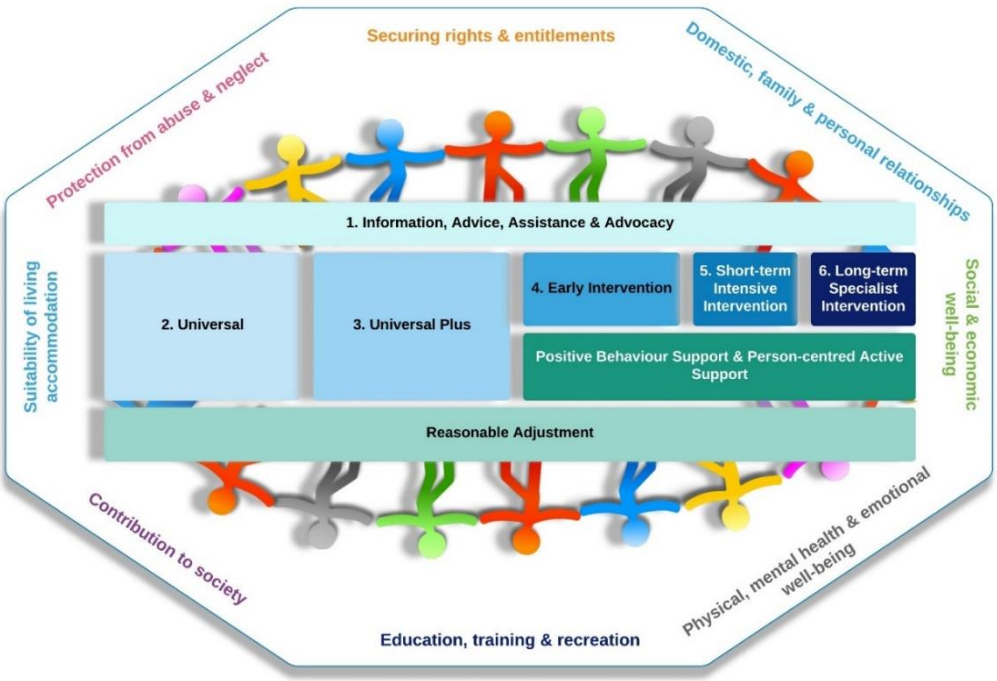
ipc institute of public care

Driving improvement and innovation in care

Institute of Public Care

Ordinary and unique lives for adults with a learning disability and/or autism: a six steps approach

September 2020



OXFORD BROOKES UNIVERSITY

http://ipc.brookes.ac.uk

Ordinary and unique lives for adults with a learning disability and /or autism: a six steps approach

Contents

Foreword

Over the last 20 years, the NHS and councils have seen several policy and legislative changes aimed at supporting and improving the lives of people with a learning disability and/or autism through the promotion of rights, empowerment, prevention, choice and control and independence. But, despite these initiatives, incidents of abuse and ill-treatment in residential settings and examples of health inequalities for people with a learning disability and/or autism remain. We also know that gaps in both universal and early help provision can exacerbate the need for more costly crisis or specialist provision for a person who could have benefitted from more timely and proportional behavioural support.

The Institute of Public Care at Oxford Brookes University strongly believes that now is the right time to build on the foundation of health and social care policy and legislation from across the UK through outcome focused 'integrated' service design, commissioning and performance management approaches. Therefore, this paper offers a whole system model of care – ordinary and unique lives - as the evidence-based framework to describe the support and services needed to promote good outcomes for adults with a learning disability and/or autism. Applying our proven 'six steps' performance management approach to this whole system model will help stakeholders across health and social care to monitor and manage the performance of local public services.

We hope that the service examples and suggested objectives and performance indicators in this paper provide an informative and helpful stimulus for national, regional and local organisations and stakeholders to explore their current arrangements and to describe the future direction and aspirations for the ordinary and unique lives for adults with a learning disability and/or autism in their communities.

Philip Provenzano
Assistant Director
Institute of Public Care

Chris Watson
Associate Consultant
Institute of Public Care

September 2020

1 Introduction and context

This paper sets out good practice in the approach to commissioning services for people with learning disabilities and/or autism. It is aimed at commissioners, working primarily within health and social care settings, who are responsible for the strategic design and development of local services for people with learning disabilities and/or autism and their families and whose role involves driving innovation and practice change.

In 2017 we published our 'six steps' approach to managing demand in adult social care (Institute of Public Care, 2017a). The paper, co-authored by Visiting Professor John Bolton and IPC Assistant Director Philip Provenzano, provided a model for measuring service delivery and identified six critical steps for managing demand in older people's services, linked to suggested performance indicators and targets.

This paper adapts our six steps approach specifically for learning disability services. It includes a set of operational principles, examples of good practice and suggested performance indicators that can be used to form the basis of an effective local commissioning plan that can offer better overall value for the public purse. It also echoes the approach that we developed for the Welsh Government, also in 2017, that emphasises the importance of holistic and community-based support so that people with learning disabilities and/or autism can lead ordinary lives:

"People with learning disabilities want to lead ordinary lives and do the things that most people take for granted. They want to study at college, get a job, have relationships and friendships and enjoy leisure and social activities."
Commissioning Services for People with a Learning Disability: Good Practice Guidance, Institute of Public Care 2017b, p.7

Current policy and national guidance - such as Think Autism, the NHS Long Term Plan and Five Year Forward View as well as Working to Achieve a Healthier Future for Wales - all advocate for a person-centred approach in which greater attention is given to prevention and early intervention with an emphasis on keeping individuals close to their families and communities rather than progressing through a pathway into high-cost placements which are often away from home. However, this ambition has not always been realised in practice.

A key challenge for commissioners is managing the complexity of needs that often result in life-long and high cost packages of support. For example, research undertaken by Deveau et al (2015) identified nine healthcare commissioning teams who were spending over a million pounds annually to support only five of their highest cost individuals. The authors concluded that a small number of support packages often accounted for a very high proportion of the budget spent on support for people with learning disabilities. Given the relatively young average age (32 years old) of those with complex needs who were supported in this manner, this has significant implications for overall lifetime costs.

Alongside this, a recent review by the Centre for Disability Research on the impact of the government's Transforming Care Programme (designed to drastically reduce inpatient numbers) suggests that the numbers of people with learning disabilities and/or autism who are in high cost out of area independent inpatient hospital units may have only reduced by about 14% since 2015, from 2,885 people to 2,495 (Brown et al, 2019).

The Centre for Disability Research's paper costed an average week for one of these inpatient beds at £3,564, which equates to £185,328 per person per annum (James et al, 2016). It is clear why there is a strong financial incentive for more radical change.

Managing demand (i.e. overall spend) in learning disability services is centred around designing better range of local services that focus on preventative early interventions, effective crisis responses, moving people out of institutional settings utilising bespoke housing solutions, and personalised services.

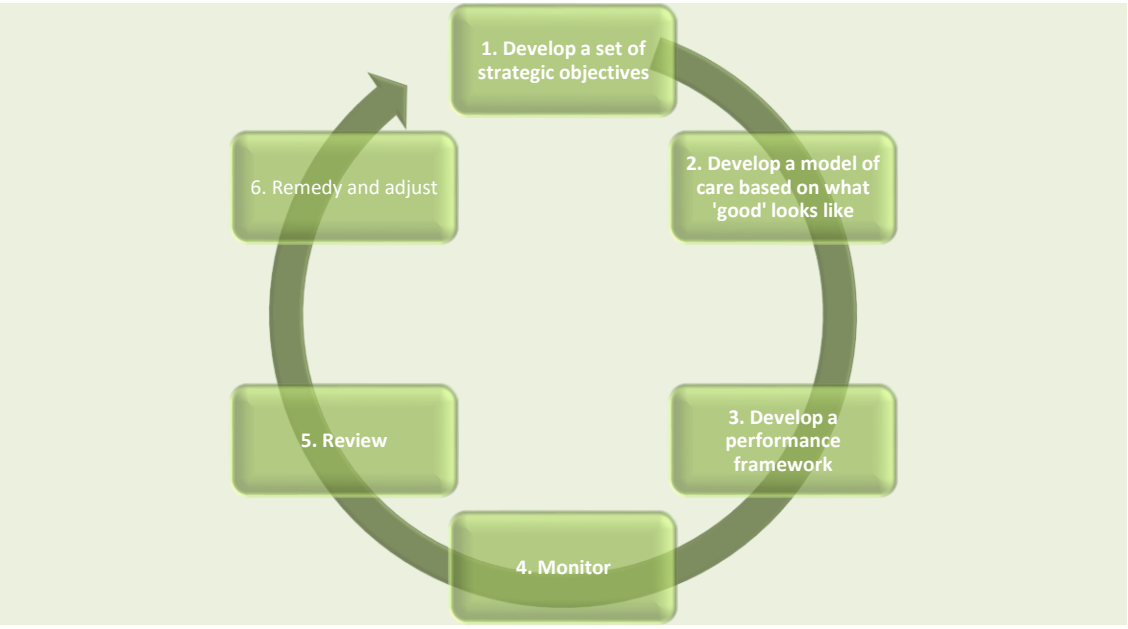
2 A 'six steps' approach to managing demand

The original 'six steps' report (Institute of Public Care, 2017a) outlined the IPC approach to managing demand in adult social care. The report argued that effective performance management arrangements, including measuring and monitoring the performance of services, can lead to better outcomes and more efficient services.

"A key underpinning principle for the development of [robust performance management arrangements] has been the mantra that 'you cannot have good performance without achievement…achievement is not possible without measurement…and measurement is pointless without the context of objectives.' We have used the essence of this discipline as the basis for transforming a set of 'good ideas' into a set of organisational intentions that are systematically monitored and reviewed."

Six Steps to Managing Demand in Adult Social Care - A Performance Management Approach, Institute of Public Care 2017a, p.5

The six steps approach is based on performance management principles and understanding 'what works' in an effective model of care. The approach requires commissioners to follow the performance management cycle as illustrated in the diagram below:



1. Develop set of strategic objectives for learning disability services.

2. Develop a model of care that describes what good practice might look like, based on available evidence, if the strategic objectives are to be achieved.
3. Develop a performance framework that includes a range of **service focused objectives** and **performance indicators** to help measure progress against targets. In this way, managers, front line workers and providers of services can all be held to account for their contribution to the strategic objectives.
4. Based on the performance framework and performance indicators, establish a timely monitoring regime.
5. Convene quarterly performance monitoring review meetings comprising representation from commissioners, providers, care management and people with lived experience.
6. The purpose of the meeting will be to review the data and fully understand the reasons for the performance, and more importantly, what remedial, adjustment or sharing of good practice actions will need to be taken.

The performance management principles established in the 'six steps' report are equally relevant in the context of better outcomes and managing demand for learning disabilities services. Commissioning can promote the right to an 'ordinary life', achieved via creative, citizen focused solutions that don't just involve health or social care inputs.

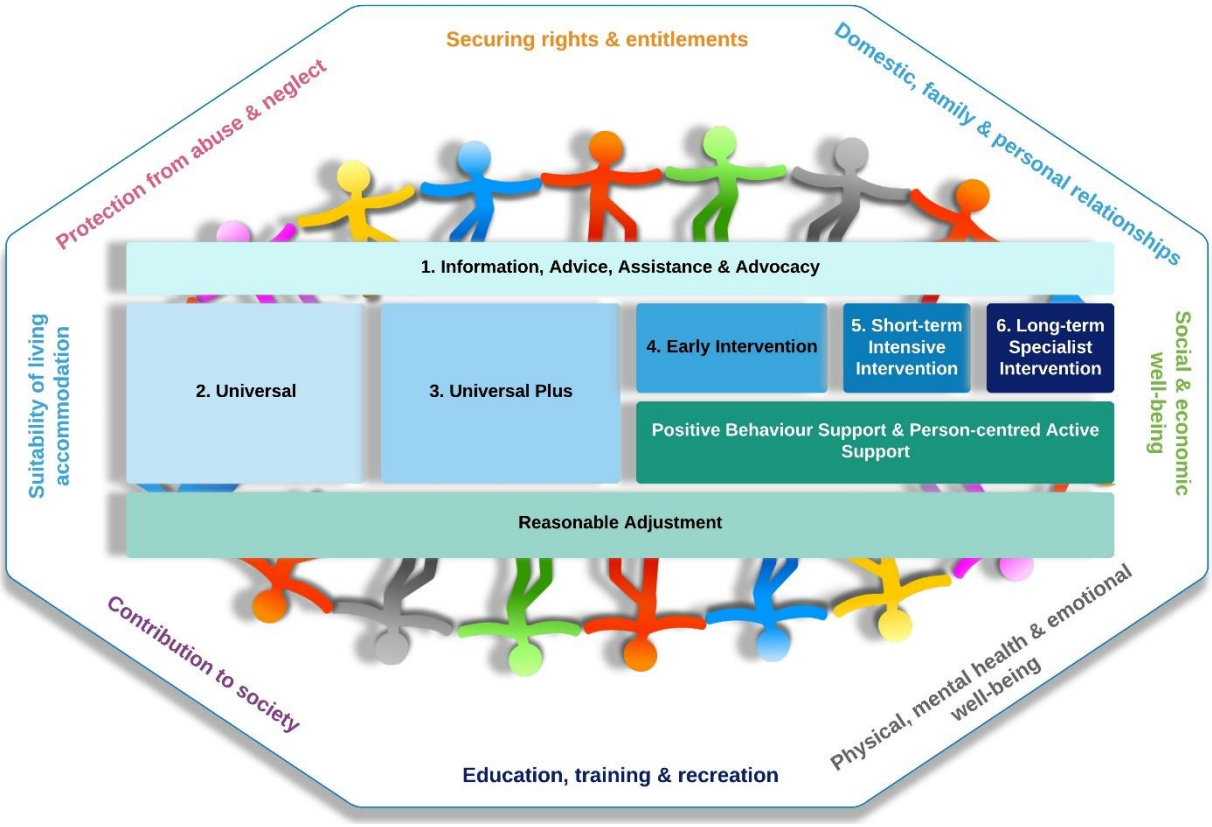
3 The 'ordinary and unique lives' whole system model

The Institute of Public Care whole-system model for commissioning lives that are ordinary (i.e. conducted in the community, in the same settings as people without learning disabilities) and unique (i.e. tailored around individual preferences and personally desired lifestyles), is an evidence-based framework to describe the support and services needed to promote good outcomes for adults with a learning disability and/or autism.

This model was developed through a range of projects undertaken in councils and clinical commissioning groups, funded by the Local Government Association in England and the National Commissioning Board in Wales. These projects focused on improving commissioning arrangements and involved engaging directly with people with learning disabilities and/or autism, families, providers of health and/or social care, commissioners, health and social care practitioners, other council departments and community groups. The purpose of the model is to support people to achieve a range of individual wellbeing outcomes, namely:

- Securing rights and entitlements
- Domestic, family and personal relationships
- Social and economic wellbeing
- Physical and mental health and emotional wellbeing
- Education, training and recreation
- Contribution to society
- Suitability of living accommodation
- Protection from abuse and neglect

A diagrammatical representation of the ordinary and unique lives model for adults with a learning disability and/or autism is shown below:



The model illustrates a spectrum of supports and services that contribute to a person achieving their individual wellbeing outcomes:

1. Information, advice, assistance and advocacy
2. Universal
3. Universal plus
4. Early intervention
5. Short-term intensive intervention
6. Long-term specialistic intervention

That spectrum ranges from effective information, advice, assistance and advocacy, through supports that are universally available (or that have reasonable adjustments) to more intensive and specialist person-centred services that utilise a positive behaviour support approach. Key to ensuring that this range of services is available, is the ability of health and social care commissioners to fully understand their local population now and in the future, and work in partnership with all stakeholders to effectively shape public and community services alongside the wider provider market.

Applying our proven ‘six steps’ performance management approach to this whole system model requires commissioners to develop a set of local objectives for people with a learning disability and/or autism. As illustrated in the performance management cycle (described in section two), we suggest developing both strategic and service objectives that support and contribute to individuals achieving their wellbeing outcomes. For example:

Strategic objectives:

- Support more people with learning disabilities and/or autism to lead healthy, meaningful lives and reduce the need for long-term service provision.
- Reduce the escalation of need and risk, improve personal outcomes and build capacity.
- Support more people to manage crises when they occur and steadily bring the situation back to one in which the problems can be tackled over the longer term.

Service objectives:

- Universal services consistently make reasonable adjustments, enabling people with learning disabilities and/or autism to access services that meet their needs.
- Advocacy services are readily available and able to work with all people with learning disabilities and/or autism no matter what their communication needs or other complexities.
- There is a multi-agency approach to crisis management, embedding positive behaviour support across all health, social care and education settings for all ages.

Example individual wellbeing outcomes:

- Successfully managing a long-term health condition.
- Getting a paid job.
- Feeling confident enough to speak up (self-advocacy).

We advocate that well-designed services that are contracted and provided flexibly, centred on the individual, will reduce or prevent the need for health and social care interventions over time and improve overall wellbeing.

4 Using the model to inform commissioning priorities

The ordinary and unique lives model provides a useful framework for commissioners to identify and take forward key areas of work that, when combined, help to improve wellbeing and reduce demand for health and social care services.

This section looks at ‘good’ examples of the spectrum of supports and services in our ‘ordinary and unique lives’ whole system model. It also explores the role of commissioning in ensuring that support and services across the whole model are available and of the quality required to meet wellbeing outcomes.

In addition to the good practice case study examples, we have made suggestions for service objectives (i.e. statements that articulate an intention/direction of travel for services and stakeholders) and their respective performance measures (i.e. what you would need to count to understand the impact of your services). We have not provided targets for these measures as we have not seen enough data collection examples to inform a benchmark. However, we do suggest that adoption of the objectives and measures relevant to local systems should be explored with stakeholders. A summary of these service objectives and performance indicators is given in the appendix.

4.1 Information, advice, assistance and advocacy

Access to high quality information and advice is fundamental to enabling people to take control of, and make well-informed choices about, their care and support. Not only does information and advice help to promote people's wellbeing by increasing their ability to exercise choice and control, it is also a vital component of preventing or delaying people's need for care and support and carers' need for support.

Providing high quality and timely information and advice should be considered a preventative service in its own right. Advice is a way of working co-productively with an individual or family to explore the options available. Organisations need to consider how to encourage digital inclusion and support people with learning disabilities and/or autism and their families to build digital skills so that they can access digital information.

Access alone doesn't ensure that services across the system are utilised though. Sometimes people need help to build their confidence to approach services and the resilience to continue using them. Assistance involves another person taking action with the individual to access care and support and ideally should follow the provision of information and advice where it is judged that an individual, or perhaps the family in the case of a child, will need extra help to enable them to access opportunities such as community resources or preventative services.

Some individuals may also require issues-based advocacy to ensure they understand what is available and so that they can engage and participate fully in decisions that affect them. Self-advocacy organisations empower people to challenge prejudice and discrimination through training education and peer support.

Training GPs about health checks in Oxford

Oxford self-advocacy group, My Life My Choice run workshops to explain to GPs how important annual health checks are for people with a learning disability. They hold sessions with GPs to explain how making small changes – called reasonable adjustments – can make annual health checks work better for people. They ask the GPs not to use difficult words, and ask them to talk to the person themselves, not the person they're with. They also show a film of members of My Life, My Choice talking about their annual health check.

Members support nursing students at Oxford Brookes University to communicate with people with a learning disability. They also hold sessions with people with a learning disability, autism or both about how important it is to go for their annual health check. They give advice on what questions to ask – things like what medication they are on and what it is for. Andy likes getting paid to train GPs: *"We've got a voice and we're speaking out on what disability means."*

By running the sessions, Dawn has grown in confidence: *"When I did the training I felt nervous at first because I get tongue tied, but I did it!"*. These sessions help GPs and student nurses to look beyond a person's disability. Dawn says: *"I am a learning disability and a learning disability is me. That doesn't mean we're all the same."*

Example service objectives:

- Advocacy services are readily available and able to work with all people with learning disabilities and/or autism no matter what their communication needs or other complexities.
- Health, social care and other partners use technology and digital solutions to maximise the ability of people with learning disabilities and/or autism to communicate their views and undertake tasks as independently as possible.
- Co-develop an offer for assistance that includes community connectors that are tasked with empowering people to contribute to their communities and reducing isolation and loneliness.
- Maintain/increase the offer of advocacy by ensuring statutory and non-statutory advocacy (such as peer advocacy) is available to all people who are leaving hospital.
- Maintain/increase the reach and impact of self-advocacy organisations.
- Provide support and empower provider groups, family support groups and self-advocacy organisations to design and deliver a local 'reasonable adjustments' campaign.

Example performance indicators:

- % of people with learning disabilities and/or autism accessing advocacy services within 28 days of referral
- % of people leaving hospital accessing advocacy services
- % of people using technology and digital solutions to communicate their views and undertake independent living tasks as independently as possible

4.2 Universal services

Universal services include:

- Leisure services e.g. sports centre, cinema, social clubs, transport, banks, community and faith groups.
- Information services e.g. library, jobcentre, citizen's advice service, charitable organisations.
- Education services e.g. college, adult education.
- Health services e.g. dentist, optician, counselling, pharmacy, GP.

Most people with learning disabilities and/or autism live in the community with limited support. People with learning disabilities and/or autism are at higher risk of many physical and mental health conditions, have fewer opportunities to work and often experience social deprivation. Supporting people to lead healthy, meaningful lives and reducing the need for long-term service provision requires universal services to be accessible. Making services accessible means that 'reasonable adjustments' need to be made to the service.

Examples of reasonable adjustments in primary healthcare include:

- Desensitisation visits
- Car parking for carers and families
- Longer consultation visits
- Alternatives to using the public waiting room
- Creating easy read and accessible information
- Linking with community learning disabilities community social work teams

Health centre makeover helps people with a learning disability and dementia

The makeover at Demontfort Medical Centre means there are now seven more clinical and treatment rooms, with scope for further developments on the second floor for more consulting space in the future. A new lift has also been installed to improve access for disabled people, along with automatic front doors and the reception desk has been improved for greater access and privacy.

Signage is now in place in both words and pictures, with clear colour schemes and labelling, plus suitable flooring and surfaces – all designed to benefit people with dementia and a learning disability.

Renovations at the practice have cost just less than £1 million, £735,000 of which was provided by NHS England West Midlands. The money used to make the changes came from NHS England's Estates and Technology Transformation Fund (ETTF) which aims to offer grants for projects across the region in line with the health service's key priorities.

Patients are already commenting on how much they like the changes and work is continuing to make the practice even more accessible for all visitors.

Example service objective:

- Increase the number of universal services that make reasonable adjustments to enable people with learning disabilities and/or autism to access services that meet needs.
- Increase the availability of tools such as patient passports and communication books.
- Ensure that all day opportunities are focused on accessing universal services for people with a learning disability and/or autism.
- Work with those who commission and manage mainstream activities/services to find ways to make them accessible, in line with Equality Act duties. This should include leisure activities that people struggle to access.
- Devise and roll out comprehensive 'reasonable adjustments training' to all primary and secondary care staff in relation to both learning disability and autism spectrum disorder. The training should include recommendations for system/process changes as well as changing culture and understanding.
- Locally accountable governance arrangements, such as Learning Disability Partnership Boards, encompass community, political, clinical and professional

leadership which transcend organisational boundaries, are collaborative, and ensure that decisions impacting upon people with learning disabilities and/or autism are taken at the most appropriate local level.

Example performance indicators:

- % of local public services that are verified by self-advocacy groups or experts by experience as being accessible to people with learning disabilities and/or autism
- % of public organisations offering information that is in easy read
- % of people with learning disabilities and/or autism admitted to hospital with an up to date patient or communication passport

4.3 Universal plus

On average, people with learning disabilities and/or autism have poorer health and die younger than other people. In part this is because they are more exposed to causes of ill health through greater levels of material deprivation, poorer health-related behaviours and physical conditions often associated with causes of learning disabilities.

But it is also partly a result of poorer understanding of physical changes and problems that indicate illnesses or conditions that could be treated and of how to get help from health services. People with learning disabilities and/or autism should be able to access primary, community and secondary healthcare services in the same way as the general population. There is a need for support for people with learning disabilities and/or autism across the life course to understand and express their needs in relation to their health and wellbeing, and to access health-based information together with support and opportunities to lead healthy lifestyles. This should include increasing opportunities and support for people with learning disabilities and/or autism to work or access further education.

Technology can enable people to achieve outcomes and to have their voice heard. There is a lot of technology that can support people on a daily basis via their phones or tablets and many applications that can be useful for individuals to help them make choices and communicate their needs. Many people are exposed to technology from an early age and it is now a way of life.

Kent County Council: supporting adults with autism through use of technology

The occupational therapy team providing enablement support for adults with autism in Kent is embracing blended physical and virtual approaches. Digital technology can help people have greater independence and self management over their lives.

For many people with autism, technology can be an accessible, autonomous and accepted way to be supported. In Kent many individuals are exploring the use of electronic whiteboards and apps to help with organisational and planning skills so that they can carry out day-to-day tasks independently. Whiteboards and apps can be set up to provide step-by-step prompts on ‘how to’ do something. Prompts can be via pictures, written or voice activated, sync with a person’s calendar on their phone and be added remotely by carers or support staff.

Day-to-day tasks such as making a hot drink or washing bed linen can be made easier by utilising personal photographs demonstrating how the process can be broken down into smaller steps.

"[technology] allows support in a way that is accepted by him. My son is 25 years old and has a degree but without the level of prompts provided by the technology to help with daily tasks, they wouldn't get done".

[Occupational therapist in Kent speaking of her experience of using technology to support her own son with autism].

Example service objective:

- Frontline professionals are trained and mentored so that they have a better awareness and understanding of learning disabilities and autism so that they are better able to make reasonable adjustments.
- All front-line staff engage in asset-based conversations that are person-centred and think holistically about wellbeing.
- GPs offer continuity of relationship between the practitioner, the wider healthcare team, the patient and their carers and family, over time.
- Commissioners develop pathways to support targeted interventions that decrease health inequalities.
- Ensure that commissioners from health continue to work with social care to maximise the numbers of known patients with learning disabilities and to share the information with the GP practices and social care teams.
- Ensure that multi-disciplinary teams are tasked with improving health inequalities for people with learning disabilities and/or autism.
- Engage educational and life-long training organisations, and a range of private sector businesses, in a strategy to increase meaningful occupation - through training, education or employment. Businesses will require evidence about benefits to them employing people with a learning disability and/or autism.

Example performance indicators:

- % of adults with a learning disability and/or autism that access further education, work or undertake meaningful activity
- % of health assessments that are asset based and holistic in nature
- % of adults with a learning disability able to access their mainstream GP surgery

4.4 Early intervention

The provision of preventative and early intervention approaches can reduce the escalation of need and risk, improve personal outcomes and build capacity. Identifying need at its earliest point and providing the appropriate intervention can delay or prevent escalating needs that can often be costly. Being responsive to low level needs must be a consistent and collaborative approach across partners, in which the ability to share information and communicate effectively is key.

Reablement and habilitation (i.e. the process of supplying a person with the means to develop maximum independence in activities of daily living through training, education, and/or treatment) are key elements of preventative and early intervention services. Reablement is about helping people to restore their skills and abilities they previously had in order to return to maximum independence. Habilitation aims to slow the progression of a disability or to enable an individual to gain new functional or communication skills. For people with complex needs who have always required a high level of input, prevention and habilitation, is about enabling and progression.

Supporting people with learning disabilities to live independently

Before going into hospital at the age of 19 Andrea had lived with family but following an operation she refused to speak for several months which resulted in her being sectioned and admitted to hospital.

Dimensions were asked to assess Andrea two years ago but it was decided that at the time she wasn't ready to be discharged so when a new referral came through staff were keen to support Andrea to leave hospital.

When a bungalow became available that was suitable it was decided that it would be a good stepping stone for Andrea. The property was funded by a grant from the Housing and Technology Fund, which gave money to local authority projects. The successful projects aimed to support new housing for people with a learning disability to support independence and help people feel included in their local community.

The team from Dimensions worked with Andrea, her team of staff and her family to collect information and went along to multi-disciplinary meetings as well as working with her to develop independent living skills. As the move to her new home got nearer the staff team spent time supporting Andrea and building relationships with the people who would be caring for her.

Andrea's home is a two-bedroomed modern bungalow decorated in her favourite colour with pots of flowers and strawberries growing, it has a conservatory where she keeps all her arts and crafts. Over the last few months Andrea has been getting used to the local community, going to a local club every Wednesday and is looking at getting into the local sea cadets. She's a familiar face at the local car boot sale, and has managed to bag a few bargains along the way for her home.

Andrea sees her family every weekend and loves tidying her house, taking great pride in showing people around. Staff have said she is much more confident and has stopped taking medication for anxiety which means she has more energy and is engaging with her support team more. As well as this Andrea has enrolled in her local college, attends therapy classes and has also joined slimming world.

All of Andrea's circle of support are now discussing plans for moving on to a more permanent home and helping Andrea to choose where she wants to live and recruiting her new staff team.

Example service objectives:

- There is a multi-agency approach to responding to low level needs across the lifespan.
- There is a multi-agency approach to embedding positive behaviour support across all health, social care and education settings for all ages.
- Increased parent carer support services are readily available and able to support parent carers throughout their caring journey.
- To increase the resilience of people with learning disabilities and/or autism and their families.
- To prevent, reduce or stop the development of future episodes of behaviour that challenges.
- To produce a clear vision, over the longer term, for achieving better health and wellbeing for people with learning disabilities and/or autism, alongside integrated activity, for which leadership can be held to account by citizens.

Example performance indicators:

- % of independent living and residential care settings that support people with learning disabilities and/or autism using positive behaviour support approaches
- % of people with learning disabilities and/or autism experiencing service breakdown or exclusion due to behaviours that challenge
- % of families receiving crisis intervention support that prevents a care breakdown in the family home environment

4.5 Short-term intensive support

Everyone involved in caring for and supporting adults with a learning disability and/or autism should understand the risk of behaviour that challenges (National Institute for Health and Care Excellence, 2015).

One important requirement of short-term intensive support services is that they can retrieve crises: to manage them while they occur and to steadily bring the situation back to one in which the problems can be tackled over the longer term. This requires specialist support provided by a range of services across the system. Support should be built around the needs of the individual through a collaborative approach, ideally using individual service design (Duffy, 2010) as a model.

Given the importance of avoiding poor placement decisions made in a crisis, emergency support for people whose behaviour presents a challenge should be available 24 hours a day, seven days a week. Services that only work ‘office hours’ or which have waiting lists for support will not be able to provide an effective service to the individuals concerned, their families or the paid staff who support them. When crises do occur, instead of the single solution of admission to a ‘challenging behaviour unit’, there needs to be a pool of staff and money which can be used more imaginatively to meet the particular needs of the situation (Mansell, 2007) and this should ideally take the form of a short notice crisis intervention team.

Individuals should also expect continuity of care and support through close collaboration between services or agencies, including between specialist and mainstream services.

Anyone who requires additional support to prevent or manage a crisis should have access to hands-on intensive 24/7 multi-disciplinary health and social care support at home, or in other appropriate community settings, including schools and short break / respite settings. This support should be delivered by members of highly skilled and experienced multi-disciplinary/agency teams. The interface between specialist routine multi-disciplinary support services and this type of intensive support service should be seamless.

People who present an immediate risk to those around them and / or to themselves may require admission to a hospital setting when their behaviour and/or mental state is such that assessment or treatment is temporarily required that cannot be provided safely and effectively in the community. Everyone who is admitted to a hospital setting for assessment and treatment should expect this to be integrated into their broader care and support pathway, with hospitals working closely with community services.

An example of prevention and early intervention in this context includes positive behavioural support (PBS) in both educational and direct support settings. PBS is an effective evidence-based approach to supporting people with learning disabilities which enhances quality of life and can reduce behaviours that challenge services (Allen et al, 2012). The use of PBS in England is not yet widespread in all areas, yet research demonstrates that PBS intervention by local behaviour support teams can also lead to potential savings by improving local support and reducing out of area residential placements (Lemmi et al, 2016).

Offering positive behavioural support across Gloucestershire: a county-wide case study

This case study (Skills for Care and the Challenging Behaviour Foundation, 2016) describes a county-wide implementation of positive behaviour support (PBS) in Gloucestershire. Gloucestershire is made up of a single clinical commissioning group (CCG) and a single local authority, and adult social care providers span across the private and voluntary sector. There are 16 adult social care employers who provide supported living under a specialist challenging behaviour framework, jointly evaluated by health and social care. The local authority also owns a self-contained 2 bedded unit for short breaks and 3 overnight learning disability and autism services.

The council set up a 'Challenging behaviour working group' to develop a Challenging Behaviour Strategy which outlines their strategic approach to supporting individuals with learning disabilities and/or autistic people who display behaviours which challenge. PBS is strongly featured in the strategy. The group meets monthly to monitor the project, making sure that the strategy is achieving its aims and outcomes. It includes representation from people who access care and support, health and social care services (specifically learning disability services), 2gether Trust, education providers, mental health teams, family and carers. PBS plays a key role in a number of strands in the strategy which includes:

Learning disability intensive support service (LDISS)

The LDISS is a multidisciplinary outreach team that supports children, young people and adults with a learning disability to prevent hospital admissions or an out-of-county

placement. The team includes speech and language therapists, occupational therapists, psychologists, PBS practitioners, social care and health providers, support workers and qualified practitioners.

Positive behavioural support service

The PBS service is funded by Gloucestershire County Council and focuses on early intervention for people with learning disabilities. It ensures multiple agencies work together to take a preventative approach and ensure that people who display behaviour which challenges have patterns of life and conditions of everyday living, which are as close as possible to regular ways of life in society. The service provides bespoke training, co-ordinates a PBS clinic with colleagues from locality community learning disability teams and delivers periodic service reviews for quality teams under a PBS framework to check the implementation of PBS. *"Before the PBS service got involved we just felt stuck"* Teaching Assistant

PBS support for individuals, their families and carers

Families can access free PBS training as part of the training strategy. For more specific support, they can access the intensive support service (LDISS) or attend the monthly PBS clinic. PBS support is integrated into commissioning frameworks across Gloucestershire and referrals to appropriate PBS services are integrated into social care practice across ages. People with learning disabilities work with clinicians, professionals, support staff and families to implement PBS through integrative working, promotion of the PBS training and principles and the PBS clinic. The council have experienced some challenges with getting 'buy in' to PBS in schools on a large scale and maintaining the early intervention – they're continuing to explore options to re-establish this.

What has worked well:

- The PBS training strategy has gone really well, with the courses consistently fully booked.
- LDISS works well to reduce the number of inappropriate inpatient placements.
- The PBS consultation clinics have been beneficial in reducing waiting times for support for carers and promoting integration between health and social care services. The PBS service has provided a link between the theory learned in PBS training and putting that into practice for people who access care and support.
- The PBS service has helped to support the work of the council's Quality Team around the support needs of individuals who challenge services.

Overall positive outcomes

Implementing the strategy across the county has led to lots of benefits for people with learning disabilities. For example, supporting people to transition from residential special schools and inpatient units from outside the county, to local community placement. There's lots of evidence suggesting a culture change in the area and better working between agencies, which has improved outcomes for individuals.

Example service objectives:

- For all inpatient provision (secure or not), people with learning disabilities and/or autism admitted to hospital are placed in a local environment suitable for their age and have access to education if required.
- Ensure that access to 24/7 outreach crisis support is available to all people who require it to prevent hospital admission.
- Maintain sufficient short break capacity for people with challenging behaviour or complex health needs, including some capacity for crisis.
- Increase the flexible use of direct payments for short breaks for family carers.
- Meet people's immediate health/therapeutic needs to reduce or stop behaviours that challenge.
- Commit to moving resources from inpatient care into community teams and settings.
- Ensure that all mental health teams are appropriately trained in therapeutic interventions and keep the use of restrictive interventions (such as physical restraint or sedation) to a minimum.
- Develop a crisis response team that provide specialist support around behaviours that challenge 24/7 and that prevents placement breakdowns and hospital admissions.

Example performance indicators:

- % of adults with learning disabilities and/or autism able to access crisis support interventions
- % of placement breakdowns and people being admitted to hospital
- % change in annual expenditure from inpatient to community-based services

4.6 Long-term specialist support

Everyone with eligible care and support needs should have a single, person-centred care and support plan, incorporating a range of other plans where appropriate, which they have been involved in developing and of which they have a copy. Plans should focus on what is important to the individual.

Where people live, who they live with, the location, the community and the built environment need to be understood from the individual perspective. People with a learning disability can live successfully in different types of housing. They can cope with the full range of tenures including home ownership. There is a need to increase the use of assistive technology to support people to live as independently as possible.

Through increased use of direct payments and individual service funds (ISF) people should have access to activities and services within the community; they should have opportunities to learn new skills, have new experiences, gain independence and employment and be supported to develop and maintain relationships. People should be able to access, co-design and co-deliver a range of services that meet their cultural and/or spiritual needs.

Supporting and developing the workforce for individual service funds: Making self-directed support work

This case study (Skills for Care, 2020) describes the implementation of individual service funds in Devon. Individual service funds (ISF) provide flexible support because the service provider holds the personal budget and works with the person to design, develop and manage their support to meet assessed outcomes, altering it with minimal bureaucracy when changes are needed.

James uses his ISF to support him with a range of activities that have improved his independence and quality of life. Here, Barry, a family carer, explains how having an ISF has made a positive difference to James's life.

"*When James finished college, he moved into residential care that was funded through a direct payment, and we managed his account. After a health scare, we contacted Devon County Council to review this arrangement and decided to try an ISF. We appointed New Key as the ISF holder, and they worked with James to choose what support and activities he wants to do. James loves the freedom of choice that he gets and takes part in a wide range of activities including art, a computer class and being a presenter on an activity centre radio station.*"

Having an ISF has allowed James to make more choices and take control of his care and support. He can see how his personal budget is being spent but doesn't have the responsibility of managing the budget. Using this arrangement has also enabled James to be more independent, for example he regularly goes to the pub for a drink by himself, which he wouldn't have been able to do whilst living in residential care.

The ISF allows him flexibility and he has been able to hand back unspent money to the local authority without a fear of losing it – knowing that when he might need more support, he can use this unspent money. This has really helped to decrease anxiety and stress levels.

Support staff have had full and intensive training and can see the obvious need for evaluation and kept informed on any monies saved. This has allowed freedom of choice which benefits James.

"James's standard phrase now is "it's my choice" and as parents we applaud this. We feel that we are an extremely lucky family that we have been given the opportunity to trial the ISF and strongly feel that this should be extended to all people who will very soon see the benefits for themselves."

Example service objectives:

- Ensure that all people with learning disabilities and/or autism have a single, person-centred care and support plan, incorporating a range of other plans and risk assessments.

- Support all individuals to explore how a direct payment or ISF could have a positive and empowering impact on their wellbeing.
- Work with providers to use personal health budgets and ISFs to develop holistic packages of support for people who display challenging behaviour.
- Develop a positive behaviour support framework of specialist providers using relationship-based commissioning.
- Improve the quality of day services for all people with profound and multiple disabilities or complex needs by training staff in and implementing person centred active support.
- Reduce support needs (and cost) by providing access to a full range of individualised housing options (including bespoke ordinary housing) designed to utilise assistive technology and floating support rather than offering a choice between residential or group supported living.
- Provide ongoing behaviour support to all families or services supporting people with complex behaviour issues in order to maintain stability and resilience and prevent family and/or placement breakdown.
- Services deliver evidence-informed interventions that prevent, reduce or stop behaviours that challenge and increase resilience.
- Co-produce behaviour support plans and provide ongoing support to all families and paid carers empowering them to successfully implement the guidelines.
- Encourage the design and build of housing that can support people to experience a good sense of health and wellbeing and create resilient communities. This is aligned within the wider strategic planning of place-shaping.
- Ensure that multi-disciplinary teams are co-located and jointly funded.
- Ensure that all practitioners offer functional assessments and behaviour support plans to everyone with behaviours that may challenge – make sure these are a fundamental part of designing the person's support in the community.
- Work with a range of stakeholders including providers and community health teams to ensure comprehensive PBS training for all staff (and families where required).

Example performance indicators:

- % of people using personal health budgets and ISFs
- Number of units of individual accommodation that are available
- % of staff that have had PBS training

4.7 Understanding population and market shaping

At a local level, a range of different people and organisations play a part in the development of an effective care and support marketplace. Commissioners have specific roles and responsibilities in relation to care market development including:

- Commissioning of continuing health care.
- A duty to promote integration between the health system and social care.
- Being a local market shaper, for example NHS vanguards and sustainability and transformation plans.

- Local partnership working to help support contingency planning and sustainability of care services.

Commissioners should proactively work to enable a sustainable and diverse range of care and support providers, whilst continuously improving quality and choice, and delivering better, innovative and cost-effective outcomes. Local market shaping means collaborating closely with providers and other relevant stakeholders including the voluntary and community sector. At the heart of this task is good quality engagement with the market and the stimulation in growth of innovative services that can meet local need. This extends beyond those providers funded by local commissioners to all those operating within the local market. Working with all care providers, regardless of how their clients' care is paid for, helps commissioning organisations to understand what their local care market looks like and the pressures on it. Market shaping is a key part of any strategic commissioning activities around understanding the market and ensuring that the needs of the local population are met.

It is important that commissioners understand local population trends and gaps in the market for services and a robust Joint Strategic Needs Assessment (JSNA) is vital to this approach. The JSNA looks at the current and future health and care needs of local populations to inform and guide the planning and commissioning of health, wellbeing and social care services within a local area. A good JSNA should:

- Be concerned with wider social factors that have an impact on people's health and wellbeing, such as housing, poverty and employment.
- Look at the health of the population, with a focus on behaviours which affect health such as smoking, diet and exercise.
- Provide a common view of health and care needs for the local community.
- Identify health inequalities.
- Provide evidence of effectiveness for different health and care interventions.
- Document current service provision.
- Identify gaps in health and care services, documenting unmet needs.

A joint approach to health, social care and housing in Moray, North East Scotland

This case study (Institute of Public Care, 2019) was first published in a report, written for the Department of Health and Social Care, that provided insight into best practice approaches to improving the health and wellbeing of people with learning disabilities.

Only 15.2% of people with a learning disability in Scotland rate their health as very good, compared with 52.5% of the general population. People with a learning disability have as many health conditions at age 20 and over as the rest of the population aged 50 and over (Scottish Learning Disability Observatory, 2011).

Considering these statistics, local leaders within health, social care and housing recognised that whole system change was needed. They embarked on a programme of transformation, underpinned by the 'progression model' with the aim of enabling

people with a learning disability to progress to the maximum degree of independence possible at each stage of their lives. Key changes that have been introduced include:

- Joining up health and social care funding: 'one population, one budget'.
- Culture change across the wider system of care and support that emphasises outcomes.
- Multi-disciplinary assessment combining health and social needs.
- Social workers re-connecting with social work, moving away from care management.
- Investment early on, working towards independence longer term.
- A new market shaping strategy to ensure providers are delivering care in line with self-directed support principles.
- Contract monitoring includes overseeing individual support plans and health objectives, e.g. checking that support workers are working alongside people with a learning disability to implement the physiotherapy exercises they have been given by health professionals.
- Moving away from traditional residential homes to new arrangements that promote independence, such as building new, bespoke housing for people with autism and challenging behaviour where they are managing their own tenancies with a support team around them. This has led to fewer assaults on staff, better staff retention and reductions in medication.

The Integrated Services Manager acknowledges that there is more work to be done to see people with a learning disability as "*citizens that need extra support"* rather than a marginalised group who require separate services. All too often they are still not having a positive experience when they access mainstream healthcare and can find themselves excluded from community activities.

Example service objectives:

- Undertake market and community asset mapping and develop an emotionally intelligent market engagement strategy.
- Writing a joint market position statement.
- Use co-production to redesign services through robust person-centred planning and use of personal health budgets.
- Work with the local voluntary sector to consider what additional or different local services are needed to ensure that people using personal health budgets have a range of services to choose from.
- Co-produce local housing solutions, leading to security of tenure, that enable people to live as independently as possible rather than in residential settings.
- Implement pooled budgets and joint commissioning arrangements.
- Develop service specifications based upon individual outcomes.
- Develop provider forums and regular market engagements that build good communication and effective relationships with existing and potential providers.
- De-commissioning outdated or outmoded services that do not meet the needs of people with learning disabilities and/or autism.

- Develop quality assurance systems that bring together relevant data on finance, activity and outcomes to review the overall impact of services.
- Develop a co- produced monitoring framework for high quality, specialist support.
- Develop long-term payment and commissioning models built around pooled budgets and resources– including jointly identifying and sharing risk, with a focus on services that increase independence and wellbeing and offer sector sustainability.

Example performance indicators:

- % of people living in community settings and with a security of tenure
- % of learning disabilities funding held in pooled budget arrangements
- % of people eligible for community health care or s117 aftercare who are using a personal health budget

5 Conclusion

Taking a whole system approach to commissioning services for people with learning disabilities and/or autism will undoubtedly deliver better outcomes for individuals and their families and lead to improved and more accessible local public services overall. We believe that taking a 'six steps' approach to the 'ordinary and unique lives' model will enable commissioners to effectively analyse and benchmark what is happening locally.

This approach can be used to understand existing gaps in provision and to identify what changes are needed to develop bespoke and person-centred services that transform the lives of people with learning disabilities and/or autism locally. The development of service objectives and performance indicators allow commissioners to review progress against these essential metrics and to adjust their approach where required to ensure success.

6 References

Allen, D., Kaye, N., Horwood, S., Gray, D., Mines, S. (2012) The impact of a whole-organisation approach to positive behavioural support on the use of physical interventions, International Journal of Positive Behavioural Support 2(1): 26-30

Brown, M., James, E., Hatton, C. (2019) Is Care Transformed? A Review of Transforming Care in England, Centre for Disability Research, Lancaster

Deveau,R., McGill P., Poyner, J. (2015) Characteristics of the most expensive residential placements for adults with learning disabilities in South East England: a follow-up survey, in Tizard Learning Disability Review, 20, 2,.97 – 102

Duffy. S. (2010) Individual Service Design Making Innovation Happen Version 3.0, The Centre for Welfare Reform, Sheffield

James, E. Neary, M. and Hatton, C. (2016) Report on the First 7 Days of Action CeDR Briefing Paper, Centre for Disability Research, Lancaster

Institute of Public Care (2020) Digital innovation in adult social care: how we've been supporting communities during COVID-19, Local Government Association, London

Institute of Public Care (2019) Best Practice on Care Coordination for People with a Learning Disability and Long-Term Conditions, Institute of Public Care, Oxford

Institute of Public Care (2017a) Six Steps to Managing Demand in Adult Social Care - A Performance Management Approach, Institute of Public Care, Oxford

Institute of Public Care (2017b) Commissioning Services for People with a Learning Disability Good Practice Guidance, Institute of Public Care, Oxford

Lemmi, Valentina, Knapp, Martin and Brown, F. J. (2016) Positive behavioural support in schools for children and adolescents with intellectual disabilities whose behaviour challenges: an exploration of the economic case. Journal of Intellectual Disabilities

Mansell, J. (2007) Services for people with learning disabilities and challenging behaviour or mental health needs, Department of Health, London

National Institute for Health and Care Excellence (2015) Guideline: Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges

NHS England (no date) Case Studies. Available at: https://www.england.nhs.uk/learning-disabilities/about/resources/caretransformed/ (Accessed 24 June 2020)

NHS Long Term Plan (no date) Case studies. Available at: https://www.longtermplan.nhs.uk/case-studies/ (Accessed 24 June 2020)

Skills for Care (2020) Supporting and developing the workforce for Individual Service Funds: Making self-directed support work (pre-print), Skills for Care, Leeds

Skills for Care and the Challenging Behaviour Foundation (2016) Offering positive behavioural support across Gloucestershire: a county-wide case study. Skills for Care, Leeds

Scottish Learning Disability Observatory (2011) Census 2011 Information. Scottish Learning Disabilities Observatory. Available at: https://www.sldo.ac.uk/census-2011-information/learning-disabilities/topics/health/ (Accessed 12 May 2020)

7 Appendix: Example objectives and performance indicators

7.1 Information, advice, assistance and advocacy

Example service objectives:

- Advocacy services are readily available and able to work with all people with learning disabilities and/or autism no matter what their communication needs or other complexities.
- Health, social care and other partners use technology and digital solutions to maximise the ability of people with learning disabilities and/or autism to communicate their views and undertake tasks as independently as possible.
- Co-develop an offer for assistance that includes community connectors that are tasked with empowering people to contribute to their communities and reducing isolation and loneliness.
- Maintain/increase the offer of advocacy by ensuring statutory and non-statutory advocacy (such as peer advocacy) is available to all people who are leaving hospital.
- Maintain/increase the reach and impact of self-advocacy organisations.
- Provide support and empower provider groups, family support groups and self-advocacy organisations to design and deliver a local 'reasonable adjustments' campaign.

Example performance indicators:

- % of people with learning disabilities and/or autism accessing advocacy services within 28 days of referral
- % of people leaving hospital accessing advocacy services
- % of people using technology and digital solutions to communicate their views and undertake independent living tasks as independently as possible

7.2 Universal services

Example service objective:

- Increase the number of universal services that make reasonable adjustments to enable people with learning disabilities and/or autism to access services that meet needs.
- Increase the availability of tools such as patient passports and communication books.
- Ensure that all day opportunities are focused on accessing universal services for people with a learning disability and/or autism.
- Work with those who commission and manage mainstream activities/services to find ways to make them accessible, in line with Equality Act duties. This should include leisure activities that people struggle to access.
- Devise and roll out comprehensive 'reasonable adjustments training' to all primary and secondary care staff in relation to both learning disability and autism spectrum disorder. The training should include recommendations for system/process changes as well as changing culture and understanding.

- Locally accountable governance arrangements, such as Learning Disability Partnership Boards, encompass community, political, clinical and professional leadership which transcend organisational boundaries, are collaborative, and ensure that decisions impacting upon people with learning disabilities and/or autism are taken at the most appropriate local level.

Example performance indicators:

- % of local public services that are verified by self-advocacy groups or experts by experience as being accessible to people with learning disabilities and/or autism
- % of public organisations offering information that is in easy read
- % of people with learning disabilities and/or autism admitted to hospital with an up to date patient or communication passport

7.3 Universal plus

Example service objective:

- Frontline professionals are trained and mentored so that they have a better awareness and understanding of learning disabilities and autism so that they are better able to make reasonable adjustments.
- All front-line staff engage in asset-based conversations that are person-centred and think holistically about wellbeing.
- GPs offer continuity of relationship between the practitioner, the wider healthcare team, the patient and their carers and family, over time.
- Commissioners develop pathways to support targeted interventions that decrease health inequalities.
- Ensure that commissioners from health continue to work with social care to maximise the numbers of known patients with learning disabilities and to share the information with the GP practices and social care teams.
- Ensure that multi-disciplinary teams are tasked with improving health inequalities for people with learning disabilities and/or autism.
- Engage educational and life-long training organisations, and a range of private sector businesses, in a strategy to increase meaningful occupation - through training, education or employment. Businesses will require evidence about benefits to them employing people with a learning disability and/or autism.

Example performance indicators:

- % of adults with a learning disability and/or autism that access further education, work or undertake meaningful activity
- % of health assessments that are asset based and holistic in nature
- % of adults with a learning disability able to access their mainstream GP surgery

7.4 Early intervention

Example service objectives:

- There is a multi-agency approach to responding to low level needs across the lifespan.

- There is a multi-agency approach to embedding positive behaviour support across all health, social care and education settings for all ages.
- Increased parent carer support services are readily available and able to support parent carers throughout their caring journey.
- To increase the resilience of people with learning disabilities and/or autism and their families.
- To prevent, reduce or stop the development of future episodes of behaviour that challenges.
- To produce a clear vision, over the longer term, for achieving better health and wellbeing for people with learning disabilities and/or autism, alongside integrated activity, for which leadership can be held to account by citizens.

Example performance indicators:

- % of independent living and residential care settings that support people with learning disabilities and/or autism using positive behaviour support approaches
- % of people with learning disabilities and/or autism experiencing service breakdown or exclusion due to behaviours that challenge
- % of families receiving crisis intervention support that prevents a care breakdown in the family home environment

7.5 Short-term intensive support

Example service objectives:

- For all inpatient provision (secure or not), people with learning disabilities and/or autism admitted to hospital are placed in a local environment suitable for their age and have access to education if required.
- Ensure that access to 24/7 outreach crisis support is available to all people who require it to prevent hospital admission.
- Maintain sufficient short break capacity for people with challenging behaviour or complex health needs, including some capacity for crisis.
- Increase the flexible use of direct payments for short breaks for family carers.
- Meet people's immediate health/therapeutic needs to reduce or stop behaviours that challenge.
- Commit to moving resources from inpatient care into community teams and settings.
- Ensure that all mental health teams are appropriately trained in therapeutic interventions and keep the use of restrictive interventions (such as physical restraint or sedation) to a minimum.
- Develop a crisis response team that provide specialist support around behaviours that challenge 24/7 and that prevents placement breakdowns and hospital admissions.

Example performance indicators:

- % of adults with learning disabilities and/or autism able to access crisis support interventions
- % of placement breakdowns and people being admitted to hospital

- % change in annual expenditure from inpatient to community-based services

7.6 Long-term specialist support

Example service objectives:

- Ensure that all people with learning disabilities and/or autism have a single, person-centred care and support plan, incorporating a range of other plans and risk assessments.
- Support all individuals to explore how a direct payment or ISF could have a positive and empowering impact on their wellbeing.
- Work with providers to use personal health budgets and ISFs to develop holistic packages of support for people who display challenging behaviour.
- Develop a positive behaviour support framework of specialist providers using relationship-based commissioning.
- Improve the quality of day services for all people with profound and multiple disabilities or complex needs by training staff in and implementing person centred active support.
- Reduce support needs (and cost) by providing access to a full range of individualised housing options (including bespoke ordinary housing) designed to utilise assistive technology and floating support rather than offering a choice between residential or group supported living.
- Provide ongoing behaviour support to all families or services supporting people with complex behaviour issues in order to maintain stability and resilience and prevent family and/or placement breakdown.
- Services deliver evidence-informed interventions that prevent, reduce or stop behaviours that challenge and increase resilience.
- Co-produce behaviour support plans and provide ongoing support to all families and paid carers empowering them to successfully implement the guidelines.
- Encourage the design and build of housing that can support people to experience a good sense of health and wellbeing and create resilient communities. This is aligned within the wider strategic planning of place-shaping.
- Ensure that multi-disciplinary teams are co-located and jointly funded.
- Ensure that all practitioners offer functional assessments and behaviour support plans to everyone with behaviours that may challenge – make sure these are a fundamental part of designing the person's support in the community.
- Work with a range of stakeholders including providers and community health teams to ensure comprehensive PBS training for all staff (and families where required).

Example performance indicators:

- % of people using personal health budgets and ISFs
- Number of units of individual accommodation that are available
- % of staff that have had PBS training

7.7 Understanding population and market shaping

Example service objectives:

- Undertake market and community asset mapping and develop an emotionally intelligent market engagement strategy.
- Writing a joint market position statement.
- Use co-production to redesign services through robust person-centred planning and use of personal health budgets.
- Work with the local voluntary sector to consider what additional or different local services are needed to ensure that people using personal health budgets have a range of services to choose from.
- Co-produce local housing solutions, leading to security of tenure, that enable people to live as independently as possible rather than in residential settings.
- Implement pooled budgets and joint commissioning arrangements.
- Develop service specifications based upon individual outcomes.
- Develop provider forums and regular market engagements that build good communication and effective relationships with existing and potential providers.
- De-commissioning outdated or outmoded services that do not meet the needs of people with learning disabilities and/or autism.
- Develop quality assurance systems that bring together relevant data on finance, activity and outcomes to review the overall impact of services.
- Develop a co- produced monitoring framework for high quality, specialist support.
- Develop long-term payment and commissioning models built around pooled budgets and resources– including jointly identifying and sharing risk, with a focus on services that increase independence and wellbeing and offer sector sustainability.

Example performance indicators:

- % of people living in community settings and with a security of tenure
- % of learning disabilities funding held in pooled budget arrangements
- % of people eligible for community health care or s117 aftercare who are using a personal health budget