence) the social worker said we’ll give her half an hour for her tea call. My Mum said no, you can’t cook a meal in half an hour and she’s not living on ready meals. The social worker said ‘isn’t she?’ I said I bloody well will not.”

**Lynn:** “At (name of housing) they didn’t believe in making in your own meals, they believed in going and buying ready-made food that you popped in the microwave. They didn’t believe in people eating fruit, people didn’t buy fruit, they just bought unhealthy food. I don’t like ready meals at all. I like the proper meals.”

**Lou:** “It’s nice for us all to sit and eat together on a Sunday but that’s proper food when sometimes the takeaways are like pizzas or burgers and to me that’s not proper food. Sometimes what they do is ask people for a fiver each, some staff will go and buy the food and two of the staff will cook it, like a Sunday dinner and it’s lovely.”

**Lou and Lynn, women with learning disabilities.**

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A review of five studies (**Study 9**) described how weight management programmes had been tailored for people with learning disabilities by using easy read and symbol communication tools, individualised sessions, and involvement of professional and family carers. The three UK studies were of the “Take 5” intervention that is designed for people with learning disabilities, and included personalised diet, activity and behaviour change to alter “bad habits” such as use of takeaway foods. Only two studies, both using the “Take 5” approach, showed clinically significant weight loss in people who were obese. However, the authors note that this intensive one to one programme may not be sustainable in routine practice. The study also interviewed 14 primary healthcare medical, nursing and allied health practitioners about their consultations with people with a learning disability on lifestyle and weight management. They found barriers included inconsistent input from professional carers or family attending with them, a lack of easy read materials when giving advice or discussing referrals, and their own lack of knowledge of suitable weight management services.

### Anxiety and depression

People with learning disabilities are more often depressed and anxious than the general population, but people with learning disabilities are under-represented as users of mainstream mental health services.

A feasibility study (31) looked at cognitive behaviour therapy (CBT) for people with learning disabilities, comparing CBT with usual care in the community. Sixteen sessions of CBT were designed for people with anxiety and/or depression to be delivered by a general therapist (not expert in learning disabilities)

“ The team at (name of Health Centre) work with the mental health team. If I get a crisis with my mental health, my doctor will refer me to the mental health team who will see me for a maximum of four weeks to look at coping strategies, diet, exercise. They will then discharge me so I don’t become too dependent on them. But I know my doctor can refer me back. They normally see me within one or two weeks.

I used to go to complex needs every day. You can self-refer. They have an out of hours support system. You can ring a number and get someone to talk to.

Katie, woman with learning disability.

and supported by a community worker to help them complete homework and attend appointments. The manual for delivering the programme provided information about communication and thinking styles in people with mild learning disability, and a leaflet to help carers support the treatment. Behavioural tasks were used to challenge unhelpful thoughts. A support worker assisted the person to carry out tasks. The therapy was completed by most who started. Comments were similar to those in other studies who experience CBT, with some seeing it as too prescriptive, others welcoming the structure. The authors recommend that a full study would be needed to see if it is effective and cost effective. This feasibility study has shown that this type of therapy can be adapted for use by general CBT therapists. But whether “mainstream” IAPT services without a trained support worker are an appropriate alternative

for people with learning disabilities would require further study.

Cognitive behavioural therapies (CBT) are provided by a range of community services for all adults in the UK and have a strong research evidence base. Mainstream services have been advised on becoming more inclusive and making reasonable adjustments, using the IAPT positive practice guidance (32, 33). While there is evidence that the cognitive components can be used with people with learning disabilities, in practice the behavioural rather than cognitive components are more often used. An approach that supports people to undertake more activities of their choice has been evaluated (**Study 10**). In a study of 161 participants, people with learning disabilities who were depressed were randomised to a programme called BeatIt. Therapists were either experienced in working with people with learning disabilities in their current role or were IAPT therapists who received additional training. A therapist met them and their supporter to choose, plan and carry out activities, sometimes where they lived. They also worked to overcome the barriers to change that are faced by people who are depressed. The comparison was a guided self-help programme called StepUp, where the therapist works through four booklets with a person and their supporter. The four booklets are about improving mood by better understanding depression, better sleep, more activity and problem solving. Both groups became less depressed and this was still improved 12 months later. Both treatments were adapted from existing mainstream NICE-recommended depression treatments and successfully adapted in the study for people with learning disabilities. Introductory online training for both BeatIt and StepUp have been developed for therapists and are being hosted by the NHS Education Scotland and Health Education England websites.

“ I think people assume that those with learning difficulties don't have feelings and do not understand feelings and are just trying to be difficult. Someone was crying and when she was asked the problem, she said that she misses her mum. Her carer said “your mum died 3 years ago, get on with it.” ”

Lou, woman with learning disability.

## Anger management

A Cochrane review (**Study 11**) of randomised controlled trials of cognitive-behavioural therapies for people with learning disabilities who showed behaviour perceived to be aggressive included six studies. Of these, five were conducted in the UK. These studies examined a range of cognitive-behavioural therapy approaches including anger management, assertiveness training and problem solving, meditation and relaxation. The studies showed some evidence of reduced aggressive behaviour ratings by others, self-reported anger ratings and aggressive incidents, and improved anger coping skills and adaptive behaviour at the end of treatment, but results were not consistent across studies. The reviewers recommend future studies should measure outward-directed aggressive behaviour. Further studies should examine the impacts on key workers and family carers and assess the wider impact on participants' mental health and quality of life and impact on service costs.

A randomised controlled trial rated as of moderate quality (**Study 12**) was the largest study in the (**Study 11**) Cochrane review. Lay therapists provided cognitive-behavioural therapy interventions to

improve self-reported anger and anger coping skills in people with mild to moderate learning disabilities attending day centres in the community. The therapy was provided over 12 weekly two-hour group sessions supplemented by homework tasks. The main outcome was the service user's self-reported anger at the 10-month follow-up, measured by a tool called a Provocation Index (34), which was used by 79% of participants. Results showed no impact of the intervention on these scores at the 10-month follow-up. The authors concluded that this particular index may not have been the best tool as it measures response to hypothetical situations that may provoke anger, which is more difficult for people with learning disabilities to imagine. This underscores the importance of selecting outcomes that reflect observed aggressive behaviour. The intervention significantly improved service user rated and staff rated anger coping skills after the intervention and was maintained at 10 months. But ratings of anger, and coping skills by home carers did not improve, while the improvement in aggressive behaviour rated by staff was only significant at 16 weeks follow-up. There were no differences in quality of life or use of other health services. Interviews showed there may be positive 'spill-over effects' of using in-house staff, and a group approach, as managers and therapists commented there was greater consistency of working between therapists and other staff in interacting with service users.

## Inequalities in accessing mainstream services

Health and social care services are obliged under the Accessible Information Standard, underpinned by the Equality Act, to identify and record disabled people's needs for support and reasonable adjustments (11) so care is safe and effective.

People with learning disabilities can suffer additional disadvantages in accessing and using services, which affect their health and well-being. NIHR has funded five small studies which look at how services address some of these issues.

Personalisation of care services has become the focus of social care reform in the UK and across Europe. This means that individual service users and family carers have some say in what services they get through holding personal budgets. However, to be effective these require adequate resources and a range of provision to be available to purchase. In a review of 11 studies (**Study 13**) exploring the effects of reduced funding over the past decade on paid and informal carers of people with disabilities, there was a common focus on loss of independence, choice and social participation in their daily lives. This in turn increased social isolation, with the care gap being filled by family carers, affecting their health and wellbeing.

People with learning disabilities from black and minority ethnic groups face additional inequities in health and social care provision. They are less likely to access care services and are less satisfied with their experience of services, as shown in national surveys of user experience of social care. However, this is largely based on the views of carers about services for their family member. Including people with learning disabilities as co-researchers (**Study 14**), 32 adults with learning disabilities from black, Asian or other minority ethnicities were interviewed about what mattered to them about care services. Views and experiences varied according to their culture, and the desire for personal independence. Reliable and consistent relationships with care

providers were very important. Participants were generally pleased with the services they received. The authors note that people with learning

disabilities may not have given critical feedback because of fears that they would lose services, a point also made by some family carers consulted as a part of this review. Participants' views also varied with regard to independence from social services, often depending on how much control the respondents had over the pace and nature of change. The researchers subsequently collaborated with people with learning disabilities to produce the Tools for Talking resources (including videos). These are discussion activities to enable service users to participate in discussions with commissioners or providers, in order to develop mutual understanding of what service users want (<https://toolsfortalking.wordpress.com/>). The authors advise that if these tools are used by commissioners, it is important that discussions are carefully facilitated and that the activities are understood to provide a means of starting conversations about service preferences, not a formal assessment of service need.

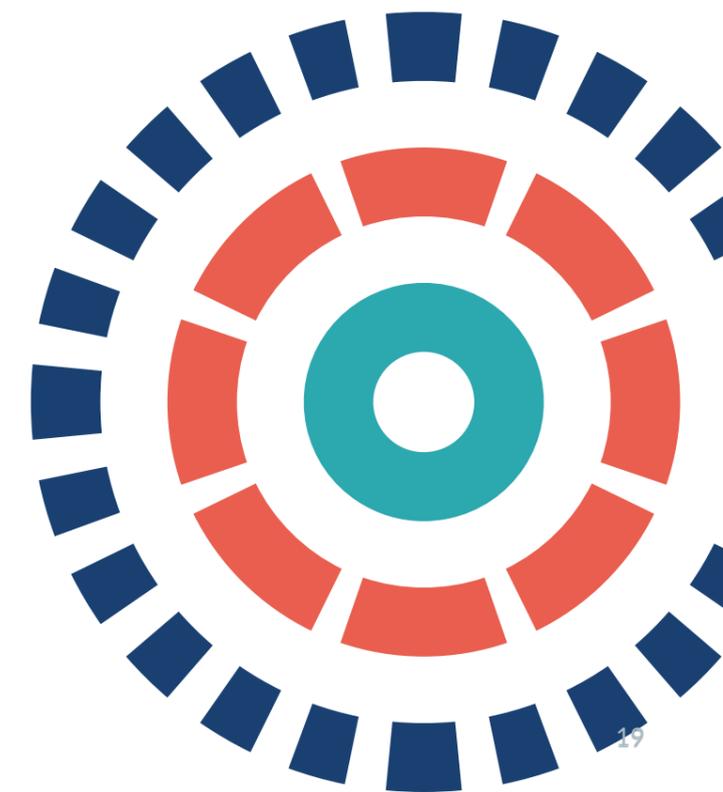
Mothers with learning disabilities and their babies are at higher risk than other mothers of poor outcomes during pregnancy and afterwards. They are more likely to have their children taken into care due to child protection or welfare concerns, although the picture is complex and removal into care seen is seen very much as a last resort (35). A small study (**Study 15**) interviewed nine women and found many examples of the mothers feeling judged, being unable to understand information given, and not getting the right support. The study recommends that for these mothers to be confident and cared for, maternity services should make reasonable adjustments when providing care to include allowing sufficient time in appointments, offering clear explanations of each aspect of care and sensitive support for fully informed choice. Some mothers may go through a formal

assessment of their parenting skills and should be supported by maternity services to give them the best possible chance of passing the assessment. A wider consultation exercise with parents with learning disabilities and maternity professionals has underpinned a report for NHSE with several recommendations for local maternity systems to better address the needs of parents with learning disabilities (36).

The Care Act 2014 introduced an eligibility outcome for adults in relation to their caring responsibilities for a child. However, most of what is known reflects the experiences of mothers. A study of eight fathers with learning disabilities who had 18 children looked at their experience of adult social care (37). They had had poor experiences of their own fathers in childhood. They experienced bullying and discrimination at school and in work. None had expected to be fathers. Some became very involved and felt it was rewarding, others experienced great stress, such as their child being taken into care. The study points to ways social care services can improve their Think Family framework (38) to inform how parents, including fathers, with learning disabilities, can be supported in caring for their children.

NICE (39) recommends that all health and social care practitioners should be trained to recognise domestic violence and abuse, yet many people with learning disabilities are not in regular social care contact and are open to abuse and exploitation. A study (Study 16) interviewed 15 women with learning disabilities who had finished an abusive and violent relationship. They experienced often life-threatening abuse including sexual violence, financial abuse and coercive control. Perpetrators were seldom people with learning disabilities. The abuse has similarities with “hate crime” against

disabled people, as aspects of their disabilities were exploited to enable them to become more socially isolated and under the control of the perpetrator, and they were humiliated by acts that highlighted their disabilities. A survey of 172 police officers and 545 health and care practitioners found strong agreement on why women with learning disabilities may be in violent relationships such as being seen as an easy target, socially isolated or having a difficult family background. Few felt their training covered the essential communication skills for working with people with learning disabilities. Alerting women to the known profiles of risky men, supporting self-advocacy, and improving training and working practices between police and social workers are steps that may make a difference.



## Conclusions

People with learning disabilities experience significant poorer health than the general population. One of many reasons for this may be because community and primary care health services in the community are not making adjustments to ensure they can more effectively use these services. Small studies suggest some of these difficulties may be more pronounced for those from minority ethnic groups and worsened by reduced funding for local authority and other services.

Research has highlighted the benefits for people with learning disabilities needing mealtime support from regular assessment by their GP and community health services and early treatment of respiratory infections to avoid emergency hospitalisation. A recent trial found no clinical benefit in reducing severity of seizures by training learning disability nurses in epilepsy management. Services designed to enable people with learning disabilities to reduce their weight or address health behaviours related to diabetes have been developed and found to be practical and welcomed. But they have not been evaluated sufficiently in these NIHR studies to say if they are effective.

With regards to mental health difficulties, two studies show that learning disability services can deliver adapted interventions for low mood and anxiety, and in both studies, included the input of the person's usual carers. Cognitive behavioural approaches to reduce anger and aggression have a modest evidence base, and evidence is needed for effectiveness in community learning disability services. Adapting programmes for people with learning disabilities may work best when their care staff or family are included to support them.

Research has not yet addressed how specialist

services for people with learning disabilities can best assist mainstream services to be more accessible and effective for people with learning disabilities with the overall aim of supporting people to achieve and maintain good health.



### Prompts for reflection

- How can professional and family carers be better supported by mainstream and specialist services to promote and sustain healthy lifestyles of adults living in community settings?
- How can GP and community services be more accessible and learning disability friendly?
- Given that experts by experience are used as self-management coaches for the general population, could people with disabilities be effective healthy lifestyle coaches for their peer group?
- The NHS Plan includes proposals for making it mandatory for all front-line NHS staff to be trained to support people with learning disabilities in their services. Evaluation is needed to examine whether training of staff benefits the health of people with learning disabilities.
- How well do commissioners engage people with learning disabilities from ethnic minorities as part of their approach to commissioning accessible and culturally appropriate services?
- How can maternity services and local authorities ensure parents with a learning disability get the support they need?
- How can women with learning disabilities be made more aware of the risks of potentially exploitative and violent relationships, and better supported to choose to keep themselves safe?
- Is it better for people with learning disabilities living in the community to have psychological therapies provided within specialist learning disability services, or would it be better if they could use mainstream provision adapted to their needs?

## Staying well and safe in hospital

Following the preventable deaths of six patients in general hospitals raised by Mencap (13), an independent inquiry published in 2008 (14) into health care for people with learning disabilities set out key principles for all NHS hospitals in England. Among the 10 essential changes to the systems of care that were recommended, one was that hospitals should appoint learning disability specialist nurses, identify people with learning disabilities, and - by law - make reasonable adjustments. This is to ensure care is safe and effective, and involving family and other carers in the care provided by the hospital. NHSE issued guidance in 2014 on making reasonable adjustments and interventions that could reduce early death in people with learning disabilities (40). This includes reference to NIHR research featured in this section. Yet the evidence from a large-scale audit of deaths of people with learning disabilities has shown that there are still many care processes not followed which could reduce the number of preventable deaths (8). The most recent LeDeR audit (16) includes recommendations that could reduce poor care in hospital, including the dangers of diagnostic overshadowing and the inappropriate use of resuscitation and deterioration protocols without discussion.

In the aftermath of these important changes in the requirements for how hospitals manage the care of people with learning disabilities, research in six studies has evidenced how adults and children with learning disabilities are treated when in general

hospitals.

“ They decided Angela needed a hip replacement. I knew she would struggle with the follow up physio exercises because she lives on her own and she just won't do it unless someone is there with her. I shared my concerns at her pre-assessment, about who would care for her after discharge. Hospital passed me to GP, GP passed me to social services, social services passed me back to GP. So when it came to it, they cancelled the operation because of fear that she wouldn't manage afterwards..... It is wasteful of time and money, distressing for Angela, and still she needs these operations. ”

Carer of Angela, woman with learning disability

A study (**Study 17**) looked at how the national inquiry principles to improve care for adults with learning disability were working in practice in six hospitals in England with data collected between 2011 and 2012. The study found some good practice, but this was inconsistent. Hospitals lacked systems to flag up and identify patients with learning disabilities and to make adjustments, with only 13% of staff finding out from these systems if a person has a learning disability. General hospital staff knowledge of learning disabilities was lacking, and family carers were often not involved in care processes while the person was in hospital. What made a difference to carers and staff was when hospitals

employed learning disability liaison nurses and when ward managers “were running a tight ship” and supporting their staff to deliver care to these patients. Systems for identifying and investigating patient safety incidents were not capturing the lapses in care identified by staff and families. The study findings supported the role that specialist learning disability nurses can make in general hospitals. Recommendations included making all staff aware of their duties in making sure patients with learning disabilities are identified, their needs documented, reasonable adjustments are made and the implementation of actions are monitored.

This study, along with the confidential inquiry (CIPOLD) report and (LeDeR) annual reports of the audit of deaths of people with learning disabilities, has been influential in highlighting changes needed. In more recent years, hospitals have introduced systems for electronic flags in the medical records to identify people with learning disabilities, appointed specialist learning disability nurses, introduced ‘Hospital Passports’ which provide healthcare staff with information about the care needs of individual patients and introduced ‘Carers’ Agreements’ which help to ensure that healthcare practitioners and family carers have a clear sense of what each can expect of the other. Some hospitals have provided staff with additional training in the needs of people with a learning disability and their duties under equalities legislation and the Mental Capacity Act.

There have been smaller scale studies relevant to how people with learning disabilities are cared for in hospitals.

To investigate what doctors in two general hospitals understood about making reasonable adjustments

for patient with learning disabilities, Redley and colleagues interviewed 14 doctors (41). They all struggled with providing care as they wanted to their patients with learning disabilities, mainly because of issues with communication with their patients, and what they called non-conforming behaviour in the ward disrupting their care. Half made little use of reasonable adjustments, and few made use of the specialist learning disability nurse or patient passports.

“ They come at 5 o'clock in the evening and then there's this issue with the food. They come around with a card on the table, on your trolley and you have to fill it in with whatever food you like. And I didn't do that - I just screwed it up and threw it away, Nobody helped me to fill it in. What if I had a disability? They just wouldn't care. They would just see to other people, ordinary people. ”

Clarence, man with learning disability, unable to complete forms without help.

A study (**Study 18**) in one teaching hospital with data from 2010-11 looked at the quality of acute hospital care, as defined by the rates of re-admission as an emergency within 30 days of being discharged from in-patient care. While rates of re-admission were not different to the general population, the reasons for re-admission were three times more likely to have been preventable by better hospital care. The hospital employed a learning disability nurse and had a system for flagging people with

learning disabilities in the notes. This study used data from just one hospital which makes us cautious in generalising to the country as a whole. But it is useful in highlighting the potential for reducing avoidable admissions for people with a learning disability.

All these studies highlight areas for improvement in hospitals' staff and care systems of patient care and discharge arrangements for people with learning disabilities. The experience of parents of children with learning disabilities suggests they have concerns about the quality, safety and accessibility of hospital care for their child. These concerns are often that the staff fail to understand the needs of their child and fail to communicate with them as parents and with their child in delivering care. A campaign by Mencap ([www.mencap.org.uk/treatmewell](http://www.mencap.org.uk/treatmewell)) is currently calling for improvements in how hospital care is delivered to people with a learning disability.

Communication in hospital can be particularly challenging for people with learning disabilities who have communication needs, and those who rely on communication aids. Families often feel unable to leave children and adults with learning disabilities because of concerns about communication. Some people may not use formal communication like words or signs and may rely on those who know them well to help identify if their behaviour is different to usual and if they may be in pain. People with a learning disability and their families may not be enabled by staff to understand their choices and have inadequate opportunity to engage in decision-making. Based on a review and interviews with staff and parents of children on a paediatric ward, a one-hour training programme for staff

has been developed and found to be feasible and acceptable in a children's ward of one hospital. Further feasibility testing has been undertaken in two general hospitals and three children's hospitals. Staff perceived it to be valuable. The training and resources are available for wider use in the NHS and could usefully be evaluated to see if they improve communication and outcomes (42).

An on-going study (43) is looking at how children with learning disabilities fare in hospital compared to children with other disabilities and with no learning disability. Children who need aids to communicate face particular difficulties when receiving health care. The study is examining who these children are, what issues they have with communication, and how professionals make recommendations for what aids are suitable for different children. These could range from equipment and techniques, which support or replace spoken communication from gesture, signing, symbols, word boards, communication boards and books, as well as electronic communication aids. The results from this work, which is in progress, will be used to create a web-based resource to support decision making by all involved in assessment.

Interim findings from the first phase reports the results of individual interviews and a large survey of staff in 15 of the 16 children's hospitals in England, and nine general and teaching hospitals. They found that hospital staff perceived that children with learning disabilities were included less, valued less, and less safe than children with other disabilities and without learning disabilities. There was great variability in the extent to which learning disability specific policies and protocols existed or were known about by hospital staff. Unsurprisingly,

therefore, they also reported having less confidence, capability and capacity to meet the needs of this population compared to children with disabilities and without learning disabilities. This part of the study concluded there is evidence of inequality in the current provision of high-quality hospital care to children and young people with LD that meets their needs (44).

This project is also ground-breaking in the way that it has involved children with severe communication difficulties in co-producing the research. The study will produce "how to guides" for such involvement as well as an economic case for how the additional resources required for such involvement on research can be considered.

More recent research has found great variation in the extent that commissioners and service providers say they are fulfilling duties on providing reasonable adjustments for people with learning disabilities (45).

NHS England has recently developed a new framework of learning disability standards for all trusts (46), and collection of data for benchmarking improvement (47).

## Conclusions

There is consistent evidence from confidential enquiries, complaints and investigations into unexpected deaths that general hospitals vary greatly in how well they identify and make adjustments for patients who have learning disabilities. Research indicates problems in how hospitals implement these recommendations including confidence of general hospital staff in addressing the needs of both adult and children

inpatients. Learning disability nurses were found to make valued contributions to care, and further research may demonstrate their impact on experience and care outcomes. Little is known about what difference patient passports make to how well staff are able to adjust the care they provide. Early research has been carried out into how staff can use aids to help children with difficulties in communication and interventions.

## Prompts for reflection

- Does the hospital have a system for flagging patients with learning disabilities, including those attending as out-patients?
- How do we tackle diagnostic overshadowing (resulting in under diagnosis) by health professionals?
- How can everyone responsible for ensuring reasonable adjustments are made for patients with learning disabilities in a general hospital ward or service be encouraged to assume this responsibility?
- Does our hospital have learning disability liaison nurses, and how are other clinicians, patients and families using this resource?
- How are family or professional carers involved in care for people with learning disabilities in a general hospital ward or service?
- How many patients have hospital passports, and how effectively are they used by hospital staff and families?
- The NHS Long Term Plan makes it mandatory for all front-line NHS staff to be trained to support people with learning disabilities in their services. How can hospitals ensure all staff are trained to better care for people with learning disabilities, for example in improving communication issues or understanding mental capacity?

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My 26 year old son had a sebaceous cyst – a lump the size of a golf ball on his forehead and growing all the time. The plastic surgeon we saw said it would have been easier if they'd seen him earlier but it would be a pretty straightforward operation that would carry limited risk. But the idea of him going into hospital filled me with fear and dread.

A few weeks before the surgery I contacted the Learning Disability Liaison Nurse at the hospital. She worked with me, his staff team the ward to ensure the right adjustments were made for him. We discussed his inability to wait, that he'd need a separate room for everyone's sake - not just his - he wouldn't keep his wrist band on or his surgical stockings, he wouldn't stay still to have the cannula put in, or tolerate pre-op checks like blood pressure. Having talked all this through I felt less anxious.

On the day of the surgery his two support staff and I went to the reception on the ward. They showed us his private room and we asked to wheel him around the ward in his wheelchair. He was happy to watch the hustle and bustle of the ward.

The anaesthetic worked! We managed to get his wrist band around his ankle and his surgical stockings on and his gown half on. We even managed to get him on the bed while he was getting sleepy. The Anaesthetist cheered when she came to see him and said I could go with him to the anaesthetics room while he had his cannula put in.

**Parent of Ed, man with learning disability**

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# Services supporting positive behaviour

As many as one in five adults with learning disabilities have been described as having behaviours that challenge (48). These can include self-injurious behaviour - repeated patterns of behaviour, outward aggression to others (e.g. hitting) and destruction of property. Behaviour that challenges is understood to have a functional and communicative purpose, express a sensory need, and may indicate unmet needs and/or distress. Behaviours that challenge may be precipitated by the interaction of individual and environmental factors. These behaviours can also be a reaction to pain or discomfort associated with undiagnosed or untreated physical problems. People with learning disabilities and behaviour that challenges are at greater risk of social exclusion, institutionalisation, exposure to ineffective or restrictive interventions, over-medication and abuse.

The evidence base from empirical and robust research on what models of service in the community should replace long stay hospitals is limited. There is insufficient evidence to show how people with complex mental health needs, which may include behaviours that challenge, can be safely and effectively supported in their local communities. Services for adults across the range of learning disabilities with mental health difficulties or who display behaviours that challenge are most commonly provided by specialist community learning disability services. Evidence for the design of these services is limited. NICE has called for more research to inform person-centred service design (1).

A 2016 Cochrane review of randomised controlled trials (**Study 19**) on the organisation of services for people with learning disabilities and behavioural problems found seven studies including five from England, all published before 2010. All participants had psychological or behavioural problems. The review found that providing a healthcare service in the community more often and with greater intensity than the usual community service has, surprisingly, no effect on behavioural outcomes and how much care and support family carers provided, nor on the cost of services. It found that community-based specialist behaviour support, which is often part of community learning disability services in England, may slightly reduce behaviour that challenges. Studies did not look at whether people also had physical health problems and how these were addressed, and no interventions looked at ways to better integrate services to address the complex nature of the specific and general health needs of adults with learning disabilities.

Positive Behaviour Support (PBS) has become a central approach in learning disability services in the UK and beyond to prevent and reduce behaviours that challenge, and is recommended in NICE service models guidance (1). PBS uses Applied Behaviour Analysis in a person-centred and values-based approach to understand the reasons for the behaviour and considers the person as a whole in order to implement ways of supporting them. PBS focuses on creating physical and social environments that are supportive and capable of meeting people's needs. It emphasises prevention and teaching people new skills to replace the behaviours that challenge. (<http://www.bild.org.uk/capbs/capbs/>).

Four rigorous large-scale NIHR studies have researched positive support interventions delivered through community and residential services support to adults with learning disability and behaviours that challenge.

Small scale studies of PBS delivered by care staff suggest that it reduces behaviour that challenges and costs of care and improves quality of life. Its use is supported in the recent NICE quality standard (49). A small-scale NIHR-funded study compared those receiving the support of a specialist team using PBS to a comparator group who only received services as usual. This study achieved positive outcomes two years later and evidence that costs were no greater to services in the intervention arm than the control (50). NIHR-funded the first full trial in the context of NHS services. A randomised controlled trial (**Study 20**) evaluated delivering PBS training to staff in community learning disability services. At least two staff members of each community learning disability team were trained for 6 days over 15 weeks and used a manual to guide their intervention with people with learning disabilities. Challenging behavior was assessed independently of the staff. There was no difference on the primary outcome of behavior at 12 months, nor other outcomes, including carer burden and quality of life. Qualitative research however suggested the programme was valued by staff, service users and carers.

There are many reasons why this training intervention in PBS produced an unexpected finding. It is not known what interventions those in the comparison group received. The service model may not have been delivered as intended including the extent to which PBS was employed

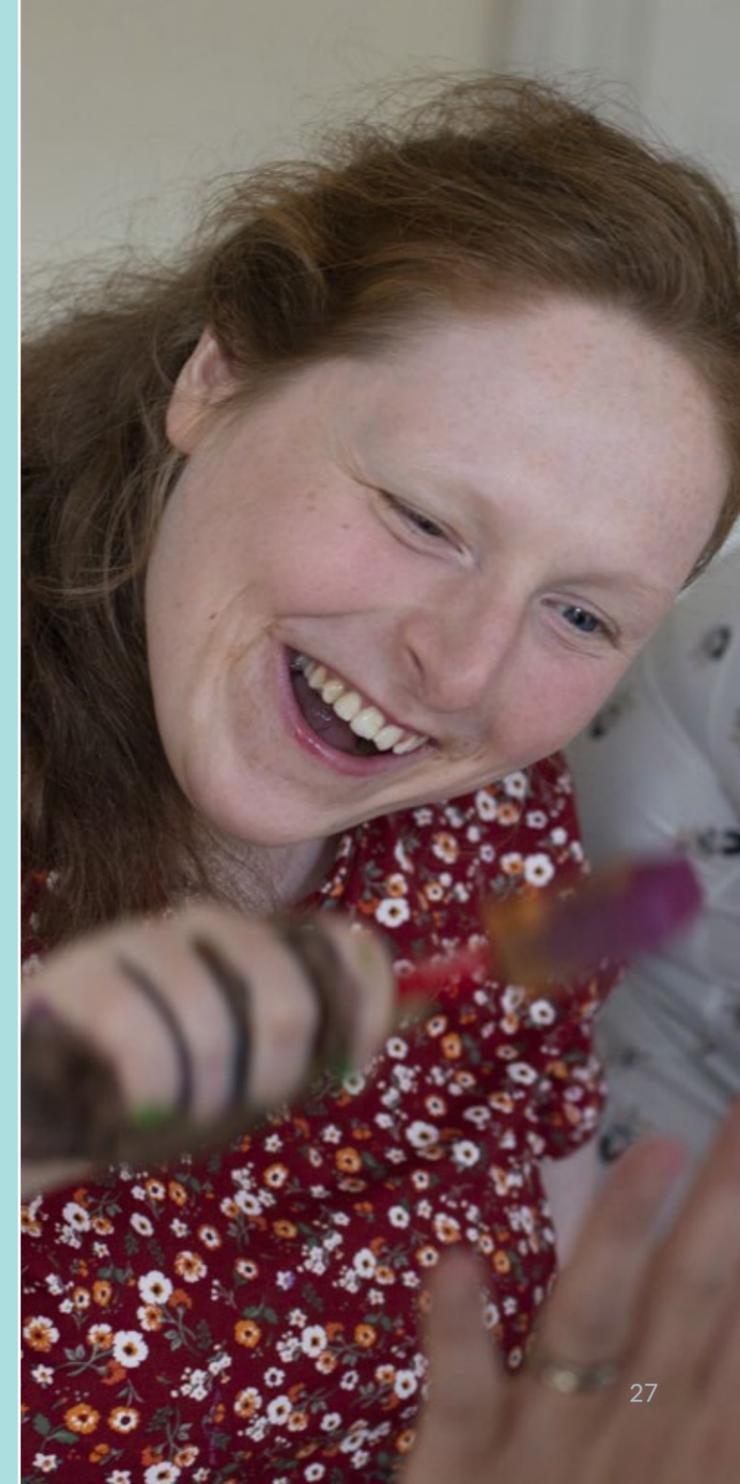
and that other staff supporting the individual with learning disabilities used the approaches as planned. While the interviews showed staff delivering the intervention, families and some service users valued the approach, the independent audit of plans showed very weak use of the key components of PBS within individual PBS plans. There was no measurement of other care staff's involvement in the implementation of care plans. Staff who were trained experienced difficulty in finding the time to complete what they saw as additional paperwork. One third of the trained staff left during the study, and given only two per team were trained, the effect of training staff was likely to have been diluted by not also providing a refresher course, by ineffective supervision and lack of managerial support.

While PBS may involve changing staff behaviour, it does not explicitly address the motivation of staff to change their work practices. This may be as important to address in those who are trained as specialists in PBS as well as those delivering care on a day to day basis. Yet their beliefs are part of the rationale of why staff behaviour can provoke or reduce behaviour that challenges. If staff do not understand why some 'attention-seeking' behaviours occur, and only respond when they become extreme or respond in a punitive way, the behaviour may escalate. Staff empathy (or understanding for the situation of another person) may be key to motivating staff to understand behaviours that challenge and their causes.

In supported group homes and residential care in the community, the occurrence of behaviours that challenge can lead to restrictive practices, over-medication for the person, and injury to staff, breakdown of placements and costly out of area

placements. Too often it is seen as an individual problem, rather than in the context of how support is offered, that is, the quality of support and organisation of the care environment. PBS can be seen as part of a system-wide approach that is relevant to these settings.

Taking a different approach to staff training, the Who's Challenging Who group training and individual coaching intervention was co-produced with and delivered by people with learning disabilities and behaviour that challenges (**Study 21**). In a randomised controlled trial this programme was tested in 118 residential care settings randomised to either receive training or to receive training after a delay. Outcome measures were collected at baseline, six weeks and 20 weeks post-randomisation. The results showed that training did not effectively improve staff self-reported empathy for people with behaviour that challenges at 20 weeks. However, staff who received training reported more positive attitudes towards people with learning disability and behaviour that challenges, in their confidence in working with people behaviour that challenges, and work-related well-being, measured at 20 weeks. The study results were however only based on just over half the staff due to high drop-outs at 20 week follow up. Also, staff were aware of the training they had received, so may have been biased towards giving positive results. Given the positive uptake of the workshop and low cost (£360/group) even the small effects achieved suggest this could be a useful training approach for staff. The study is notable for rigorous evaluation of a co-produced intervention, and for data gathered that showed the trainers with learning disability delivered the staff training to a high degree of fidelity.





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When my son Douglas was sectioned we were extremely concerned by the use of seclusion as a behaviour management strategy on a mainstream psychiatry ward, and the trauma he could suffer as result. He does not have the mental capacity to understand ‘punitive’ approaches (i.e. seclusion) when displaying distressed behaviour in a state of poor mental wellbeing - often referred to as his ‘challenging’ behaviours.

We successfully challenged the hospital’s seclusion policy, which we believed failed to account for his substantial disadvantage compared with those who are not disabled.

Detailed preventative, de-escalation and response strategies were documented in a support plan, developed over many years with input from a multi-disciplinary team, working closely with him and his family and support staff. The support plan detailed the adaptive technologies needed to manage his learning disability. He needs a combination of systems and strategies to cope, function and communicate.

We successfully requested:

- He should immediately have his iPad and use it with staff to build relationships and enable him to communicate more effectively
- He should be involved in creating an activity timetable giving him therapies and opportunities for interaction
- Seclusion should be used only as a last resort once all other behaviour support strategies have been attempted
- If seclusion or removal to a ‘safe space’ is necessary, it should be to a space with familiar items and resources he can use to help him cope; ideally his own room, with focused interactions from trusted individuals as part of a de-escalation strategy
- His family and support staff should be fully involved with decisions made around his care, as they are most qualified to help him to communicate his needs and to coach hospital staff.

**Parent of Douglas, a man with learning disability.**

”

In a residential care context, a study (**Study 22**) set out to develop and evaluate an approach to improving the quality of social care in supported accommodation settings by changing staff practice using positive behaviour support principles. The study was a pragmatic, cluster randomised controlled trial (RCT) in 24 homes. The approach taken was for an expert practitioner/researcher to observe practice and implement changes with the staff over 8-11 months. After a week of observation, feedback was given on how the home met the eight key areas of social care in relation to influencing behaviour that challenges, and developed into an improvement plan. Taking a system-wide approach, they met with staff and managers, and were involved in problem-solving, coaching and training them. There was a significant improvement in staff-rated behaviour that challenges post intervention, where behaviour that challenges reduced by two thirds, far more than in the controls. Much of this was maintained at 18 months after the study started. Staff and families generally rated the intervention positively. Importantly, the intervention met 80% of the standards set about how it should be delivered, and this rose across the 18- month period during which the intervention was implemented. As it was delivered in one care provider (Dimensions), the intervention needs to be tested more widely. Although the intervention was intensive, and could therefore be costly, the extent of change achieved could reduce costs to services in future.

### Case Study: Making Improvements

Steve and Richard lived in a staffed group home with two other men. At baseline, both men were reported to display frequent challenging behaviour including physical aggression. Neither took part in community-based activities. Health input with Steve was organised to better manage his allergies and to deal with incontinence. A greenhouse and summerhouse were added to the previously little-used garden -Richard greatly enjoyed pottering about outside. Staff morale had been poor following problems getting overtime pay and disputes over rotas. Payment problems were investigated and sorted, managers were supported to develop fair rotas. Staff had also been concerned about being regularly woken at night so a meeting with care managers was organised to discuss the possibility of waking night cover. Outcomes for both men, and the setting as a whole, were very positive. Serious incidents of challenging behaviour now only happened every couple of months rather than every week. There was daily use of community settings and positive feedback from Steve's family. Night-time problems had been resolved and staff were no longer needing to get up at night so discussion of waking night cover was no longer required.

Source: McGill (**Study 22**)

A community group home can be challenging for many people with a learning disability. Those with more complex needs may rely on those who provide their care only to them. Those people whose support is shared with others may find this particularly challenging, because they are often reliant on support staff to present opportunities, and to provide help and encouragement to undertake and enjoy activities of their choice. Many studies have shown the generally low levels of physical, social and economic activity that people with learning disabilities engage in, especially those with more complex needs. Active support from staff and carers is key to engagement. The introduction of training of care staff in active support aims to increase the amount and quality of contact. A study (**Study 23**) examined the link between staff assistance and meaningful activity in 25 homes nominated as "good" by the home provider and 10 randomly selected comparators. Direct observations were recorded, and assessment made of activities on offer, methods of communication in use, the quality of staff interactions and empathy, and use of Positive Behaviour Support. Active support included support to do gardening, or to take part in a community group. Only one-third of people received consistently good active support, and these were generally the least disabled. On average people were spending at least three-quarters of their time with no contact from anyone. Verbal communication was seen often to be used with people whom staff rated as not having any verbal understanding. The number of staff available was high, so considerations are more about how the resources are used and the staff supported to provide consistent active support.

### Conclusions

Recent abuse scandals at places such as Winterbourne View, Muckamore Abbey and Whorlton Hall show how people with behaviour that challenges can be abused when out of sight in institutional settings and cared for by staff with little training and inadequate supervision. While there has been a strong policy push for people with learning disabilities who display behaviours that challenge to live in community settings and receive specialist services from learning disability community service teams, there has been little evidence to support this model of services. Overall, we do not know enough about the impact of community support for behaviour that challenges in the long term.

Using person-centred approaches such as Positive Behavioural Support has some evidence of effectiveness in addressing behaviour that challenges from smaller studies, particularly where it is delivered by specialist staff working with learning disability community and social care staff. NIHR-funded one large trial to test training of community learning disability team staff in a PBS approach in community learning disability services. This showed little effect, but few staff delivered the intervention as planned. A second study showed that people with behaviour that challenges can successfully deliver training to residential care staff. A third trial using a PBS-informed approach to improve social care for residents reduced behaviour that challenges by two thirds. This study focused on how the staff apply the approach to each individual in their personal context. It is evident that PBS is an intervention that cannot be effectively applied without also

addressing how all staff within a team (and the person's personal supporters in their everyday life) are motivated to use it and are involved in the approach. This is important given that one study found that only one third of people in community group homes received consistently good support to stay active and engaged in enjoyable day to day tasks and that these were the least disabled people.

### Prompts for reflection

- How do you ensure that staff receive appropriate training as individuals and in teams to support people with behaviour that challenges? What support are staff given to carry out their role, such as supervision?
- When implementing training for staff who work with the same service users is it more effective to train them as a team, refreshing training when new staff join, to maintain a culture that supports behaviour change?
- How far do recruitment practices focus on selecting people with values compatible to working with people whose behaviour they may find to be challenging?
- Enabling staff to empathise more with people with learning disabilities whom they find challenging may be good for their morale at work and self-confidence in their practice. How might that be achieved?
- How much are staff engaging in their daily work with residents, and do they engage with those who have the greatest difficulty engaging socially or taking up activities on offer on their own? How do you know whether this is working?
- Improving the amount and quality of active support by care staff to enable people to use social and other activities may help to prevent the development of behaviours that challenge in people in supported community living settings. How might this improvement be achieved?

# Conducting research together

NIHR has a strong record of funding studies that involve the public and patients /service-users in the research process. The studies in this review exemplify how this can be achieved. As participants, the research had included some of the most vulnerable populations where the ethical issues of consent require careful navigation. Some studies have co-produced interventions with people with learning disabilities (**Study 21**). Others have routinely demonstrated how they have consulted people with learning disabilities and their families in the design and recruitment (**Study 9**), and in interpreting and commenting on findings (**Studies 1 & 3**) as well as in dissemination (**Studies 2 & 3**). Some have published an account of how they have gone about this (51, 52).

Photo (c) Royal Mencap Society

A recently completed NIHR study (53) was designed to ensure that the lived experiences of people who use communication aids and their families were central to the research delivery and the resources developed from the work. The study employed public involvement co-researchers who had personal experience of the use of communication aids and of supporting those with learning disability. These people had communicative disabilities but did not have learning disabilities. Some of the research participants had learning disabilities. The co-researchers were equal members of the research team at every stage of the research: at the idea stage; undertaking the research by helping develop data collection materials and interviewing participants; contributing to the coding and analysis process and how the study findings and resources are communicated to others. From the research results, they played a full role in developing project resources which included tools to ensure the voices of children, young people and families are heard during clinical assessment for communication aids.

# Conclusions and future directions

The research funded by NIHR in the past decade has helped to drive forward research on topics that our consultation groups found matter to people with learning disabilities. We know that people with learning disabilities can be involved as participants, giving their voice directly in research studies. People with learning disabilities have been successfully recruited into large multi-centre studies in research which feeds into guidelines affecting their care. With academics, they can co-produce excellent research that provides new insights. Research into services for people with learning disabilities can contribute to debates about the best use of public money, with evidence of cost-effectiveness, and the prevention of future ill health and unnecessary service use being part of the picture. We have highlighted some small but high-quality studies in social care and non-NHS settings, which may be a stepping-stone for larger and more robust studies in the community, where

most people with learning disabilities spend most of their lives.

## What do we know already?

NIHR research has shown that GP annual health checks can improve health and health care of people with learning disabilities. The health check consultation can identify important health conditions, like diabetes and heart disease as well as specific issues like thyroid and gastrointestinal problems more likely to affect those with learning disabilities. Health checks can reduce the use of unplanned hospital services, particularly for those whose conditions may be preventable by better primary and community healthcare. People who are particularly vulnerable include those who need mealtime support and who need regular GP checks to avoid respiratory disorder related emergency hospitalisation.

We have seen early testing of services designed specifically for people with learning disabilities to help them lose weight, or address health behaviours related to diabetes. They are accessible and acceptable, but there needs to be larger scale and more robust evaluation of their implementation at scale to know if they are effective. Similarly, these studies have shown learning disability services can deliver adapted interventions for low mood, anxiety and anger. Delivering programmes for people with learning disabilities may work best when their care staff or family are included to support them.

This review also included research looking at people with learning disability who may face particular problems. This includes studies with tools to help commissioners address the needs of different ethnic groups (**Study 14**), and the support needed for parents (**Study 15**), with learning disabilities. One qualitative study indicates the way in which reduced

central and local funding has impacted particularly hard on social care services for people with learning disabilities and their families (**Study 13**). A small study looking at the vulnerability of women with learning disabilities to domestic violence and abuse provides insights for the learning disability community, schools, police, social care and housing services as to how to make choices and to be safe (**Study 16**).

There is consistent evidence in the studies reviewed that general hospital services vary greatly in how well they identify and make adjustments for patients who have learning disabilities. We know that poor care in hospital makes people with learning disabilities more likely to be readmitted within a month. Research is on-going looking at the extent that children with learning disabilities in hospitals are receiving the care they and their families have so often voiced as being needed (43).

While there has been an important policy shift towards community health and social care services to support people living in their community, there is little research underpinning these new models of care. A form of person-centred care, known as Positive Behavioural Support (PBS), is recognised as best practice. NIHR studies to date showing its effectiveness in reducing behaviour that challenges were based on models where specialist teams in the NHS or in residential care settings delivered PBS interventions. When staff in community learning disability teams were given PBS training, the intervention showed no evidence of effectiveness (**Study 20**). A second trial (**Study 22**) using a PBS informed approach and with feedback to staff on their use of the approach in small community residential settings showed sustained impact in reducing behaviour that challenges. It is likely that PBS is an organisational level intervention requiring

not only the skills of staff in PBS but the involvement of the person's family carers and/or other supporters.

## What types of research have been used?

There is a wide range of health services research methods used in these NIHR studies. This includes the largest trials of interventions in real-life settings (**Study 20**) on behaviour that challenges in NHS services and (**Study 22**) in residential services, and the use of administrative datasets around hospital admissions (**Study 3**). It also includes important qualitative research on experience of people with learning disabilities and families and mixed-methods studies on the organisation and quality of care. Many studies include people with lived experience not just as participants but as part of the research process, including co-designing and delivering the intervention. (**Study 21**) (54).

## What do we still need to know?

This report has highlighted some important national research on the health and care of people with learning disabilities. But there is still much we do not know. Organisations such as the James Lind Alliance, (Appendix B) and NICE when producing its guidelines, continue to highlight many areas where more research is needed. Exercises to identify future research needs or design new services will be strengthened by involving people with learning disabilities and their families. Below are some of the areas highlighted by this review.

The positive effect of health checks on people with learning disability is supported by the research in this review, but there is considerable scope to improve uptake. Research is needed on how practices can reach more people, particularly those with complex needs who may find attending their



GP problematic without family or carer support. Given that currently only half the people eligible are having these checks, there is scope to improve accessibility, uptake and effectiveness of follow-on actions in the health action plans. Given that health checks apply to people from age 14 years, research on outcomes for adolescents and young people with learning disability is needed.

There were no NIHR studies on the organisation and delivery of learning disability services for children, although new models of child and adolescent mental health services may include such provision. Research could usefully be undertaken on the links with special education services, and focus on the implementation of education, health and care plans for children and young people in transition to adulthood.

Further research is needed to develop and evaluate mental wellbeing promotion and mental health self-management programmes for this population, whether this is designed to be delivered through specialist learning disability services, or through mainstream mental health services delivered in England known as Improving Access to Psychological Therapies (IAPT) and through public health services.

Given the success of self-advocacy and the large body of research on peer approaches by NIHR, and national programmes such as the Expert Patients Programme and the Health Foundation's Co-creating Health which used experts by experience along with clinicians to deliver self-management (55), there is scope for research into peer-led long term condition self-management programmes.

Despite the policy push for models of service provision and supported living outside secure inpatient units, there is limited research into the organisation and delivery of these services. Studies

here provide a useful basis on which to build further evaluations of how best to deliver targeted or strengthened Positive Behaviour Support in community learning disability services. There is need for research into the impact of community support for people with behaviour that challenges in the long term, wherever they live. Also, given that people spend most time in their residential or home setting, we need more research evaluating interventions to promote self-management of health and healthy lifestyles in these contexts.

Evidence suggests there is little research in the UK on how people with learning disabilities access and use mainstream community services, such as opticians or sexual health clinics. Little is known of how maternity services, parenting support and health visiting services are experienced, or the extent to which making reasonable adjustments results in better support to parents with learning disabilities.

There is scope for research across the health, social care and criminal justice systems on prevention and intervention in relation to domestic abuse for women with learning disabilities.

Research is needed into how effective adjustments can be made to better care for people with learning disabilities in general hospitals. As an example, research reviewed here has highlighted the need for more effective use of the communication aids used by people with learning disabilities with general hospital staff. There is a need for research into how services are applying the Mental Capacity Act and are following through on its application in hospitals.

Given the improved life expectancy of the general population, including people with learning disabilities, there is a research gap concerning how services can support older people with learning

disabilities. This may be particularly problematic for those who develop early onset dementia and who may no longer be able to be supported in the family home or community supported living. In addition, there is a gap around how services can support the families of people with a learning disability, as they become ageing carers, for example in terms of end of life care planning.

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It is encouraging to see the evidence gathered here on aspects of learning disability services. To achieve the NHS Long Term Plan goals of improving health and care for people with learning disabilities, we are now working in close collaboration with people with learning disabilities, autistic people, their families and other stakeholders to identify gaps and priorities for future research in a systematic way. We need good and relevant evidence to achieve these ambitions.

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Dr Roger Banks , National Clinical Director, Learning Disability and Autism NHS England and NHS Improvement

Photo (c) Royal Mencap Society



# Acknowledgements

Designed by Kate Searle

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# Study Summaries and References

## Study Summaries

### STUDY 1

#### Impact of the English Directly Enhanced Service (DES) for Learning Disability. 2012

Principal Investigator Umesh Chauhan

(Funding: Department of Health Policy Research Programme supported by NIHR)

In a study of 171 GP practices in six different locations in England, data was examined from GP records over two years from 2009/10. The recording of health checks increased over the two years with greater numbers of patients identified with learning disability. Health checks were associated with increased identification of disease conditions already incentivised by existing quality schemes, such as coronary heart disease and diabetes. Health checks were also associated with increased screening, immunisation and health promotion activity. Those incentivised through GP contracting scheme (the QOF) were more likely to be recorded. Processes which are specific for learning disability were also more likely to be recorded through a health check (such health action plans, hearing and visual checks) and there were more referrals to services for conditions common in people with learning disabilities. But few people had feeding or behaviour assessments, and there was considerable variability in the level of recording. The experience of 32 people with learning disabilities, 19 of whom had received health checks, was examined by interview. Obstacles included already known issues not specific to health checks such as communication problems in consultations and between professionals in the practice and elsewhere, such as hospitals. Staff interviews found practices were making some adjustments, such as home visits. While largely welcoming the scheme, GPs identified many barriers to its implementation, including insufficient training of staff, and poor engagement with community LD services.

U Chauhan, J Reeve, E Kontopantelis, S Hinder, P Nelson, T

Doran. Impact of the English directly enhanced service (DES) for learning disability 2012.

<https://www.networks.nhs.uk/nhs-networks/national-health-facilitation-network-learning/documents/Impact%20of%20DES%20-%20Chauhan-%20Reeve-%20Kontopantelis%20et%20al.pdf>

### STUDY 2

#### Health checks for people with Learning Disabilities – improving their uptake and effectiveness. 2013

Principal Investigator Professor Andre Strydom

(Funding: NIHR Programme Grants for Applied Research - RP-DG-0611-10003)

People with learning disabilities are much more likely to have health problems and die earlier than the general population. Since 2008 a directed enhanced service (LD-DES) incentivises GPs in England to offer LD adults annual health checks, but only half are having these checks. This study looked the clinical conditions picked up in these health checks. Not only were diabetes and epilepsy detected as for those screened in the general adult population, but also conditions more prevalent and problematic in people with learning disabilities. These include thyroid and gastrointestinal problems. There were also more tests undertaken, health assessments of lifestyle, medication reviews and health action plans. The study looked at the costs and effect on healthcare use of the health checks. From a database of 587 practices, data was collected on 208 people who had the health check and 102 who did not. The study found in both groups there was an increase in the use of healthcare in subsequent years from when checks were introduced in 2008. People with learning disabilities who did not have an annual health check had a significant increase in unplanned health care use (such as hospitalisation) which was not seen in people who had had a check, where there was significant increase in GP phone consultations, and outpatient appointments, better health monitoring and more preventive care which may have reduced the use of unplanned care. The average cost of the check was

estimated at £142.57, which may be because more than half were delivered by GPs.

Buszewicz M, Welch C, Horsfall L, Nazareth I, Osborn D, Hassiotis A, Chauhan U, Hoghton M, Cooper SA, Moulster G, Hithersay R, Hunter R, Heslop P, Coutenay K and Strydom A. Assessment of an incentivised scheme to provide annual health checks for adults with intellectual disability: a longitudinal cohort study. The Lancet Psychiatry 2014;1(7):522-530

[https://doi.org/10.1016/S2215-0366\(14\)00079-0](https://doi.org/10.1016/S2215-0366(14)00079-0)

### STUDY 3

#### An Evaluation of the Effectiveness of Annual Health Checks and Quality of Health Care for Adults with Learning Disability. 2017

Principal Investigator Dr Iain Carey

(Funding: NIHR HS & DR - 12/64/154)

People with a learning disability have more health problems than the general population, leading to more unplanned visits to hospital. In 2008 NHSE introduced a payment to GPs to offer LD adults annual health checks, but by 2017, only half were having these checks. This study aimed to understand whether or not health checks make any important lasting difference to health, such as preventing unplanned hospital admissions. The study used databases of GP records (Clinical Practice Research Datalink) linked to national hospital admissions (Hospital Episode Statistics) and mortality data sets (Office for National Statistics). In 451 English GP practices the data was extracted from health records of 21,859 people with learning disabilities who were matched with more than 152,846 people in similar practices and of similar age, sex without learning disability. Patients were registered between 2009 and 2013. The study found that although health checks did not reduce overall unplanned admissions, they were associated with a reduction in potentially preventable hospital admissions. These included conditions such as COPD, where hospitalisation could be avoided by good primary care management. Practices with high levels of health

checks for people with learning disabilities had lower rates of preventable emergency admissions than those practices who did fewer health checks. Also, adults with a learning disability had more recorded illnesses such as epilepsy and mental health problems and consulted with their GP more than the general population. But these consultations were shorter and less likely to be with the same GP. This may mean that for health checks to be more effective, primary care may need to make further adjustments. The study also showed variation between practices in levels of recording and detail of health checks, particularly for mental health and bowel or bladder conditions. The results show that health checks for patients with a learning disability can be effective in preventing some unnecessary hospital visits, and that practices should be encouraged to ensure that more eligible patients receive them.

Carey IM, Hosking FJ, Harris T, DeWilde S, Beighton C & Cook DG. An evaluation of the effectiveness of annual health checks and quality of health care for adults with intellectual disability: an observational study using a primary care database. Health Serv Deliv Res 2017;5(25)

<https://doi.org/10.3310/hsdr05250>

### STUDY 4

#### Gaining entry access to primary and community health care services for adults with intellectual disabilities: Mapping and targeted systematic review. 2019

Principal Investigator Anna Cantrell

(Funding: NIHR HS&DR - 16/47/17)

This review mapped the evidence on factors affecting how people with learning disabilities access general primary and community healthcare services. It included a systematic review of 80 studies published between 2002 and 2018. The overall strength of evidence was poor due to small size of studies and weak designs, adding little to what was already found in an earlier Albotz (2003) review. Most studies were focussed on GP services, with a smaller number on referral to mental health for mood disorders, optical, sexual health and dental clinics. Health checks were found

to help identify health needs and improve the care of long-term conditions. Although the overall quality of research was poor, there are some common themes that emerged. Important factors across the studies for accessing health services for adults with learning disabilities were consistency of care and support provided by the practitioner, staff training in awareness of the Mental Capacity Act in relation to consent, and the time in consultations to provide accessible information. The health needs of a particular individual should be accurately recorded, along with clear communication with people with learning disabilities and between professionals and services. Professionals need to ensure that there is joint working between different services including involving learning disability services in general and community healthcare, awareness of health needs related to the causes of learning disability and common problems such as polypharmacy. The findings are consistent with the recommendations of the second Learning Disabilities Mortality Review (LedeR) programme annual report.

Cantrell A, Croot E, Johnson M, Wong R, Chambers D, Baxter S, Booth A. Gaining entry access to primary and community health care services for adults with intellectual disabilities: mapping and targeted systematic review.

<https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/164717/#/> Web report 10 July 2019

### STUDY 5

#### The incidence of healthcare use, ill health and mortality in adults with intellectual disabilities and mealtime support needs. 2017

Principal Investigator C M Perez

(Funding: NIHR under its Research for Patient Benefit (RfPB) Programme - PB-PG-0906-11098)

Adults with learning disabilities commonly experience problems with eating, drinking and swallowing (EDS), and studies have found around 15% require mealtime support. In a cohort study in East Anglia caregivers of 127 adults with learning disabilities were interviewed and followed up two years later. The study found that adults with learning

disabilities who had a history of respiratory infection, epilepsy, difficulty swallowing were at risk of respiratory infections year later. Adults with greater mealtime support needs (such as being fed by someone else) and epilepsy were at greater risk of emergency hospitalisation. Having epilepsy strongly predicted both respiratory infections and emergency hospitalisation. The authors point out that epilepsy is more prevalent among individuals with learning disabilities than the general population, generally harder to control in this group, and is associated with more severe learning disabilities. In line with other research, they conclude that increased risk of aspiration and asphyxiation post-seizure may explain why epilepsy is associated with an increased risk of respiratory infections and emergency hospitalisations. Nearly all participants had one or more consultations with a general practitioner each year and, in the first year, 20% reportedly had one or more emergency hospitalizations. The study has helped to identify those who may require closer monitoring at mealtimes, and that GP health checks should include inquiry into mealtime support, particularly because of the link to preventable respiratory infections.

Perez CM, Wagner AP, Bal ISL, White SR, Clare ICH, Holland AJ and Redley M. Prognostic models for identifying adults with intellectual disabilities and mealtime support needs who are at greatest risk of respiratory infection and emergency hospitalisation. Journal of Intellectual Disability Research (2017);61(8): 737-754.

<https://doi.org/10.1111/jir.12376>

### STUDY 6

#### Training nurses in a competency framework to support adults with epilepsy and intellectual disability: the EpAID cluster RCT. 2018

Principal Investigator Howard Ring

(Funding: NIHR HTA -10/104/16)

This trial investigated whether learning disability nurses can cost-effectively improve outcomes for adults with a learning disability and epilepsy, using a competency framework which provides guidelines describing a structure

and goals to support the delivery of epilepsy care and provides management by learning disability-trained nurses. This was a two-arm cluster randomised controlled trial of 312 adults with range of mild to severe learning disability from 17 research sites across the UK. Eight of the sites were randomised to the competency framework (n=184) for a minimum of 24 weeks and compared to treatment as usual where the nurses were not working to the framework. Results showed no difference in the primary outcome (available for 76% of participants), which was a measure of seizure severity as noticed by somebody providing care for them, using the Epilepsy and Learning Disabilities Quality of Life questionnaire. However, for those with a mild to moderate learning disability, the competency framework may be associated with a small reduction in concerns over seizure severity. Likewise, in terms of the secondary outcomes, which included an economic analysis, health-related quality of life, carer strain, seizure frequency and side effects, there were no significant differences between the arms. Economic analysis suggested that the competency framework intervention might be cost-effective. Family members' perceptions of nurses' management depended on the professional status of the nurses, regardless of trial arm. The author noted that treatment as usual was the existing management approach for each participant and varied widely between the sites.

Ring H, Howlett J, Pennington M, Smith C, Redley M, Murphy C, et al. Training nurses in a competency framework to support adults with epilepsy and intellectual disability: the EpAID cluster RCT. *Health Technol Assess* 2018;22(10)

<https://doi.org/10.3310/hta22100>

#### STUDY 7

**Development of a structured screening and lifestyle intervention for prevention of Type 2 Diabetes Mellitus in a population with Learning Disabilities. 2017**

*Principal Investigator Kamlesh Khunti*

This team aimed to screen people with learning disabilities for diabetes and high blood sugar (risk of diabetes) in the community in specialist learning disability services and through general practices. 930 people with learning

disability were recruited. They found that around 1 in 100 people screened had Type 2 diabetes and 5 in 100 had raised blood sugar levels, which are below levels found in the general population. However, the authors noted that 68 in 100 people were overweight or obese. They developed and trialled a group education programme. The STOP diabetes group education sessions were run for 8 weeks, and attended by 5 - 7 people with a learning disability, along with carers (paid and family members). The programme was run 3 times with good attendance. The last time the programme was run, outcome measures were taken (body measurements, blood pressure, diet and activity), both before and after 3 months follow up. There were some changes in weight and activity at follow-up but numbers were too small for meaningful analysis. The study showed that it was feasible to deliver the intervention and retain people in the programme, and to gain good quality data on the key measures. Although not powered to provide definitive results, early estimates from the study suggested the intervention was unlikely to be cost-effective unless more closely targeted at older people or those who are obese, and if the intervention were to cost less.

Dunkley AJ, Tyrer F, Spong R, Gray LJ, Gillet M, Doherty Y, et al. Screening for glucose intolerance and development of a lifestyle education programme for prevention of type 2 diabetes in a population with intellectual disabilities: the STOP Diabetes research project. *Programme Grants Appl Res* 2017;5(11)

<https://doi.org/10.3310/pgfar05110>

#### STUDY 8

**Weight management interventions for adults with intellectual disabilities who are obese OR Managing with learning disability and diabetes. 2018**

*Principal Investigator Allan House*

*(Funding: NIHR HTA/PR10/102/03)*

The team developed and evaluated the first self-management programme in the UK for people with long term health conditions and mild to moderate learning disabilities living

in the community. The programme was tailored with help from specialist learning disability experts. Modified elements included easy read materials, identifying and engaging supports in helping set personal goals and supporting them in these activities in and outside the home-based diabetes nurse sessions. The most frequent goals identified were to increase physical activity and to modify diet.

In a two-arm feasibility RCT, 82 (89%) of those adults contacted with diabetes who were not on insulin were randomised and 35/41 (85%) completed all of the two to four sessions offered. The study found that the tailored programme was acceptable and feasible, and people who start it are likely to complete it. Measures such as additional blood testing and body measurement were acceptable. The quality of life measure was completed by almost all, but a patient health questionnaire self-report measure was not well understood by up to half of the participants. A fully powered trial with a meaningful follow-up would be required to establish if the intervention is effective. Although not definitive, early results suggested minimal effects on post-treatment measures. It may be that a more sustained programme of support beyond the two hours of intervention is needed to sustain lifestyle changes in people with learning disabilities.

House A, Bryant L, Russell AM, Wright-Hughes A, Graham L, Walwyn R, et al. Managing with Learning Disability and Diabetes: OK-Diabetes - a case-finding study and feasibility randomised controlled trial. *Health Technol Assess* 2018;22(26)

<https://doi.org/10.3310/hta22260>

#### STUDY 9

**Weight management interventions for adults with intellectual disabilities who are obese. 2018**

*Principal Investigator Professor Josephine Gibson*

*(Funding: NIHR Collaboration for Leadership in Applied Health Research and Care North West Coast (CLAHRC NWC))*

A small study conducted in Lancashire asked 19 volunteer adults with learning disabilities, (whose weight was not

reported) about what helped them to eat healthily. They reported many barriers to eating well such as lack of carer support and access to affordable healthy food options. Those who had accessed weight management services welcomed the group support. They interviewed 14 primary care and community healthcare professionals, who identified barriers such as inconsistent professional carer input in consultations, lack of easy read material to support advice and referral to weight management services, their own lack of knowledge of these services, and incentive for providing advice. They also perceived that their patients lacked motivation to change their habits. A review of five studies described how weight management programmes had been tailored for people with learning disabilities; by using easy read and symbol communication tools, individualised sessions, and involvement of professional and family carers. Three UK studies in the review were of the "Take 5" intervention that is designed for people with learning disabilities, and included personalised diet, activity and behaviour change to alter "bad habits" such as use of takeaway foods. Only two studies, both using the "Take 5" approach, showed clinically significant weight loss in people who were obese. The authors note that the intensive one to one programme may not be sustainable in routine practice.

Doherty AJ, Jones SP, Chauhan U, Gibson JM. Eating well, living well and weight management: A co-produced semi-qualitative study of barriers and facilitators experienced by adults with intellectual disabilities. *Journal of Intellectual Disabilities*. 2018 Jan 1:1744629518773938.

<https://doi.org/10.1177/1744629518773938>

#### STUDY 10

**BEAT-IT: A randomised controlled trial comparing a behavioural activation treatment for depression in adults with learning disabilities with an attention control. 2018**

*Principal Investigator Andrew Jahoda*

*(Funding: NIHR HTA 10/104/34)*

People with learning disabilities are at least as likely to become and stay depressed as the general population, but

their depression is less likely to be diagnosed and treated. This study looked at two approaches recommended by NICE for the general population to help with this (and no controls). It compared behavioural activation, delivered by a therapist tailored to the person's own goals (BeatIt) with tailored self-help materials focused on general ways to improve mood (e.g. improving sleep and problem-solving) (Step Up). These were delivered by community nurses and allied health professionals experienced in working with learning disabilities, to people where they normally lived and supported by carers and family. These supporters participated in the programme. There were 161 participants randomised to the two treatments and 88% completed the programmes. People improved their activity and reduced depression as much on average in both groups, with the effects on depression evident at 4 months and maintained for 12 months. Professional and family carers' confidence to support them in the activities also improved. The BeatIt programme cost more to deliver. Interviews with therapists and participants showed the importance of good therapeutic relationships, and tailoring of activities and support outside the session by the supporter were seen as key to success on both programmes. The successful delivery of this trial, with high rates of adherence and carried out in existing services, shows the possibility of training professional groups, who are already working with people who have learning disabilities and depression, to deliver focused psychological interventions such as behavioural activation and guided self-help. The updated manuals and a training video have been produced and online training is to be launched in Scotland and by Health Education England.

Jahoda A, Hastings R, Hatton C, Cooper SA, McMeekin N, Dagnan D, et al. Behavioural activation versus guided self-help for depression in adults with learning disabilities: the BeatIt RCT. *Health Technol Assess* 2018;22(53)

<https://doi.org/10.3310/hta22530>

#### STUDY 11

**Behavioural and cognitive-behavioural interventions for outwardly-directed aggressive behaviour in people with intellectual disabilities. 2015**

*Principal Investigator Afia Ali*

*(Funding: Cochrane Developmental, Psychosocial and Learning Problems Group, University College London, UK)*

This systematic review explored the impact of psychological therapies in reducing aggressive behaviour in people with learning disabilities. It included 6 studies, four of which were conducted in the UK, involving people aged 17 years and over (n=309) with learning disabilities (mild-to-severe/profound) who exhibit aggressive behaviour. The interventions were conducted in community settings (one in a forensic inpatient setting), either individually or in a group, and lasted for 9 to 52 weeks. These studies examined a range of cognitive-behavioural therapy approaches including anger management, assertiveness training and problem solving, meditation and relaxation. These were compared with those waiting for treatment or receiving standard care. The authors found some evidence of reduced anger ratings and aggressive incidents, and improved anger coping skills and adaptive behaviour at the end of treatment. No studies reported adverse events. In terms of secondary outcomes, the evidence suggested that psychological therapies may improve mental health symptoms, but did not improve quality of life or reduce costs to health services. Due to the diversity of the interventions and participant groups, the author was unable to make conclusions about the effectiveness of any particular approach.

Ali A, Hall I, Blickwedel J, Hassiotis A. Behavioural and cognitive-behavioural interventions for outwardly-directed aggressive behaviour in people with intellectual disabilities. *Cochrane Database of Systematic Reviews* 2015;(4):CD003406.

<https://doi.org/10.1002/14651858.CD003406.pub4>

## STUDY 12

**A cluster randomised controlled trial of a manualised cognitive behavioural anger management intervention delivered by supervised lay therapists to people with intellectual disabilities. 2013**

*Principal Investigator Paul Willner*

*(Funding: NIHR HTA - 08/53/34)*

This trial investigated the effectiveness of a lay therapist-led CBT intervention to improve self-reported anger and anger coping skills in people with mild to moderate learning disabilities. It was a two-arm cluster randomised controlled trial with participants (n=179) with problem anger from 28 centres across England, Scotland and Wales, aged 28-48, 70% male. Half the centres received the intervention, comprising 12 weekly two-hour group sessions supplemented by 'homework', delivered by lay therapists (n=2 on average) who received training and ongoing supervision from a clinical psychologist. The mean hourly cost per service user was £25.26, compared to £12.92 for treatment as usual. The main outcome was the service user's self-reported anger at the 10-month follow-up, measured by a tool called a Provocation Index which was used by 79% of participants. Results showed no impact of the intervention on these scores at the 10-month follow-up. The authors concluded that this particular index may not have been the best tool as it measures response to hypothetical situations that may provoke anger, which is more difficult for people with learning disabilities to imagine. The intervention significantly improved service user and staff anger coping skills post intervention and was maintained at 10 months, but other secondary outcomes were not changed. The experience of service users, lay therapists and service managers was positive when interviewed post intervention.

Willner P, Rose J, Jahoda A, Stenfert-Kroese B, Felce D. A cluster randomised controlled trial of a manualised cognitive behavioural anger management intervention delivered by supervised lay therapists to people with intellectual disabilities. *Health Technol Assess* 2013;17(21).

<https://doi.org/10.3310/hta17210>

## STUDY 13

**Becoming less eligible? Intellectual disability services in the age of austerity. 2018**

*Principal Investigator Rachel Forrester-Jones*

*(Funding: National Institute for Health Research (NIHR) School of Social Care Research- C088/CM/UKJF-P100)*

This review investigated the impact that global austerity has had on the lives of people with learning disabilities and on the people who support them. Eleven research articles were included, almost all were qualitative including focus groups and interviews. They comprised five studies from the UK and the rest from US, Canada and the Netherlands. Using a mix of qualitative methods, the viewpoints of people with learning disabilities, informal carers and paid caregivers gave rise to one main theme, which was loss. Two subthemes emerged, one of which was people with learning disabilities experienced a loss of independence, choice and social participation in their daily lives, which in turn increased social isolation. The other subtheme was that austerity measures negatively affected the quality of care they were receiving, as resources are spread more thinly and day services are closed, further increasing social isolation. Cuts in disability services have negatively affected the wellbeing both of people with learning disabilities and their informal carers, with family carers having to increase or take on the role of caring. Family carers described how increased caring responsibilities also increased financial burden, stress and emotional exhaustion. The author noted that the studies included were poor quality with participation bias, including the exclusion of specific groups with learning disabilities.

Melina Aikaterini Malli, Lara Sams, Rachel Forrester-Jones, Glynis Murphy & Melanie Henwood. Austerity and the lives of people with learning disabilities. A thematic synthesis of current literature. *Disability & Society* 2018;33(9):1412-1435.

<https://doi.org/10.1080/09687599.2018.1497950>

## STUDY 14

**People with learning disabilities from black and minority groups: An exploration of their experiences and views of services. 2018**

*Principal Investigator Michael Larkin*

*(Funding: National Institute for Health Research School for Social Care Research- T976-T11-017-UBML)*

This study explored people with learning disabilities' perception of social care and its meaning for them, through their relationship with those services, and in the context of their cultural identities. Adults (n=32) with a mild learning disabilities from any minority population in the West Midlands, namely people with Pakistani, Bangladeshi, Indian, Caribbean, and African heritage, were recruited from a range of organisations. Participants (n=32) took part in individual or group interviews, in their preferred languages, lasting on average 45 minutes. A series of broad topics were identified as important to the participants, including culture and identity, independence, relational networks, current and desired activities, and good support from staff. Participants were generally positive about the services that they received, which they evaluated primarily in terms of their continuing good relationship(s) with the specific person providing the support. Daily activities were also important, whereas views and experiences around independence varied depending on whether respondents felt they were in control of the pace of change for them, or other people were. A set of resources were developed for service providers to use with people with learning disabilities, in order to facilitate culturally-sensitive communication and information sharing, service planning and delivery through improved mutual understanding. These resources were developed as part of the study in a Partnership Event designed to get specific feedback from service users and providers. They are called 'Tools for Talking', and are comprised of five illustrative videos and activities addressing issues that emerged as important, and aim to provide a framework for people with learning disabilities to tell the people around them about their preferences and the meanings they attach to these preferences.

Michael Larkin, Gemma Unwin, Malvika Iyer, Ioanna Tsimopoulou, Sofia Zahid, Kulsoom Malik, Biza Stenfert Kroese & John L Rose. Cultural affordance, social relationships, and narratives of independence: Understanding the meaning of social care for adults with intellectual disabilities from minority ethnic groups in the UK. *International Journal of Developmental Disabilities* 2018;64(3):195-203.

<https://doi.org/10.1080/20473869.2018.1469807>

## STUDY 15

**Pregnancy, parenting and intellectual disability (ID): experiences of maternity and postnatal care. 2017**

*Principal Investigator Maggie Redshaw*

*(Funding: Policy Research Programme in the Department of Health)*

Women with learning disabilities can experience disapproval when they say they are pregnant. They are more likely to have their children taken into care due to child protection or welfare concerns. Mothers with Learning disabilities and their babies are at higher risk of poor outcomes during pregnancy and afterwards. Using qualitative interviews, this small study looked at nine women with varying levels of learning disability. They had been pregnant or given birth in the past three years. The main themes were 'I hate being treated differently', 'I find it harder to understand than other people', 'We've had to prove ourselves' and 'Make sure you've got very good support around you'. Subthemes included: 'Negative attitudes and denial of choice', 'Understanding of normal care', 'Written information' and 'Being judged by professionals'. The study recommends that maternity services should make reasonable adjustments including adapting to their patients' individual communication and learning needs, supporting autonomy and fully informed choice. The study also recommends that mothers whose parenting skills are formally assessed by social services should have clear information about the process, their choices and the level of skill they must demonstrate. They recommend that maternity services

should provide sufficient antenatal and postnatal support to give them the best possible chance of passing the assessment.

Malouf R, McLeish J, Ryan S, Gray R, Redshaw M. 'We both just wanted to be normal parents': a qualitative study of the experience of maternity care for women with learning disability. *BMJ Open* 2017;7(3):e015526.

<http://dx.doi.org/10.1136/bmjopen-2016-015526>

## STUDY 16

**Domestic violence and women with learning disabilities. 2018**

*Principal Investigator Michelle McCarthy*

*(Funding: NIHR School for Social Care Research)*

Domestic abuse is common but vastly under reported in the general population. There is nothing about having a learning disability that protects women from abuse. Interviews were conducted with 15 women with mild and moderate learning disabilities (aged 20-67), who had experienced domestic violence, and had left the abusive relationship. A survey was conducted of 172 police officers and 545 practitioners, including from social care, completed the research survey. Only 20% of police felt they had had a lot or enough training in learning disability issues, compared to 58% of the other practitioners. There was strong agreement from both groups on why women with learning disabilities may be in violent relationships: being seen as an easy target, socially isolated, having a difficult family background. Six who were raising their children described their experience of abuse. Rape featured in all their experiences. Violence occurred - and got worse - in pregnancy. The violence "sabotaged" the mother-child bond, including interfering with access to children taken into care. The survey highlighted that police and social care are able to identify characteristics of partners likely to prey on vulnerable women, and that information should be shared with women with learning disabilities to enable them to be aware of the risks of their choices. The study recommends social workers (including those in adult safeguarding roles and those in domestic violence services)

should train police and work jointly with them wherever possible.

McCarthy M, Bates C, Triantafyllopoulou P, Hunt S, Skillman KM. "Put bluntly, they are targeted by the worst creeps society has to offer": Police and professionals' views and actions relating to domestic violence and women with intellectual disabilities. *J Appl Res Intellect Disabil*. 2018;32(1):71-81.

<https://doi.org/10.1111/jar.12503>

<https://www.sscr.nihr.ac.uk/PDF/Findings/RF39.pdf>

## STUDY 17

**Identifying the factors that affect the implementation of strategies to promote a safer environment for patients who have learning disabilities (LD) in NHS hospitals. 2013**

*Principal Investigator Professor Irene Tuffrey-Wijne*

*(Funding: NIHR Health Services and Delivery Research - 10/1007/22)*

In the light of the recommendations from an inquiry in 2008 into the healthcare of people with learning disabilities in NHS general hospitals, the study in six general hospitals examined what factors promote or compromise a safe environment for adult patients with learning disabilities. Methods included questionnaire surveys, interviews and observation with senior hospital managers, clinical staff, patients and carers (a total of 1251 participants). While some good practice was found, it was not consistent within each hospital. The commonest safety issues were delays and omissions of basic care. The main barriers to better and safer care were a lack of systems that flag a person having a learning disability in their records. This leads to a failure to identify patients with learning disabilities within hospitals. General hospital staff were found to lack training and knowledge in learning disability issues. Carers were too often not encouraged to be directly involved in care in hospital, and often their role and expertise was misunderstood. Hospitals lacked policies and procedures to ensure each person was cared for to

the expected standards as for other patients. What made a difference from both staff and carer perspectives was when hospitals employed learning disability liaison nurses, and ward managers were running a “tight ship” and supporting their staff to deliver care to these patients. Systems for identifying and investigating patient safety incidents were not capturing the lapses in care identified by participants. Incident reports focused mostly around events causing immediate or potential physical harm, such as falls. But the events leading up to these failures was not understood, such as failures to make reasonable adjustments resulting in poor care and adverse events. The research recommended that proactive actions by all healthcare staff around making reasonable adjustments, and how these are accounted for in the investigation of safety incidents, are needed

Tuffrey-Wijne I, Giatras N, Goulding L, Abraham E, Fenwick L, Edwards C, et al. Identifying the factors affecting the implementation of strategies to promote a safer environment for patients with learning disabilities in NHS hospitals: a mixed-methods study. *Health Serv Deliv Res* 2013;1(13)

<https://doi.org/10.3310/hsdr01130>

## STUDY 18

**Investigating the widely held belief that men and women with learning disabilities receive poor quality healthcare when admitted to hospital: a single-site study of 30-day readmission rates. 2015**

*Principal Investigator C L Kelly*

*(Funding: NIHR Collaboration for Leadership in Applied Health Research and Care)*

This study based in one hospital aimed to find out if men and women with learning disabilities receive poorer quality hospital care than those without a learning disability. The measure is a well-used yardstick of quality of acute hospital care, the rates of re-admission as an emergency within 30 days of being discharged. This hospital employed a learning disability nurse and had a system for flagging people with

learning disabilities in the records. There were 256 people aged 16 or older with a learning disability, of which 32 were re-admitted. The records were also examined to see if the reasons for re-admission were for conditions that could have been prevented. Data was retrieved from medical records for 12 months from April 2010. The study found overall readmission rates were similar for patients with learning disabilities and those from the general population. But patients with learning disabilities had a much higher rate of potentially preventable readmissions (69%) when compared to the general population (23%). This was a small study based in one hospital, which limits the generalisability of findings, but the analysis prompts useful questions for others. The authors suggest there is still work to be done to ensure that this patient population receives hospital care that is both safe and of high quality.

Kelly CL, Thompson K, Wagner AP, Waters JP, Thompson A, Jones S, Holland AJ and Redley M. Investigating the widely held belief that men and women with learning disabilities receive poor quality healthcare when admitted to hospital: a single-site study of 30-day readmission rates. *Journal of Intellectual Disability* 2015; 59(9):835-844.

<https://doi.org/10.1111/jir.12193>

## STUDY 19

**Organising healthcare services for persons with an intellectual disability. 2016**

*Principal Investigator Robert Balogh*

*(Funding: Cochrane Infrastructure to the Effective Practice and Organisation of Care group, University of Ontario Institute of Technology, Canada)*

This updated systematic review explored the effectiveness of organisation of healthcare services for adults in the community with mild to severe learning disability and other physical, mental or behavioural problem. It included 7 randomised controlled trials with 347 participants, 5 of which were UK studies. These published studies suggested that increasing the frequency and intensity of service delivery and outreach treatment has no effect

on behavioural problems and caregiver burden, nor does it decrease healthcare costs for persons with a learning disability. Community-based specialist behaviour therapy may slightly decrease behavioural problems. None of the included studies reported on the effect of organisational interventions on physical health or adverse events. Likewise, there was insufficient evidence that the interventions improved the secondary outcomes, which were psychological health and quality of life. This was an international review with health systems that may be very different from UK learning disability services. They would not necessarily include important features of services in this country, such as learning disability liaison nurses, limiting their relevance. The authors found the quality of evidence was low to very low for most of the interventions, due to the small size and number of studies, but all had a low risk of bias. They concluded that more robust research was needed in this area.

Balogh R, McMorris CA, Lunskey Y, Ouellette-Kuntz H, Bourne L, Colantonio A, Gonçalves-Bradley DC. Organising healthcare services for persons with an intellectual disability. *Cochrane Database of Systematic Reviews* 2016;(4):CD007492.

<https://doi.org/10.1002/14651858.CD007492.pub2>

## STUDY 20

**Positive behaviour support training for staff for treating challenging behaviour in people with intellectual disabilities: a cluster RCT. 2018**

*Principal Investigator Angela Hassiotis*

*(Funding: NIHR HTA- 10/104/13)*

This trial investigated whether therapists training in the delivery of Positive Behaviour Support (PBS) is clinically and cost effective in reducing challenging behaviour in community learning disability services among people with learning disability. PBS is a person-centred approach that aims to improve people's quality of life and reduce challenging behaviour by helping the person exert some control over their environment. It was a two arm parallel-

cluster randomised controlled trial with participants that have mild to severe learning disability (n=246), from 23 community ID service teams in England, aged 25-51, 64% male. Teams were randomly assigned to receive face-to-face training (11 teams, n=109) or treatment as usual. All participants received a baseline assessment and were followed up at 12 months, and 75% were assessed at 36 months. The mean cost per participant in the intervention arm was £1201. Results showed no differences in the main outcome, which was carer-reported changes in participants' challenging behaviour between the two groups at 12 or 36 months. Whilst there was a gain in quality-adjusted life-years at 12 months, this was not maintained at 36 months. Service users reported a positive experience in a small qualitative study alongside the trial, and training was well received by staff and carers, but there were challenges in the delivery of PBS including low compliance, fidelity and low reach of the intervention.

Hassiotis A, Poppe M, Strydom A, Vickerstaff V, Hall I, Crabtree J, et al. Positive behaviour support training for staff for treating challenging behaviour in people with intellectual disabilities: a cluster RCT. *Health Technol Assess* 2018;22(15).

<https://doi.org/10.3310/hta22150>

## STUDY 21

**Who's Challenging Who: A cluster randomised controlled trial to test the effectiveness of a staff training intervention to improve support staff attitudes and empathy towards adults with learning disability and challenging behaviours. 2018**

*Principal Investigator Richard Hastings*

*(Funding: National Institute for Health Research School for Social Care Research- CO88/T14-035/WURH-P64)*

This trial investigated the effectiveness of a manualised staff training intervention to improve staff attitudes and empathy towards adults with learning disability and challenging behaviour. It was a two-arm cluster randomised controlled trial with two staff from 118 residential care

settings randomised to either receive training (n=59) or to receive training after a delay (n=59). The Who's Challenging Who intervention is a half day training course delivered by a trainer with learning disability and challenging behaviour with the support of a trainer without disability, with some follow-on coaching with staff from each setting to ensure implementation. The training explores the lived experiences of people with learning disability in six key areas: communication, problems at home, medication, restraint, inclusion and qualities of support staff. Outcome measures were collected at baseline, 6 weeks and 20 weeks post-randomisation. The results (available for only 51% of staff and 64% of settings) showed that training did not substantially improve the primary outcome, which was staff self-reported empathy for people with challenging behaviour at 20-weeks, using a questionnaire. However, staff who received training reported positive outcomes on several secondary measures including attitudes towards people with learning disability and challenging behaviour, self-efficacy in working with people with challenging behaviour, and work-related well-being, measured at 20 weeks. This was the first large trial of a co-produced staff training intervention of this kind.

R. P. Hastings, D. Gillespie, S. Flynn, R. McNamara, Z. Taylor, R. Knight, E. Randell, L. Richards, G. Moody, A. Mitchell, P. Przybylak, B. Williams & P. H. Hunt. Who's challenging who training for staff empathy towards adults with challenging behaviour: cluster randomized controlled trial. *Journal of Intellectual Disability Research* 2018;62(9):798-813.

<https://doi.org/10.1111/jir.12536>

## STUDY 22

**Preventing challenging behaviour of adults with complex needs in supported accommodation. 2018**

*Principal Investigator Peter McGill*

*(Funding: National Institute for Health Research (NIHR) School for Social Care Research)*

The study developed and evaluated an approach to improving the quality of social care in supported

accommodation settings. The intervention was based on learning from other settings, such as quality improvement work in schools to address behaviour problems in students at a whole system level and tailoring it for residential care. The study was a pragmatic, cluster randomised, controlled trial (RCT). There were 11 homes randomised to the intervention and 13 not to have the intervention. The intervention was implemented in each site by one of two researchers working in the homes alongside staff. The study ran from 2012 to 2016 in residential settings for 1-8 adults with learning disabilities, provided by one care provider. After a week of observation, feedback was given on how the home met 8 key standards for high quality social care, in relation to influencing behaviour that challenges. For example, this included communication, since research shows if people understand what is going on, they are less likely to display challenging behaviour. These were developed into an improvement plan. Over 8-11 months the researchers were involved in meeting staff, problem-solving, coaching and training them. For the outcome of challenging behaviour the average scores for each setting reduced in nine of nine experimental settings with the group mean reducing from 39.2 (range: 18.5-61) to 12.5 (range: 4-21). The control group mean reduced from 42.3 (range: 15.7-70) to 34.9 (range: 14-51.7) with seven of twelve settings reducing. Three settings (two experimental, one control) were lost to post intervention data collection. Results were sustained at follow-up. Post intervention, researchers not aware of which home had received the intervention or not, were able to correctly identify almost all of them. Two thirds of the 72 staff in intervention homes who completed ratings of the intervention, rated it as having a positive impact.

Peter McGill, Leah Vanono, Will Clover, Emmett Smyth, Vivien Cooper, Lisa Hopkins, Nick Barratt, Christopher Joyce, Kate Henderson, Sheila Sekasi, Susy Davis, Roy Deveau. Reducing challenging behaviour of adults with intellectual disabilities in supported accommodation: A cluster randomized controlled trial of setting-wide positive behaviour support. *Research in Developmental Disabilities* 2018;81:143-154.

<https://doi.org/10.1016/j.ridd.2018.04.020>

## STUDY 23

### Uncovering the staff culture of good quality supported accommodation for people with intellectual disabilities. 2016

Principal Investigator Professor Julie Beadle-Brown

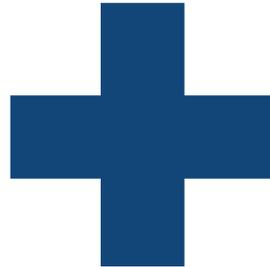
(Funding: National Institute for Health Research (NIHR) School of Social Care Research)

The study examined the link between the quality and amount of staff assistance to engage in meaningful activity, the amount of activity undertaken and the quality of life of residents in 25 group homes. The study compared homes nominated as “good” by the home provider and 10 randomly selected comparators. Direct observations were recorded for 107 individuals. The researcher assessed the range of activities the home offered, the methods of communication in use, the quality of staff interactions and empathy, and use of positive behaviour support (PBS). The ratings of active support showed only 38% of the nominated “good” services showed consistently high levels of active support, and just 12% of the comparator homes. Observations were made on 107 people, many of whom had more severe disabilities. On average they spent 26 minutes in each hour in meaningful activities, although much of it did not involve other people. On average people were spending at least three-quarters of their time with no contact from anyone. When outside the home, one third only interacted with staff and other residents. Just over a third received consistent active support, and these were generally the least disabled. There was a lack of non-verbal communication by staff. Nearly 4 fifths of people whom staff rated as not understanding verbal communication only received communication verbally at least some of the time. In only 17% of homes was PBS well implemented, with a particular lack of providing activities to prevent challenging behaviour. Those who received the most consistent active support, and those who were least disabled, were the most engaged. Staff ratios were high. The authors conclude it is what staff do and how they do it that improves the quality of life of residents.

Beadle-Brown J, Leigh J, Wheton B, Richardson L, Beecham J, Baumaker T and Bradshaw J. Quality of life and quality

of support for people with severe intellectual disability and complex needs. *Journal of Applied Research in Intellectual Disabilities* 2016;29(5):409-421

<https://doi.org/10.1111/jar.12200>



## Appendix A: Policy Background

### Getting it Right For Every Child (GIRFEC)

GIRFEC has been since 2014 the Scottish Government’s national approach to improving the outcomes of, and support for, children and young people. The initiatives arising from GIRFEC are relevant to all children and young people by aiming to ensuring they receive access to early interventions and support, necessary to help them reach their potential. <https://www.gov.scot/policies/girfec/>

### Welsh legislation and Scottish legislation

Wales passed the Social Services and Wellbeing (Wales) Act 2014, which focused on keeping people as independent as possible, reducing or preventing the requirement for targeted services and in particular keeping people out of long term and institutional care.

Additional key Welsh legislation include The Wellbeing of Future Generations Act 2015, the Equality Act 2010 and the Health and Social Care Act 2008 where health and social care organisations have to make “reasonable adjustments” in how services are provided in order to reduce preventable inequalities in health in people with a learning disability.

In June 2018 the Welsh Government published the Learning Disability Improving Lives Programme, to make recommendations to improve services across government (56).

In Scotland additional legislation also supports direct payments (The Social Care (Self-Directed Support) Scotland Act 2013, and the Public Bodies (Joint Working) Act 2014 provide a framework for integration across health and social care services.

### Northern Ireland

People with a learning disability are supported by laws and policies in Northern Ireland to have ‘access to high quality health services that are as locally based as possible and responsive to the particular needs of people with a learning disability’ (DHSSPS 2005) and that ‘All people with a learning disability should have equal access to the full range of health services including services designed to promote positive health and wellbeing.’ (DHSSPS 2015, p13) as described by the healthcare regulator (the Regulation and Quality Improvement Authority, 2018) (57). The Bamford action plan of 2012-15 (58) made 76 recommendations for change across all areas of government affecting people with mental ill health and people with learning disabilities, but an All Party group (59) has highlighted that many recommendations have not been implemented.

### Mental Capacity Act

The Mental Capacity Act 2005 (MCA) is central legislation to the management of the healthcare needs of adults with learning disability because it is the law on decision-making capacity in England and Wales. Applying to people over 16 years old, the MCA stipulates how to determine whether a person has cognitive capacity to consent to medical treatment or social care intervention. It also defines ‘mental incapacity’ and provides legal means to treat or care for people who are incapacitated. The MCA outlines five underpinning principles, which translates as the following for adults with learning disabilities in health and care settings:

- Professionals must assume that the adult with learning disabilities can make their own decisions about their care and treatment needs unless there is information to the contrary;
- Adults with learning disabilities must be supported to make their own decisions about care and treatment before establishing whether they are unable to do so;
- It should not be assumed that the adult with learning disabilities lacks capacity because they have made an ‘unwise decision’ – for instance refusing a treatment or intervention that professionals believe is beneficial does not

necessarily mean that the person is incapacitated;

- Any intervention or treatment for an incapacitated adult with learning disability must be in their ‘best interest’;
- Where deciding on care and medical options for adults with learning disability, the starting point should be the ‘least restrictive’ intervention.

The MCA (Amendment) Act 2019 introduced the Liberty Protection Safeguards (LPS), a legal framework for healthcare interventions for people with learning disability which might otherwise constitute a deprivation of their liberty. Examples include interventions for people whose behaviours are difficult to manage which might result in them being unable to exercise their rights. The MCA and the LPS are the legal bedrock to the care and treatment of adults with learning disability.

### The Care Act 2014

In England, the Care Act 2014 enshrines local authorities’ statutory duties and powers to care, support and safeguard adults with learning disabilities and their carers. It is central to analysis of learning disability services because it is the primary legislation on adult social care. It also encapsulates the policy agenda on choice, personalisation and marketisation of services, and the quest to provide ‘seamless services’ through integration of health and social care. The Act emphasises ‘preventative services’ aimed at maintaining wellbeing (60). This implies that local authorities are responsible for ensuring that adults with learning disabilities live well in the community. In order to achieve this, local authorities have a parallel duty to assess needs, considering the outcomes desired by adults with learning disabilities. Within the Care Act, the duty to assess needs is separate from the statutory responsibility to meet them. Local authorities are required to meet eligible needs (those that the local authority have a duty to provide) through various means including direct provision, ‘brokerage’, direct payments, or even assistive technology. However, the Act emphasises the need for person-centred care plans designed to address the specific needs of the adult with learning disability. This also means that adults with learning disability have a right to be involved in the arranging

of services intended to meet their needs.

Another important local authority duty towards adults with learning disability is safeguarding, which means protecting an adult's right to live in safety, free from abuse and neglect. It is about people and organisations working together to prevent and stop both the risks and experience of abuse or neglect, while at the same time making sure that the adult's wellbeing is promoted including, where appropriate, having regard to their views, wishes, feelings and beliefs in deciding on any action. Implicit in this duty is the supposition that some adults – for example people with learning disability – are susceptible to certain risks, including human rights abuses and require state intervention to keep them safe (61). The Care Act is therefore central to how people with learning disabilities are protected from harm in any setting – e.g. within their homes, in hospital, employment, community centres, etc. It stipulates the process that local authorities must follow to investigate and identify the risk(s) and how they should establish a plan to protect the adult with learning disability.

### Protecting the rights of individuals

Children and adults with learning disabilities have the same human rights as everyone else, but often they are not supported to exercise those rights. Services are required not to discriminate under disability discrimination legislation and to make reasonable adjustments for access under the Equality Act, 2010 (11) but we know many people experience indirect discrimination and exclusion.

Services are required to support personal decision-making under the Mental Capacity Act 2005 (62). Independent advocacy should be available to a person with a learning disability. As a minimum, it should be offered as described in the Care Act 2014 (63), Mental Capacity Act 2005 and Mental Health Act 2007 (64).

The Equality Act 2010, including the Public Sector Equality Duty is UK-wide legislation that provides the legal framework to protect the rights of individuals and advance equality of opportunity for all, including those with disabilities. How the Equality Act and Public Sector Equality Duty apply varies in the countries of the UK.

## Appendix B:

### Outcome of James Lind Alliance priority setting partnership on learning difficulties (Scotland)

<http://www.jla.nihr.ac.uk/priority-setting-partnerships/learning-difficulties-scotland/top-10-priorities.htm>

1. What knowledge, skills and training do educational professionals need to identify the early signs of learning difficulties and provide optimal support for children and young people affected to help them achieve the best possible outcomes?
2. What is the best educational and community environment for children and young people with learning difficulties?
3. How can multiple types of professionals work together with parents and carers to improve identification, diagnosis, interventions and treatments and achieve the best outcomes for children and young people with learning difficulties?
4. Which early interventions are effective for children and young people with learning difficulties, at what ages and stages are they best introduced and what are the long-term outcomes?
5. What knowledge, skills and training do health, social work and “third sector” (e.g. charities and support services) professionals need to understand the best support to give children and young people with learning difficulties and their families/carers?
6. How can parents, carers, brothers and sisters and extended families of children and young people with learning difficulties, be best supported to achieve their best quality of life before, during and after the diagnosis or identification in home, school and community contexts?
7. How can we best identify early features, symptoms and signs of learning difficulties amongst children, young people and their families/carers?

8. What is the best way to assess learning difficulties in children and young people?

9. Which strategies are effective in preventing stigma and bullying towards children and young people with learning difficulties?

10. Which strategies are effective in helping children and young people with learning difficulties live independent lives, including during times of transitions?

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