

National Commissioning Board

Commissioning Services for People with a Learning Disability

Good Practice Guidance



November 2017



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1. Introduction

The National Commissioning Board (NCB) has developed this guidance. The NCB has no executive authority, but it has a remit to develop, publish and support the implementation of good practice both in relation to the commissioning of services and creating an appropriate environment to support the development of effective solutions to enable individuals and their families to achieve the outcomes most important to them in relation to their care and support arrangements.

The Welsh Government published statutory guidance on commissioning in 2010 *Fulfilled Lives, Supportive Communities: [Commissioning Framework Guidance and Good Practice](#)*. This established a set of standards for commissioning. It has since been superseded by the Social Services and Well-being (Wales) Act 2014 and now only exists as good practice. In 2011, the Welsh Government also published [Practice guidance on developing a commissioning strategy for people with a learning disability](#). This was a good technical document, but required updating principally because of legislative changes and the values underpinning them. It is still a useful reference document.

The NCB held a workshop with stakeholders in 2016 to discuss how we could improve the commissioning of services for people with learning disabilities. The consensus, at the meeting, was that the NCB should develop and publish an overarching guidance document on commissioning to be followed by the publication of guidance in relation to specific service areas. This approach was shared and agreed with the Learning Disability Advisory Group, members of which had participated in the workshop. The NCB commissioned the Institute of Public Care at Oxford Brookes University as a key partner to work with it, together with stakeholders, to develop the guidance.

The Institute of Public Care (IPC) has contributed expertise both in terms of commissioning together with a detailed understanding of the needs of individuals with learning disability and their families. Discussions concerning the development of this guidance have been both robust and challenging.

The purpose of this good practice guidance is to help Regional Partnership Boards to develop their own approaches to the integrated commissioning of services for people with learning disabilities. It will be important that Regional Partnership Boards follow the principles underpinning the Social Services and Well-being (Wales) Act 2014 in terms of starting from the point of helping individuals to lead an ordinary life with dignity, and co-producing appropriate solutions to help the individual and their family achieve the outcomes important to them. This, rather than immediately focusing on expensive service options, should be the starting point.

This guidance also applies to people with learning disabilities and autism. Much of it can be applied to the commissioning of services for people with autism but the NCB does not wish to intrude into this area of work at this stage prior to any discussion with stakeholders.

In relation to other work streams, the NCB will shortly begin work to develop guidance in relation to supported living services for people with learning disabilities. Guidance in relation to other services will follow. The Integrated Health and Social Care Collaborative Commissioning Programme is already working with health boards, local authorities and

providers to improve the commissioning of residential care services for people with learning disabilities and / or with mental health needs. The NCB is also developing guidance for the commissioning of services for children and young people with complex needs due to disability and / or ill health. Although this extends beyond the needs of people with learning disabilities, there will be some overlap with this guidance and we will endeavour to ensure these guidance documents complement and reinforce each other rather than develop competing priorities. Further work is also underway to improve practice in relation to the procurement of services.

Developing good practice is never finished. The NCB will continue to work with stakeholders to learn the lessons from implementation and develop appropriate solutions.

2. Question: What is strategic commissioning? Answer: The commissioning cycle

At its most basic, commissioning involves understanding need and then ensuring there is a supply of services to meet that need.

Commissioning is... the process of identifying needs within the population and of developing policy directions, service models and the market, to meet those needs in the most appropriate and cost effective way.

Institute of Public Care (2016) National Commissioning Board (Wales): Procurement Options in Social Care in Wales. Draft Discussion Paper

Commissioning is a set of activities by which local authorities and partners ensure that services are planned and organised to best meet the ... outcomes required by their citizens. It involves understanding the population need, best practice and local resources and using these to plan, implement and review changes in services. It requires a whole system perspective and applies to services provided by local authorities, as well as public, private and third sector services.

Fulfilled Lives, Supportive Communities: Commissioning Framework Guidance and Good Practice (2010)

The Welsh Government Fulfilled Lives, Supportive Communities commissioning cycle and its associated Commissioning Framework Guidance and Good Practice no longer have a statutory status, but do still represent good practice and are relevant today. The commissioning cycle (shown below) describes a range of activities and illustrates the relationship between them. It is underpinned by six key principles, namely:

- 1.** Focus on client group needs across agencies.
- 2.** All four activities are equally important.
- 3.** The activities follow sequentially.
- 4.** Commissioning drives procurement.
- 5.** The procurement experience informs the ongoing development of the commissioning strategy.
- 6.** There is an on-going dialogue with service users/carers, case/care managers, providers and the third sector.



It should be noted that partners may use different models, although these usually reflect similar activities and relationships.

Integrated and collaborative commissioning

The legislative drive to commission in partnership suggests that there needs to be a shared understanding of what integrated and collaborative commissioning looks like, and when it is appropriate.

Joint commissioning: the process in which two or more organisations act together to co-ordinate the commissioning of services, taking joint responsibility for the translation of strategy into action.

Welsh Government Social Care Procurement Route Planner¹

The Welsh Government Social Care Procurement Route Planner describes the potential benefits as including seamless care but also achieving better value for money through: *"Improving service user experience by integrating care, extending choice and securing good outcomes; and achieving greater efficiency from minimising duplication and improving co-ordination"*.

Integrated and collaborative commissioning is a complex strategic activity combining traditional disciplines of strategic planning, service design, procurement, internal service

¹ <http://prp.gov.wales/planners/social/>

planning and performance management, and applying these disciplines in a new multi-agency environment. It is not simply about contracting between purchasers and providers, but concerns the whole range of ways in which services are developed and secured, including grants, service agreements, voluntary and community contributions and co-production.

As policy places greater emphasis on individual choice and control through self-directed support and person-centred care, the role of public agencies as facilitators of service development, rather than only as direct purchasers or suppliers, has become more important. When collaborative and integrated commissioning is undertaken, these activities have to be re-designed, to ensure that they are fit for their purpose in a new, multi-agency environment.

For further information see [Leading Integrated and Collaborative Commissioning \(2017\) National Commissioning Board.](#)

Key Culture Change

All stakeholders agree that integrated and collaborative commissioning is the only way forward.

Commissioners must stop working in their silos.

3. Question: What is the role of the strategic commissioner?
Answer: Leader of culture change

Collaborative and integrated commissioning will demand new skills and new practices, and a new level of maturity in the system as we try to ensure that every penny spent from the public purse (and by individuals) is used wisely and effectively, and that services are cost-effective, of good quality and sustainable into the future.

Current role	Example of new skills and knowledge which might need to be developed
A local authority social care leader responsible for planning and procuring community and residential care	How integrated commissioning of community health and social care services can be used to safely and effectively reduce demand for acute care
An NHS manager responsible for planning the distribution of local NHS acute services	<p>How social care services can be commissioned to reduce acute health demand through better planning and procurement with public, private and third sector providers</p> <p>A clinical professional responsible with colleagues for implementing locality health and care plans</p> <p>How they can work with specialist colleagues to plan together on the basis of systematic analysis of integrated service data, population profiles and service user and community experience</p>

People involved in commissioning may already have experience in some aspects of the overall cycle, and with particular service areas, but they now need to draw on new models, new relationships and new skills to be successful in collaborative and integrated commissioning across the whole system. They also need to be able to apply these skills across agencies involved in social care, community and acute health, housing, education, welfare benefits, and community development.

Types of role and activities

There are a mix of roles and activities potentially involved in the collaborative and integrated commissioning task. These will include both strategic and operational roles and activities, which sit within a number of different organisations as well as in joint posts across organisations.

There can be considered to be four role types where appropriate skills and capacity will be required to deliver the integrated commissioning agenda and thus help to achieve the best outcomes for people.

Leadership and governance

- Maintaining an overview of the commissioning system, what outcomes it is trying to achieve and what risks need to be managed.
- Ensure a co-production approach to commissioning services.
- Leading the development of joint commissioning plans and securing partners' commitment to them.
- Ensuring that all partners engage with the implementation of agreed plans.
- Ensuring that the delivery of strategic service change and improvement across the system.
- Reviewing the strategic impact of services and getting partners to change direction when needed.



Management

Managing the detailed design and delivery of joint commissioning arrangements is a second key area. Commissioners have to be able to look beyond arrangements that might work in their own particular agency or setting to understand the challenges that different partners are experiencing, and develop a response which promotes mature relationships.

Partnership

Working in partnership to deliver effective joint commissioning is the third key area involved in the joint commissioning agenda. Real partnership goes beyond the ability to negotiate with partners to get the best for your individual agency or service, and requires the desire to work across boundaries to get the best outcomes for people with learning disabilities and / or autism and their families.

Production

The final area is working within a partnership to produce, implement and monitor joint commissioning plans. There are commissioning professionals from many different backgrounds and organisations already involved in securing health, well-being and social care services, each with their own skills and experience. Joint commissioning demands that those skills and experiences are pooled in an effective way to ensure that joint commissioning plans really do reflect priorities across the whole system which will best help to secure the best possible outcomes for people with learning disabilities and / or autism and their families.

For further information see [Leading Integrated and Collaborative Commissioning \(2017\) National Commissioning Board.](#)

Key Culture Change

Commissioners see themselves and are seen by others as leaders of culture change.

Commissioners must develop their leadership skills.

4. Question: What should you be commissioning? Answer: Good lives

Research indicates that 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. The key theme that has run through national policy and good practice guidance for almost 40 years is the need to provide services that support people to have healthy, meaningful, ordinary lives. 'The concept that people with a learning disability have the same rights and aspirations as those without is the foundation upon which commissioners and providers should develop services that prevent the need for social care'².

Policy

The *Statement on Policy and Practice for Adults with a learning Disability*³ laid out the rights for people with a learning disability living within Wales:

'All people with a learning disability are full citizens, equal in status and value to other citizens of the same age. They have the same rights to:

² Parrott (2013) 'Promoting independence, preventing dependency' Tizard Learning Disability Review Vol 18(4) p161-170

³ Welsh Assembly Government (2007) Statement on Policy and Practice for Adults with a Learning Disability

- Live healthy, productive and independent lives with appropriate and responsive treatment and support to develop to their maximum potential.
- Be individuals and decide everyday issues and life-defining matters for themselves, joining in all decision-making which affects their lives, with appropriate and responsive advice and support where necessary.
- Live their lives within their community, maintaining social and family ties and connections which are important to them.
- Have the support of the communities of which they are a part and access to general and specialist services that are responsive to their individual needs, circumstances and preferences.'

This was mirrored in the 2011 commissioning guidance⁴ that set out guidelines for commissioning sustainable services which promote independence and encourage commissioners to think longer term about what might be needed for the learning disability population in Wales.

To date these still form central tenets of learning disability provision across Wales and as such there has been no subsequent review or update of policy. Therefore the most significant piece of policy and legislation impacting people with learning disabilities across Wales in recent years is the Social Services and Well-being (Wales) Act 2014. A key aspect of the Act is that services should be co-produced. This is defined as follows: *Co-production refers to a way of working whereby practitioners and people work together as equal partners to plan and deliver care and support.*⁵ It is fundamentally about doing things 'with' rather than 'to' people. Arguably the concept of genuinely involving people and communities in the design and delivery of public services, appreciating their strengths and tailoring approaches accordingly is the really transformative aspect of the Act.

For people with learning disabilities this Act has significant potential to improve their experiences of services as it provides a single legislative framework for the provision of services across the age ranges. This means that local authorities and their partners should be considering the well-being of individuals at all stages of their development, including through the traditional 'transitions' phase from children and young people's services through to adult services, and through the provision of care and support into older age. It also legislates for the provision of advocacy services and for people to have strengths based assessments of need which considers all aspects of well-being as defined by the Act. It provides for carers through a right for their needs to be independently assessed beyond that of the person they care for.

The Social Services and Well-being (Wales) Act 2014 includes a National Well-being Statement (outlined below) which describes the well-being outcomes that people who

⁴ Welsh Assembly Government (2011) Practice guidance on developing a commissioning strategy for people with a learning disability

⁵ Welsh Government (2014) Code of Practice and guidance on the exercise of social services functions and partnership arrangements in relation to part 2 (General Functions) of the Social Services and Well-being (Wales) Act 2014.

need care and support, and carers who need support, should expect in order to lead fulfilled lives. The approach to commissioning good lives aims to support people with learning disabilities and their families to experience these outcomes.

National Well-being Domains	Well-being outcome statements (taken from the National Well-being Statement)
<p>Securing rights and entitlements Also for adults: Control over day-to-day life</p>	<ul style="list-style-type: none"> • I know and understand what care, support and opportunities are available and use these to help me achieve my well-being • I can access the right information, when I need it, in the way I want it and use this to manage and improve my well-being • I am treated with dignity and respect and treat others the same • My voice is heard and listened to • My individual circumstances are considered • I speak for myself and contribute to the decisions that affect my life or have someone who can do it for me
<p>Physical and mental health and emotional well-being</p>	<ul style="list-style-type: none"> • I am healthy and active and do things to keep myself healthy • I am happy and do things that make me happy • I get the right care and support, as early as possible
<p>Protection from abuse and neglect</p>	<ul style="list-style-type: none"> • I am safe and protected from abuse and neglect • I am supported to protect the people that matter to me from abuse and neglect • I am informed about how to make my concerns known
<p>Education, training and recreation</p>	<ul style="list-style-type: none"> • I can learn and develop to my full potential • I do the things that matter to me

National Well-being Domains	Well-being outcome statements (taken from the National Well-being Statement)
Domestic, family and personal relationships	<ul style="list-style-type: none"> • I belong • I contribute to and enjoy safe and healthy relationships
Contribution made to society	<ul style="list-style-type: none"> • I engage and make a contribution to my community • I feel valued in society
Social and economic well-being	<ul style="list-style-type: none"> • I contribute towards my social life and can be with the people that I choose • I do not live in poverty • I am supported to work • I get the help I need to grow up and be independent • I get care and support through the Welsh language if I want it
Suitability of living accommodation	<ul style="list-style-type: none"> • I live in a home that best supports me to achieve my well-being

The full version of the Well-being Statement can be found at: <http://gov.wales/docs/dhss/publications/150722well-beingen.pdf>

The design features of accommodation for people with learning disabilities have been a major focus of policy and best practice in Wales since the start of the process of closing “mental handicap” hospitals in the 1980s. As a general rule, and on the basis of considerable evidence regarding how best to achieve positive outcomes for people, and similarly how best to meet the requirements of dignity and human rights, people with learning disabilities should be supported to live in small-scale, community-based flats and houses, indistinguishable from other accommodation in the vicinity, and close to their family and community roots. Some adaptations for physical accessibility and for safe moving and handling may be required, and occasionally some especially robust materials for additional safety and to reduce repair bills. However, this should not affect the overall homely look of the home, or make it stand-out as different to its neighbours. By using or replicating existing ordinary housing, the risk of creating large-scale, congregated accommodation is reduced. As a rule the number of people sharing a single home should not exceed four. The number of self-contained flats on one site can be greater than four, but care must be taken not to create the impression of a ghetto, or reduce the likelihood of community acceptance and integration for individuals through over-congregation. Wales can be proud of its record in closing inappropriate large-scale, long-term accommodation facilities, and for having The Independent Health Care (Wales) Regulations 2011, regulation 27 of which restricts the size of any new hospital that private investors may

wish to develop for people with learning disabilities. However, there are still some large-scale, long-term establishments in Wales, and many more in England. Facilities with these large-scale design features have on occasion been the subject of scandals relating to abuse and neglect. They should be used with caution and only in exceptional circumstances. When they are used, they must be used for a clear purpose with clear outcomes in mind and the commissioning authority must ensure the placement is regularly reviewed, and every step taken to bring people back home at the earliest opportunity.

Commissioning good lives for people with learning disability and their families (This will include people with a learning disability and autism)

Our vision is that people with a learning disability and / or autism and their families have the opportunity to make the most of their lives and talents. That people and their families experience equality of opportunity and will be able to access options that promote a sense of belonging to and inclusion in their local community. Approaches that maximise both interdependence and independence reduce dependency on services and emphasise choice and control. Children, young people and adults with a learning disability (including those people with autism and complex needs) will be able to access efficient and effective support that enable citizen-centred well-being outcomes and minimise escalation of need and risk through the promotion of access to universal services, early intervention, prevention, and specialised support. Achieving this requires a whole system, community, lifespan approach to commissioning not least because access isn't just about physical or financial barriers. Access is also about having the confidence to approach, the ambition to achieve and the capacity to sustain.

Definition of a good life

Somewhere to live, something to do, someone to love (home, occupation, relationships)

The principles underpinning the approach to commissioning good lives

The following principles underpin the approach to commissioning good lives:

- Designing options from the individual up, but with their relationships right upfront as well.
- Designing options so that they reflect, and maintain or strengthen, the assets of the person and their relationships.
- Consequently, involving the person and their relationships fully in the design of support.
- Designing support so that it reflects best practice in relevant professions.
- Consequently, promoting social inclusion, autonomy, choice, respect, and valued roles for the person, as well as effective specialist skills and techniques.

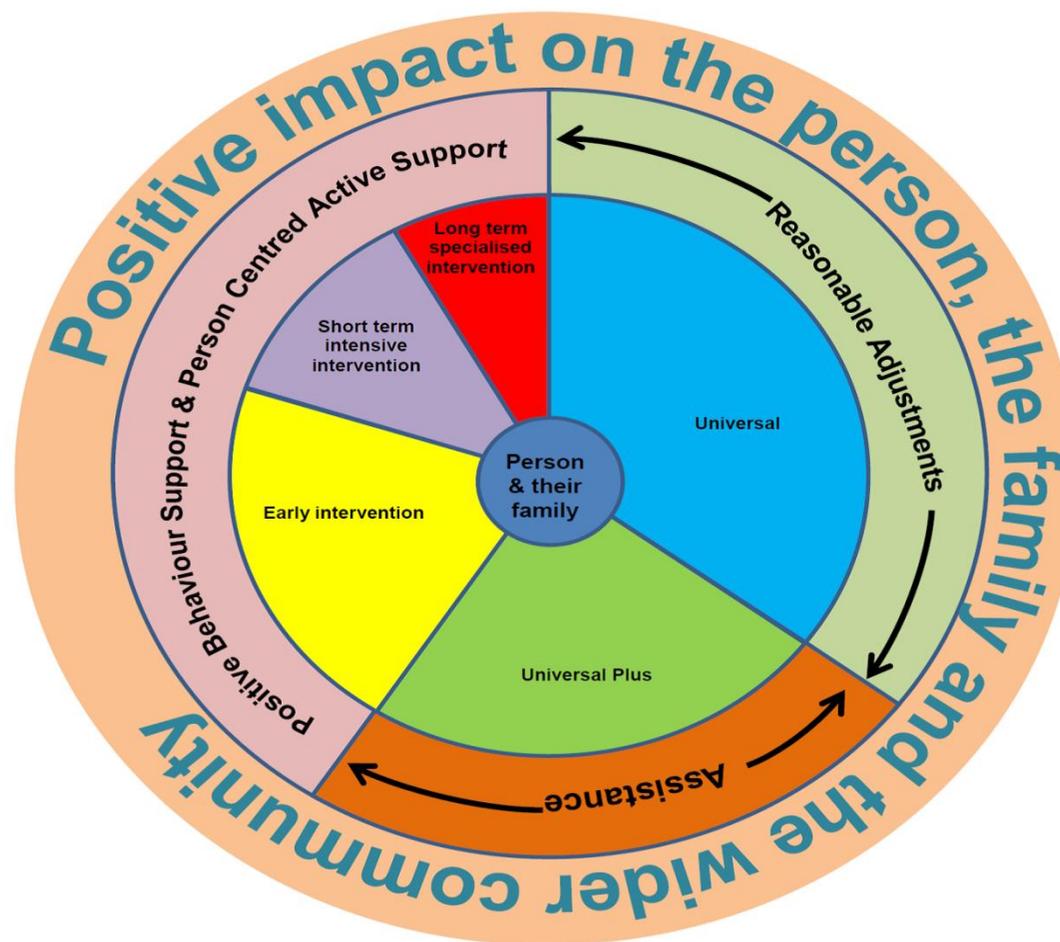
At the heart of the approach is the concept of dignity. Commissioning good lives must result in a positive impact on the person, a positive impact on the carer and a positive impact on the wider community. Encouraging and empowering everyone in the system to work with dignity is crucial for successfully commissioning good lives. The core principles of dignity are:

- Value the uniqueness of every individual.
- Uphold the responsibility to shape and support services around each individual.
- Value communicating with individuals in ways that are meaningful to them.
- Recognise and respect how an individual's dignity may be affected when supported with personal care.
- Recognise that an individual's surroundings and environments are important to their sense of dignity.
- Value workplace cultures that actively promote the dignity of everybody.
- Recognise the need to challenge care and support that may reduce the dignity of the individual and the carer.

An Approach to commissioning good lives in community settings for people with learning disabilities and their families

Well-being Domains

- Protection from abuse and neglect
- Securing rights and Entitlements
- Domestic, family and personal relationships
- Social and economic Well-being
- Physical and mental health and emotional well-being
- Education, training and Recreation
- Contribution made to Society
- Suitability of living accommodation



Information, advice, assistance and advocacy

Commissioners understand their local population now and in the future and work in partnership with all stakeholders to shape the market

Martha

When Martha was in primary school she was taught to use an electric wheelchair. This greatly improved her chances of independence.

Martha now attends her local college. The college have made reasonable adjustments by ensuring that her classes are held in accessible rooms.

Martha received some short-term intervention to teach her to use public transport to get to college.

Martha was put in touch with a community connector to assist her to find and access a 'knit and natter' club. She now co-facilitates special sessions on crochet.

Martha lives in supported accommodation.

Universal Services

Universal services include: leisure services (e.g. sports centre, cinema, social clubs, community and faith groups etc); information services (e.g. library, job centre, citizen's advice, charitable organisations etc); education services (e.g. college, adult education, etc); health services (e.g. dentist, optician, counselling, pharmacy, GP etc).

The vast majority of people with learning disabilities live in the community with limited support. People with learning disabilities are at higher risk of many physical and mental health conditions, have fewer opportunities to work and often experience social deprivation. Supporting people with learning disabilities 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.

Example

Reasonable adjustments making access to primary health care easier include:

- **Desensitisation work / visits**
- **Car parking for carers / families**
- **Longer consultation slots**
- **Alternative arrangements in relation to using the waiting room**
- **Easy read information leaflets**
- **Liaising with community learning disability teams**

Example

MySafeHome is a specialist mortgage broker that provides help and support for disabled people who want to buy their own home. MSH uses shared ownership models where the homeowner buys a share of the property and pays rent on the remainder. It is targeted at people with long-term disabilities who do not work.

<http://www.mysafehome.info/>

Information and advice

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 well-being 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.

Examples

Public Health Wales Screening Division has:

- Produced a suite of public information in a range of accessible formats to support people who may have a specific communication or literacy needs, this is inclusive of people with a learning disability. Accessible information is produced co-productively, involving people with a learning disability and relevant organisations and community members at every stage of the development. Accessible resources can be accessed at:

<http://www.screeningforlife.wales.nhs.uk/community-resources>

- Used a co-productive approach, to produce a film in partnership with Cardiff People's First, to support women with a learning disability attending the G.P. surgery for their cervical screening appointment.

<http://www.screeningforlife.wales.nhs.uk/learning-disability-resources>

The Downs Syndrome Association recently co-designed and co-delivered training to midwives and NHS staff about living a full life with Downs Syndrome.

<https://www.downs-syndrome.org.uk/about/training/tell-it-right/>

Universal Plus

On average, people with learning disabilities 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 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 across the life course to understand and express their needs in relation to their health and well-being, and to access health-based information together with support and opportunities to lead healthy lifestyles.

Technology can also 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. Young people are exposed to technology from an early age and it is now a way of life.

Examples

Public Health Wales Screening Division has introduced a [Community Champions scheme](#) which is being piloted with people with a learning disability who have undergone training to become champions and provide peer support to others in terms of raising awareness of bowel screening. This work is ongoing with further scope to roll it out across Wales.

[Talking Mats](#) is a social enterprise whose vision is to improve the lives of people with communication difficulties by increasing their capacity to communicate effectively about things that matter to them. Talking Mats is an interactive resource that uses three sets of picture communication symbols – topics, options and a visual scale – and a space on which to display them. This can either be a physical, textured mat, or a digital space, for example a tablet, smart board or computer screen. <http://www.talkingmats.com/>

Assistance and Advocacy

Access alone doesn't ensure that services are actually utilised though. Universal plus requires services across the system to help people build their confidence to approach universal services and the resilience to sustain using them. Assistance and advocacy are two ways of achieving this. Assistance involves another person taking action with the individual to access care and support. Assistance 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 advocacy to ensure they understand what is available to them so that they can engage and participate fully in decisions that affect them. Self-advocacy organisations empower people with learning difficulties to challenge prejudice and discrimination through training education and support.

Examples

Keyring houses people with learning disabilities in a range of housing options within a small area and then helps them to make connections and build their own sense of community via a volunteer support worker who lives rent free in the same area.

<http://www.keyring.org/home>

Arts Factory creates life-changing opportunities for individuals who feel marginalised and excluded. Arts Factory is based in the Rhondda Valleys in South Wales. The Arts Factory focuses on people's strengths and enables people to become providers of valued services to the wider community. All of the businesses run by the Arts Factory are social enterprises and any profits are ploughed back into the communities they serve.

<https://www.artsfactory.co.uk/>

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 information, advice, assistance and, where required, intervention can delay or prevent escalating need 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. The Social Services and Well-being (Wales) Act 2014 specifically mentions 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) as being key elements of preventative services. Reablement is about helping people, including children, 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. Examples include therapy for a child who is not walking or talking at the expected age or teaching adults with learning disabilities the fine motor coordination required to dress themselves. Most local authorities in Wales employ mobility specialists in education or Rehabilitation Officers Visual Impairment (ROVIs) in social services to support children and young people with visual impairment.

Example

Facing the Challenge is a multi professional team for children and young people with learning disabilities and behaviours that challenge. It is based in Neath as part of Abertawe Bro Morgannwg University Health Board and works in conjunction with partner agencies, providing an additional, specialist behavioural element to existing services. It is based on Positive Behaviour Support (PBS) in line with NICE Guidelines on prevention, assessment and intervention for Challenging Behaviour and Learning Disabilities.⁶

Short-term Intensive Intervention

One important requirement of services is that they are able to 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 Care' model. Individuals should expect continuity of care and support through close collaboration between services / 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 and / 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.

For all inpatient provision (secure or not) children admitted to hospital should be placed in an environment suitable for their age and must have access to education.

Example

The Ealing Intensive Therapeutic Short Break Service (ITSBS) is for young people with learning disabilities who are at risk of being placed in residential care. This is usually due to their challenging behaviour. The ITSBS aim to keep children in their family homes and communities, long term. They provide intensive support and follow up focused around the child aiming to reduce challenging behaviours and provide a break for the parents/young person. <http://pavingtheway.works/works/local-crisis-response-ealing-intensive-therapeutic-short-break-service/>

⁶ NICE (2015) Guidelines on prevention, assessment and intervention for Challenging Behaviour and Learning Disabilities

Long-term Specialist Intervention

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. For children and young people up to the age of 25 with an additional learning need (ALN), this should take the form of an Individual Development Plan (IDP).

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 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.

Example

Cartrefi tenants are using videos to explain what matters to them, what they enjoy, their personalities and achievements. These, often moving, films are used in different contexts to help ensure that they are given appropriate support but also that their strengths are developed and extended. The films also provide a brilliant way of communicating achievements, even for those with limited verbal communication.

<http://www.cartrefi.org/en/>

Active Support⁷ is an approach that is fundamental to providing effective, person centred support. It isn't about supporting a particular person to get involved in a specific activity. It is about understanding that there isn't anything we shouldn't be supporting people to be involved in. We know when active support is being implemented because staff no longer have any discussions about WHAT they should be supporting people to be involved in, instead there is plenty of discussion about HOW they involve people in everything. <http://arcuk.org.uk/cymru/active-support-project/>

Key Culture Change

All stakeholders truly believe that everyone with a learning disability and / or autism can live a good life in the community no matter what challenges they face in relation to physical disabilities, health problems or behaviour issues.

Commissioners must stop commissioning or creating services that isolate people from their communities.

⁷ Jones et al (2013) Active Support as a Primary Prevention Strategy for Challenging Behaviour. International Journal of Positive Behavioural Support, 3(1)16-30.

5. Question: How do you commission 'good lives'? Answer: Co-produce solutions

Public services rely on an underpinning operating system that consists of family, neighbourhood, community and civil society. Outcomes cannot be achieved by any one service or individual on their own. Indeed the only way of achieving positive outcomes is by co-producing them. Co-production is about relationships, not about services⁸. The central idea in co-production is that people who use services are hidden resources, not drains on the system⁹. They come with a range of skills and abilities and a social network that often provides informal support.

Co-production challenges the usual relationship between professionals and people who use services. It requires the latter to be acknowledged as experts in their own circumstances and therefore capable of making decisions and having control as responsible citizens. At the same time, co-production also implies a change in the role of the professionals from fixers of problems to facilitators who find solutions by working with their clients¹⁰.

The Co-production Network for Wales describes co-production in the following way:

Co-production enables citizens and professionals to share power and work together in equal partnership, to create opportunities for people to access support when they need it and to contribute to social change.

What co-production means in practice is acknowledging that everyone is an expert in their own life, everyone has something to contribute, and that enabling people to support each other builds strong, resilient communities, strengthening the relationship between citizens and service providers and improving the outcomes for everyone.¹¹

The approach is underpinned by a set of key principles:

- Value all participants and take an asset-based approach.
- Develop peer-support networks and social capital.
- Focus on personal outcomes, what matters to the individual.
- Build relationships of equality and reciprocity.
- Work in partnership with the people who use our services, as catalysts for change.

The Co-production Network for Wales state that: '*At its most transformative, co-production requires a relocation of power and control. New structures and systems embed*

⁸ Boyle D, Slay J, and Stephens L. (2010) Public Services Inside Out. Putting co-production into practice. London: NESTA

⁹ Boyle D, Harris M. (2009) The Challenge of Co-production. How equal partnerships between professionals and the public are crucial to improving public services. London: NESTA

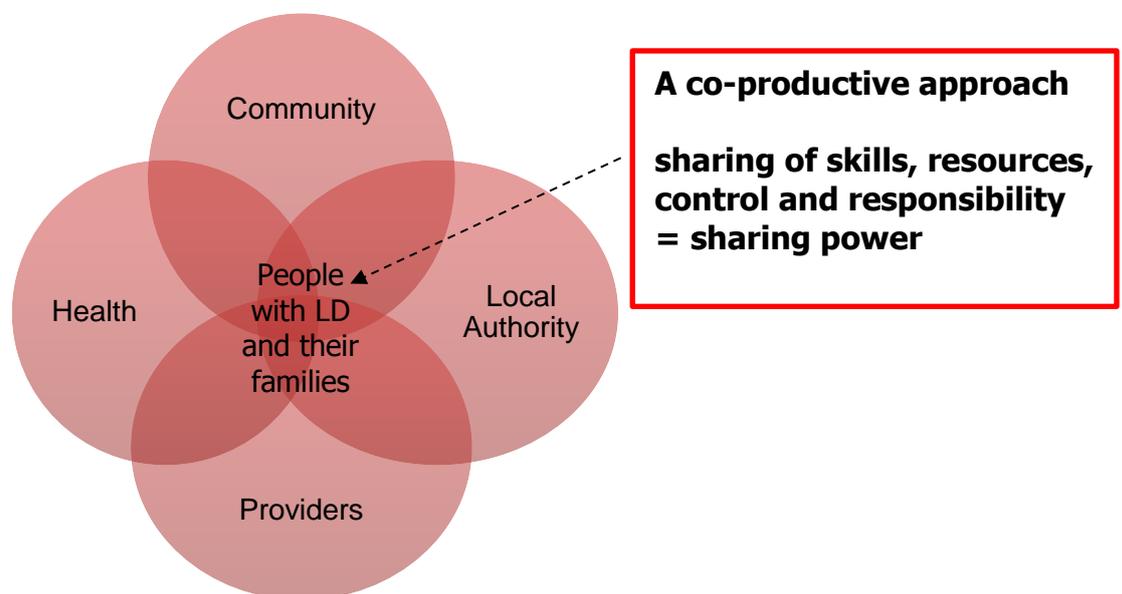
¹⁰ The Health Foundation (2010) *What is co-production?* London: The Health Foundation

¹¹ Co-production Wales and Public Health Wales (2015) 'Seeing is Believing'.

co-production as 'the way we do things', bringing together professionals and those they support as partners in the commissioning, design, delivery and evaluation of services. The culture of the organisation changes, mutual trust and reciprocity between professionals and communities become the norm. The impact of public services is amplified as latent assets within the community, such as peer support, informal care networks, and faith and civil society groups, are supported and flourish'.¹²

The Co-production Network Wales has developed an [audit tool](#) aimed at supporting organisations to benchmark the degree to which they are working co-productively.

Commissioners are the strategic leaders for a co-productive approach. Therefore, commissioners need to set the scene, facilitate the environment and influence others to embed a co-productive approach. Building a new culture is about changing the basic relationship between people with learning disabilities and their families, the community, providers and commissioners to one where the power is shared.



Co-production requires frontline professionals to have 'What Matters' Conversations.

What Matters Conversation

1. Tell me a bit about yourself.
2. Tell me a bit about what's been happening?
3. What are you most concerned about?
4. Can we spend a little time exploring what matters to you?
5. What things prevent you from being able to achieve the things that matter to you?
6. Could support help you to achieve the things that matter to you?
7. What are the risks if you are unable to achieve the things that matter to you?
8. What skills and strengths do you have that will help you achieve the things that matter to you?
9. What skills, capacity and support do you think your friends and family have to offer that might help you achieve the things that matter to you? (E.g. do you

¹² Co-production Wales and Public Health Wales (2015) 'Seeing is Believing'

- share any common interests)
10. What skills, capacity and support do you think the community has to offer that could help you achieve the things that matter to you?
 11. Are the skills, support and capacity available sufficient to enable you to achieve the things that matter to you?

Commissioners need to collate the information gathered in What Matters conversations and use it to help them analyse need, identify gaps in service provision and develop pathways across the system so that people can move easily between universal and specialist services and back again.

Below are some practical examples of strategic activities commissioners can use to help co-production flourish.

Commissioning Stage: Analyse

- People with learning disabilities and their families leading analysis of future needs by using 'Working Together for Change'.
- People with learning disabilities and their families gathering information on the reasonable adjustments and assistance required within universal services by being involved in access audits.
- People with learning disabilities and their families gathering information on the quality of services across the system by being mystery shoppers.
- People with learning disabilities gathering information on what matters to people and their families by self-advocate groups leading 'What Matters to Me' listening events with people with learning disabilities.

Working Together for Change

Working Together For Change uses an 8-step process to make sure that you are taking into account the needs, wishes and aspirations of the people you support and your other stakeholders. The process collates person-centred information gathered from Person-Centred Reviews and person-centred care and support plans and helps the organise see the emerging trends in the data. This will show both what is working well, and what people would like to see change. Following this, the process supports participants to create a plan to take them forward, which can then be implemented over time and regularly reviewed.

<http://helensandersonassociates.co.uk/person-centred-practice/working-together-change/>

Commissioning Stage: Plan

- People with learning disabilities members of decision-making bodies.
- People with learning disabilities and commissioners jointly running consultation exercises with the public, providers or other groups.

- Scenario analysis workshops where proposed arrangements are tested and changes are agreed with workshop members.

Involve Me

Involve Me aims to increase the involvement of people with PMLD in decision making and consultation. The Involve Me summary booklet and practical guide are a result of the 3 year project, supported by the Renton Foundation and run by Mencap in partnership with the British Institute of Learning Disability (BILD). People with PMLD and staff took part by learning about using different approaches to communication: sharing stories, creative communication, peer advocacy and multimedia advocacy.

<https://www.mencap.org.uk/advice-and-support/pmld/pmld-involve-me>

[Summary Booklet](#)

[Practical Guide](#)

Commissioning Stage: Do

- Commissioners must ensure that people with learning disabilities have access to community connectors.
- People with learning disabilities using direct payments to secure their choice of support empowered by professionals. Groups of people with learning disabilities sharing resources to secure combined support. Increasing the use of direct payments and the sharing of resources will only happen if commissioners across children and adult services ensure people have access to good brokerage services, good transition services that teach skills and provide access to life navigators, introduce payment cards, and work to increase the number of suitable PAs.

Powys Community Health and Well-being Coordination Service

The service helps people in Powys (aged 18+) and their families or carers, to access community-level services and activities that will help them maintain independent lives and which help prevent their circumstances deteriorating to a point where they might need higher level health or social care services. The service can also help support people when they return to home from hospital by helping other Third Sector services, such as Red Cross, identify additional local services that may be needed. The service is provided at a community level in many areas of Powys by locally based Community Connectors, as well as through the central point of contact in Powys People Direct.

<http://www.pavo.org.uk/policy-and-partnerships/partnerships/health-social-care-and-wellbeing/community-connectors.html>

Commissioning Stage: Review

- People with learning disabilities supported to design performance indicators and performance monitoring arrangements.

The Association of Quality Checkers (AQC)

AQC is a not-for-profit organisation dedicated to supporting the work of Quality Checkers with disabilities in England, Northern Ireland, Scotland and Wales. Quality Checkers perform a unique role in monitoring services. People who provide and procure services can miss important information or fail to ask a crucial question as they have not experienced that service. Quality Checkers have direct experience of using services and know what to ask and where to look to find answers. Quality Checkers are paid by provider organisations, Clinical Commissioning Groups, Local Authorities and other mainstream organisations to check the quality of the services they provide.

<http://qualitycheckers.org.uk/about-aqc/what-is-a-quality-checker>

Top tips for moving towards co-productive commissioning

Be clear about where you are going

- Be clear about what a co-productive approach to commissioning is and how it differs from simply engaging with people and communities. Commissioners are the strategic leaders for a co-productive approach.
- Explore the views of stakeholders and embed co-productive approaches into your strategic vision and leadership so that you can create the right environment for co-production.

Build alliances and relationships with allies

- Identify those who want to engage in a co-productive relationship.
- Take time to understand their perspective, how much they want to be involved, why, and how sustainable their engagement might be.
- Make links with other public bodies working in a co-productive way with people to see if there are links that can be made.

Build skills and knowledge

- Explore the skills that are needed by commissioners, by contractors, by people with learning disabilities and carers.
- Find examples of co-production projects which can act as blueprints for your activities, and analyse the skills and activities needed in them.
- Build a learning community by developing skills together.

Build co-production into everyday activity

- Make sure that there are clear expectations about the tasks and activities that result in a co-productive approach in all aspects of the commissioning and procurement cycle – for example in work on needs analysis, on service

reviews, on strategies, in specification and contract design, and in service monitoring and review.

Develop effective feedback and challenge

- Find ways to ensure that your co-production strategy is reviewed and challenged and refreshed regularly – perhaps work with a local user group to review your progress.

Keep going

- Co-productive, citizen-centred commissioning is not about introducing a few isolated initiatives involving people with learning disabilities and their families. It is about a long term culture change in the way in which services and support are designed and developed. Having a clear idea of the end goal and an understanding of the complexity in delivering this will help to deliver change in the long term.

Key Culture Change

People with learning disabilities, their families and commissioners are equal leaders in the commissioning and procuring of services.

Commissioners must work with all stakeholders to develop ways of empowering all people with learning disabilities and their families.

6. Question: How do you lead whole systems change? Answer: Communication

Developing a local whole system, community, life span approach to commissioning good lives will require commissioners to effectively communicate the case for change. To communicate the case for change commissioners must engage with stakeholders who may have little understanding of the issues faced by people with learning disabilities and their families. Leading whole systems change means commissioners must set the scene, facilitate the environment and influence others. Doing this well requires effective communication. IPC have taken the 'ladder of participation'¹³ and applied it to communicating a whole systems change.

Communication activities should be undertaken across the whole system. Commissioners should promote the right communication for people at the right time. Not everyone who starts the change journey will end up being a change champion as some people will only engage for a short time. Ultimately, the communication activities should aim to build consensus for the changes.

The Commissioner



The Stakeholder



¹³ Hart (1997) 'Children's Participation from Tokenism to Citizenship'. Florence: UNICEF Innocent Research Centre.

Designing the activities to use at each stage of the communicating change journey should be informed by a stakeholder analysis categorising stakeholder groups as to whether they a) might like to know b) need to know c) are directly involved d) key champions. The stakeholder categories can then be mapped against the engagement journey. The communicating change activities should aim to:

- Achieve a shared understanding of what we are doing and why.
- Ensure that a whole system approach is taken towards the agenda for change and that the relevant individual parts of the system understand their contribution towards its delivery.
- Maximise the opportunity for participation of stakeholders into the development and implementation of the changes.
- Build credibility and trust and create an environment that encourages openness and meaningful dialogue.
- Ensure all stakeholders know what is happening, when and how it will affect them.

The following principles of engagement should be adhered to throughout the communicating change journey:

- Address the needs of individual stakeholders in both 'what' and 'how'.
- Use existing channels of communication and tried and tested methods that work.
- Give people feedback on what difference their involvement has made and if not, explain why.
- Deliver consistent messages through a variety of vehicles.
- Be clear and simple – avoid jargon and make the complex simple.
- Make reasonable adjustments to maximise the ability for everyone to participate e.g. accessible formats and venues, use of interpreters and advocates.
- Keep promises – communicate when we say we will even if there is nothing to say.

Checklist of Stakeholders to Engage in the Communicating Change Journey

✓ People with learning disabilities	✓ Adult Social Services
✓ Their families and carers	✓ Children Services
✓ External providers whom you don't currently commission	✓ Education Services
✓ Other council departments	✓ Commissioners and managers across the system (e.g. health, social care, education, public health, community well-being)
✓ Universal services	✓ Providers of health
✓ Voluntary and community services	✓ Providers of education
✓ Internal providers of social care	✓ Providers of housing
✓ External providers of social care that you currently commission with	✓ Public health

Example Activities throughout the Communicating Change Journey

Stage of Journey	Purpose	Method	Message
<p>Communication:</p> <p>Commissioner: We have informed people about what we are doing and why.</p> <p>Stakeholder: I know what we are doing and why</p>	<p>Providing information to all stakeholders who would like to know, need to know, are directly involved and potential champions</p>	<p>Make electronic copies of the Statement of Intent available via website:</p> <ul style="list-style-type: none"> • Full Version • Easy Read <p>Advertise and deliver dissemination events across the area covering the full range of stakeholders</p> <p>Dissemination campaign using websites, facebook and twitter. Ensure community organisations add it to their website and facebook page as a news story with a link to the document.</p>	<p>The case for change.</p> <p>The approach for Commissioning 'Good Lives'</p> <p>How people can get involved in discussing what it means locally.</p>

Stage of Journey	Purpose	Method	Message
<p>Consultation:</p> <p><u>Commissioner</u> We have listened to peoples' suggestions and comments and it is informing our local approach.</p> <p><u>Stakeholder</u> I've had an opportunity to give feedback and make suggestions</p>	<p>Securing ideas, suggestions and feedback from those whom, at this stage, need to know but in the future might be more directly involved.</p>	<p>Facilitate focus groups between 5 and 10 people at a time.</p> <p>Electronic Suggestion Box. (Raise awareness of suggestion box at dissemination events and via social media campaigns mentioned above)</p>	<p>Share rationale and approach to commissioning 'Good Lives'.</p> <p>Explain the requirement for services to be accessible.</p> <p>Discuss ideas for reasonable adjustments and how to work together going forward to achieve strategic outcomes.</p> <p>Explore what 'universal plus' and 'assistance' should look like locally.</p> <p>To provide an opportunity and mechanism for everyone to submit ideas or suggestions they may have</p>

Stage of Journey	Purpose	Method	Message
<p>Negotiation:</p> <p><u>Commissioner</u> We have discussed and agreed with stakeholders across the system a whole system approach</p>	<p>Securing agreement to the approach and change journey from those who are, or who need to be, directly involved</p>	<p>Facilitated, themed discussions that are solutions focused.</p> <p>Community change assessment.</p>	<p>To articulate and agree the detail of the local approach for commissioning Good Lives</p> <p>A community change assessment that asks agencies, and groups across the whole system:</p> <ul style="list-style-type: none"> • What do you need to achieve the outcomes?

Stage of Journey	Purpose	Method	Message
<u>Stakeholder</u> I've contributed to developing an agreed local approach for commissioning 'Good Lives'			<ul style="list-style-type: none"> What can you contribute to moving the change forward?

Stage of Journey	Purpose	Method	Message
Participation: <u>Commissioner</u> We have a shared ownership and commitment to delivering the approach <u>Stakeholder</u> I am a change champion	Working together with champions, doers and key managers to move the change journey forward	Create a network of community champions Action learning sets Practice Leadership	Raising awareness of people with learning disabilities and reducing stigma Test and agree how to do things differently Professionals are challenged by their managers and peers when they do not engage in good co-production

Key Culture Change

That all stakeholders truly believe that the only way to achieve good lives in the community is via an all age, whole systems approach.

Commissioners must engage and work with the wide range of stakeholders when communicating the change journey and co-producing solutions.

7. Question: How do you shape local services and keep the person at the centre? Answer: Co-produce whole systems pathways, across the lifespan

Effective commissioning that enables citizens to achieve desired well-being outcomes is mutually dependent on other disciplines for success. For example:

- Procurement and contracting activity should unambiguously support person-centred services and a sustainable workforce.
- Assessment and care pathway arrangements need to be consistent with

commissioning objectives.¹⁴

A well designed pathway should mean we have:

'The right people, in the right order, in the right place, doing the right thing, in the right time, with the right outcome, all with attention to the user experience'.¹⁵

A good pathway design should include the following features:

- Negotiable, workable and understandable.
- Multiple points of entry.
- Integrated services to remove barriers to movement.
- Minimises need for transition between services or providers.
- Enables services to be built around the pathway...not the pathway around services.
- Family focused.
- Engage staff groups in consensus building.
- Ensure learning and change.
- Optimise and recalibrate resources to needs.

A high-level pathway should be used to agree and commit to the medium and longer-term strategic aims for services. The use of pathways as a tool to facilitate integrated working is becoming increasingly commonplace within the health and social care service sectors. Indeed, they have been described as the 'lynchpin' of integrated services. Pathways can be both a means and an end to service integration. At the same time, pathways don't necessarily require formal or structural integration to be effective e.g. in terms of improving the degree and quality of collaborative practice or its impact.

However, collaboration between professionals is not enough because collaboration does not necessarily result in co-production. Pathways must be co-produced with people with learning disabilities and their families. This is significant. If we want pathways for co-producing good lives then they have to be co-produced. One way of doing this is to use What Matters conversations with a wide range of people with learning disabilities and their families who are at different stages of the life span.

¹⁴ IPC National Commissioning Board (2017) 'Integrated and Collaborative Commissioning'

¹⁵ Davis (2005) 'Integrated Care Pathways. A guide to good practice' National Leadership and Innovation Agency for Healthcare

What Matters Conversations and Co-producing Pathways

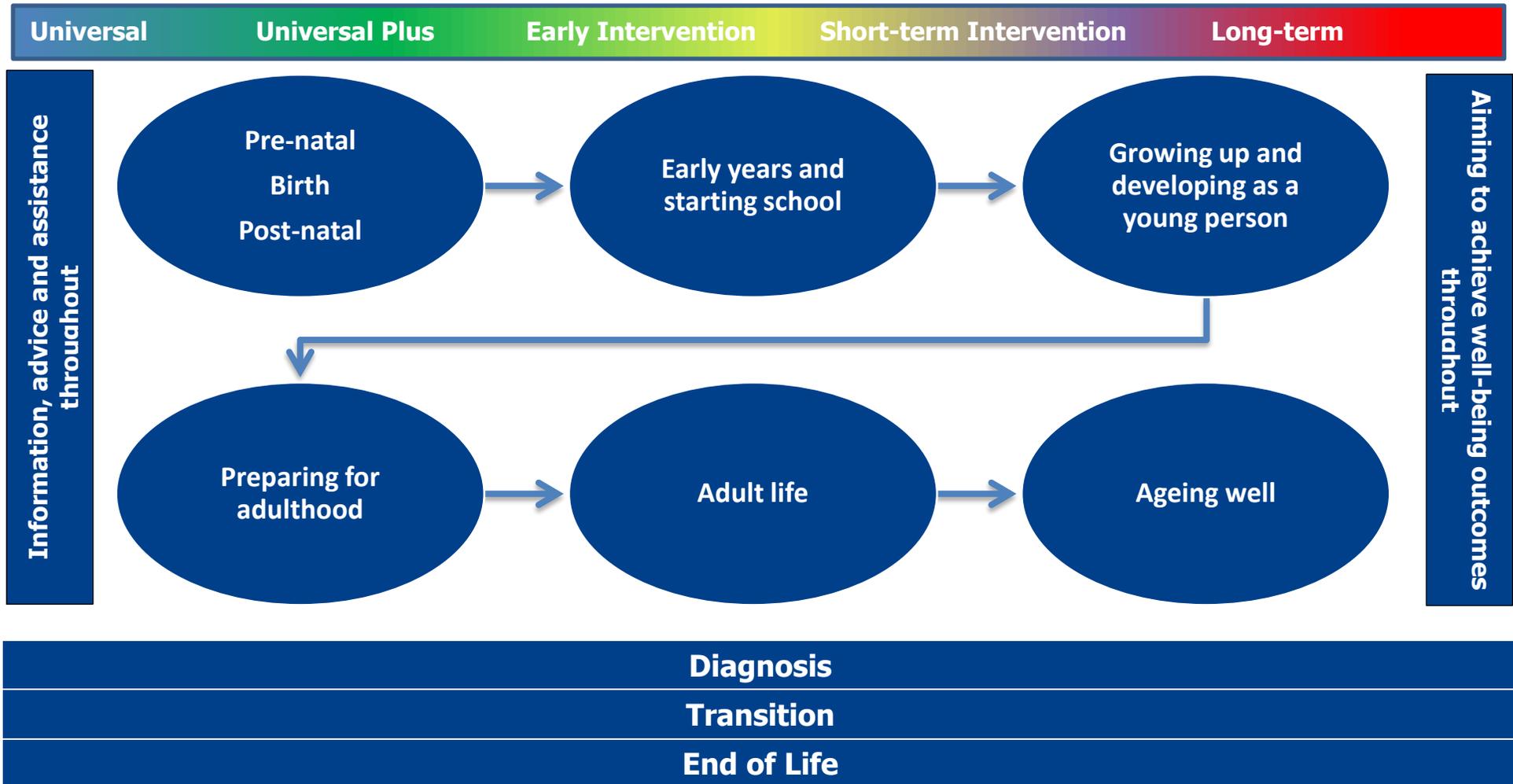
1. Tell me a bit about yourself.
2. Tell me a bit about your journey.
3. What matters to you?
4. Along your journey what has helped you to achieve the things that matter to you?
5. What things have prevented you along your journey from being able to achieve the things that matter to you?
6. What has been the impact on you (and your family)?
7. What might have helped?
8. When were you given opportunities to contribute (using your skills and strengths) to your community?
9. Throughout your journey how accessible were the skills and support in your community?
10. Were the skills, support and capacity in your community sufficient to enable you to achieve the things that matter to you? What might have helped?

Whole system, lifespan pathway for co-producing good lives

Below is a high-level support pathway that can be used to develop co-produced local pathways. A clear and effective support pathway will enable accessible information, and where required access to and provision of services and support. The lifelong support pathway below shows a person's journey over time and is grouped into a series of key stages.

There are a number of issues that can occur at any point in the pathway. These are depicted by the boxes running along the bottom.

When applying pathways to the approach for commissioning good lives in the community it is crucial to consider that at each life stage there is a need for pathways that enable people to move from universal and universal plus through to short-term and long-term intervention and back again. This is depicted by the box running along the top.



Pre-natal, birth, post-natal

The aim at this stage is to ensure that parents feel supported from the start. Parents should be given clear explanations about what is going to happen next, and where to get further information and help. Professionals should recognise the vulnerability of families where there is a child with disabilities. Universal services should have accessible information about the support available to families. Professionals in universal services should have access to advice and guidance from specialist children's services so that they can support families within universal services. There should be clear pathways for families to access early and short-term intervention if appropriate. There should be clear pathways for supporting families to transition back to universal services when appropriate. Parents should be supported to begin to build peer support networks (physical, virtual or both). This helps to ensure that parents are valued as contributors from the start rather than feeling passive, anxious and helpless.

Early years and starting school

The aim at this stage is to establish early networks and ensure smooth moves into child care and school, and to ensure that families continue to receive support and services early on to help minimise problems from arising in the future, in line with the Additional Learning Needs Education Tribunal (Wales) Bill. We aim to ensure that services are outcome focused and when new services are started, the parents do not have to retell their journey. Professionals in universal services (e.g. mainstream schools) should have access to advice and guidance from specialist children's services (e.g. specialist schools) so that they can support families within universal services. This may include advice and guidance around reasonable adjustments and assistance. It may also include co-designing and co-delivering early intervention programmes in universal settings.

Growing up and developing as a Young Person

The aim at this stage is to ensure that families know what is available and that children and young people have opportunities to engage in a range of activities appropriate to their wishes and needs. It is also to ensure that young people have a smooth route into secondary school and receive the information they need to support them growing up. Parents are regularly provided with up to date information about what opportunities are available via the key worker and support groups. A range of play and sport activities are available on a regular basis. Socialisation opportunities for parents are provided, for example music therapy groups for children include a space for parents to meet. Transport to and from activities is available, if required. Schools are community-focussed and provide opportunities for children without disabilities to act as mentors to help support disabled pupils. Existing play facilities are accessible by children and young people with disabilities. Play work staff are trained to effectively support disabled children within community based provision to provide socialization opportunities both with other disabled children and with non-disabled children. Health, social services and education departments work closely together to ensure families and children have their parenting and educational needs met locally, in so far as this is possible, to build and sustain local capacity, and to reduce dependence on remotely located residential schools, sometimes offering variable outcomes and high costs. Services need to be focused on achieved positive outcomes and value for money.

The key worker and the family meet with teachers to plan the move to secondary school. This meeting is also used to review existing services and progress towards outcomes. Support for young people is provided during adolescence – sex and relationship education for young people with disabilities and support for families is given via the school and/or school nurse. True inclusion is experienced – the young person has social opportunities including after school activities, and is actively encouraged to access these.

Preparing for adulthood

The aim at this stage is to ensure that the family begins to prepare for the young person's move to adulthood. That they have clear expectations about what options and services are available and are able to make informed choices about the future. Annual school reviews involve the young person, parents and all professionals involved with the family. Reviews look at services and support currently being provided and outcomes are reviewed across all areas of the young person's life. Support needs for family are also reviewed. Services are available that together can support a meaningful life for the young person, and to help them make the transition to greater independence, including opportunities for further education, training, work experience and volunteering. When an individual is at school or residential college this also serves the function of providing respite care for families. It will be important for Health, social services and education departments to work closely together to ensure that both families and young people can cope with a life without school / college-time respite and support, and to plan carefully to avoid the risk of crisis-generated placements.

Adult Life

The aim at this stage is to ensure that the adult with a learning disability has the same opportunities as anyone else to live a satisfying and valued life. They should have a home within their community, be supported to develop and maintain relationships and get the help they need to live a healthy, safe and fulfilling life. They should have access to education, training, volunteering, paid employment, social and leisure activities and opportunities to be part of and contribute to their local community. They should have genuine choice and control over whom they live with and whether they live alone, with family or in a friendship group.

Ageing Well

Older people with learning disabilities share many of the same experiences of growing older as everyone else and they have the same needs as other older people. Like others, people with learning disabilities have the potential to age successfully and so the aim at this stage is to ensure that older people with learning disabilities have choice and control over their lives to enable them to age well. Most people with learning disabilities live with their parents and these families are growing older together. The situation can be complex, as the person with learning disabilities may also be supporting the older family carer. Older people with learning disabilities and their carers therefore need a wide range of information, advice, assistance, person centred care and support options, and early planning for living arrangements in later life.

Diagnosis

Diagnosis can occur at various times in the person's pathway. The aim at this stage is to ensure that parents (and depending on age the person themselves) are given clear explanations about the disability, know what services are available and understand what support is available to them. Where there are ongoing health challenges, these need to be looked at within the context of the person's disability.

Transition

Transition can occur at any time in the individual's life pathway, e.g. from childhood to youth; youth to adulthood; changing care needs; ageing parents / carers; death of parents / carers. Where the transition can be planned, for example in preparation for adulthood, transition planning is person-centred with the young person's preferences, goals and aspirations taking centre stage. The transition process brings together the people who will ensure that families and young people with a disability can plan ahead for the future as they enter adulthood. The transition plan is focused on individual needs, regardless of what those needs might be, and agreed with young people and their parents. Early engagement is crucial in the preparation for transition as it helps to broaden views about what is possible and provides time to thoroughly investigate options.

End of Life

People with a learning disability are as prone to the full range of ill-health conditions as the rest of the population, including malignant and non-malignant life-limiting conditions. The aim is for early diagnosis and effective health outcomes for everyone, including access to specialist palliative care services if appropriate. While some people with a learning disability recognise their own ill health, many cannot. Families and professional carer workers play a major role in noticing symptoms of potential ill health, and encouraging people to seek out medical advice. Once ill health is noticed, some people with learning disabilities need help to access clinics and attend appointments. Holistic care is central to the delivery of quality end-of-life care and support, regardless of disability, race, culture or creed. As death approaches, the person should be given the opportunity to express their preferences about their end of life care. The person may wish to say goodbye to their friends, families and carers, and every opportunity to help them to do this should be made. All people involved with the person's life will need varying degrees of support to manage their sense of loss.

Key Culture Change

All stakeholders understand the need to have clear pathways between universal services, universal plus, early intervention, short-term intervention and long-term specialist services for each life stage. Pathways must enable people to move back from specialist services towards universal services.

Commissioners must work with all stakeholders across the system to develop these pathways, co-producing them with people with learning disabilities and their families using What Matters conversations.

8. Question: How do you reduce placement breakdown and prevent hospital admission? Answer: Whole systems, lifespan approach to positive behaviour support

Positive Behavioural Support (PBS) is an ethical, comprehensive, evidence-based approach developed within the learning disability field. It is person-centred and proactive in that it focuses on improvements in individuals' quality of life and prevention of challenging behaviour. PBS is accepted internationally as current best practice and is specifically recommended by key national government and professional organisations in numerous recent guidance documents as part of the ambitious transformation agenda across all vulnerable client groups.^{16 1718}

PBS is in full accord with the Social Services and Wellbeing (Wales) Act 2014, in that it:

- promotes physical and emotional well-being,
- addresses physical and mental health issues,
- emphasises personal and skill development,
- supports and encourages family and personal relationships,
- provides opportunities for social well-being and inclusion,
- promotes human rights, dignity and respect,
- enhances living accommodation and the person-environment fit.

It is worth emphasising that the comprehensive nature of PBS means that it embraces the social model of disability and the insights of social role valorisation (SRV). The social model emphasises the importance of the environment as a factor in enabling or disabling people to live a good life. SRV also highlights the potentially negative impact of service design features that stigmatise, segregate and congregate people at risk of societal prejudice. It is therefore a fundamental feature of PBS to promote small-scale, homely living environments other than in exceptional cases. It is also a core aim of PBS to prevent people from being placed in stigmatising, segregated and congregated environments, and to support their return to a homely place in the community. PBS is not just a therapeutic technique to be applied in any environment with no regard for the "fitness" of that environment.

PBS uses the least restrictive interventions and totally rejects any use of punishment. As such, it is accepted as the most effective protection for vulnerable people at risk of abuse and neglect.

¹⁶ Gore et al (2013) Definition and Scope for Positive Behaviour Support. International Journal of Positive Behavioural Support 3(2), 14-23.

¹⁷ NICE (2015) Guidelines on prevention, assessment and intervention for Challenging Behaviour and Learning Disabilities

¹⁸ Royal College of Psychiatrists and the British Psychological Society (April 2016) Challenging behaviour: A unified approach – Update. Joint statement by the Faculties of Intellectual Disability of the Royal College of Psychiatrists, and the Learning Disability Professional Senate of the British Psychological Society

Key aspects are detailed below:

PBS is values led

The key aim of PBS is to help vulnerable people to have the same human rights and opportunities as other people, and to be treated fairly, with compassion, kindness, dignity and respect. It focuses on what services, carers and professionals need to do to meet individual people's needs in the best ways possible.

PBS focuses on improving quality of life

PBS defines a good quality of life as what most people would want on a day to day basis, such as a comfortable home, contact with family and friends, engagement in a wide range of activities, such as running a home, work and leisure, as an accepted and equal member of the community, free from pain, distress and abuse. PBS helps people to do more things for themselves. It includes active support which helps carers to give people more opportunities to learn, practice their skills and abilities and participate more fully in daily life, helping to maintain or develop independence as far as possible, which increases dignity and self-esteem. Active support comprises a set of tools and guidance for carers that includes a technology of positive interaction that provides individualised assistance to maximise participation and skill development. Also included is a detailed, flexible system for planning service user activities together with the requisite support.

By enhancing these aspects, PBS improves quality of life not just for the individuals but also for their carers.

PBS is inclusive

PBS assessments and interventions are designed with the active involvement of key people in the person's life. These are the people who know the person best and actually put PBS into operation. They, therefore, need to understand and agree with all that has to be done.

PBS is person-centred

The starting point is to get a clear picture of the person, how the person copes with their environment and gets the things they require. This allows their unique needs, aspirations, experiences and strengths to be recognised and puts them at the centre of their care, and gives them a voice and control over the outcomes they want to achieve.

PBS is evidence-based

PBS is evidence-based in two ways. Firstly, there is growing research that shows it improves quality of life and reduces behaviours that challenge, and that this is maintained over time. Secondly, PBS is evidence-based at every stage, as it is based on information about the individual from initial assessment through to checking if the intervention plan is working in practice.

PBS is a framework for multi-component intervention

PBS is not a single intervention. In order to meet each person's unique needs, it may include a wide range of methods and therapies such as value-based behavioural approaches, physical and mental health treatments, communication systems, active support, skill teaching, activity planning, goal setting, behaviour management procedures, staff and carer training and stress management.

PBS is a collaborative approach

PBS builds strong partnerships between agencies, with a particular emphasis on joint working between health and social care, and innovation with the third sector

PBS is a three-stage intervention approach:

- Primary prevention focuses on person-centred ways of improving quality of life, and guides what the person's carers should do to help them in the most effective way. This mirrors Sustainable Social Services which emphasises that what frontline staff do on a day-to-day basis makes the ultimate difference in quality of care outcomes. Primary prevention is the main part of PBS intervention and, when this works well, there may be no need to put the other two stages into operation.
- Secondary prevention is used if a person starts to become agitated, which indicates that things aren't quite right for them. Calming, distracting or problem-solving approaches remove the need for the person to use behaviours that challenge to exert control or express their feelings.
- If secondary prevention fails, then reactive strategies are used to manage any challenging behaviour that may occur, in a safe and ethical way.

PBS is proactive because, although it includes ethical reactive strategies, it places the greatest emphasis on primary prevention, which enhances quality of life and pays attention to the person's health and wellbeing, to ensure things go right for most of the time. Many current services are opposite to this, where the main focus is on restrictive interventions, which are used in reaction to challenging behaviour after things have gone wrong.

PBS is a skilled approach

For successful widespread implementation, staff and carers will require specialised training in PBS and support, and many organisations may need to undergo cultural change. Indeed, the adoption of PBS can be a driver for such cultural shift so that different things are done rather than the same things done differently. Wales is at some advantage, as several agencies have been developing the PBS approach and associated training, and an active All Wales Community of Practice has existed for some years.

Further information about Positive Behavioural Support

<http://www.bild.org.uk/our-services/positive-behaviour-support/capbs/>

<http://pbsacademy.org.uk/>

<http://arcuk.org.uk/activesupport/>

<https://www.unitedresponse.org.uk/active-support?qclid=CI3TwIrKq9MCFRc6GwodLjgK7g>

Why do we need all age positive behaviour support teams?

My name is Claire and I am the mum of a 16 year old boy with learning disabilities and autism. My son Hayden is a caring, friendly, happy boy but he struggles to process what is happening around him, causing him great anxiety and distress. When Hayden is upset he will run around screaming, throwing things and hitting people.

We have never received support to help manage Hayden's behaviour despite our numerous and increasingly desperate requests. The lack of support meant that our physical and mental health suffered with both my husband and myself being prescribed antidepressants and taking time off work.

The most frustrating thing is that Hayden has always behaved like this. His behaviour has not significantly changed since he was 2 years old but age 16 he is almost 6 feet tall, 13 stone and it became impossible for us to keep him or ourselves safe. This year we made the heart-breaking decision that Hayden could no longer live with us. Allowing our son to be taken into care has been the worst moment of our lives. We miss him every day. I truly believe that had we received behaviour support throughout his life our son would still be living with us. Our hearts would not be broken and the State would not be paying in excess of £3000 a week to care for him.

The structure of an all age positive behaviour support (PBS) team



The model for an all age PBS team describes a preventative approach aimed at reducing or stopping behaviours that challenge; preventing family or placement breakdown; preventing or reducing out of area or hospital admissions and improving the quality of life and sense of well-being of children, young people and adults with learning disabilities whose behaviour challenges; and the quality of life and sense of well-being of their families and paid carers.

PBS Early Intervention

The provision of 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 need that can often be costly. Everyone involved in caring for and supporting children, young people and adults with a learning disability should understand the risk of behaviour that challenges and that it often develops gradually.¹⁹



Aim: To work with children and young people with learning disabilities, their families and schools to really understand the functions of the behaviours that challenge and how to minimise the impact of the behaviour on the quality of life of the child/young person and their family. To prevent, reduce or stop the development of future episodes of behaviour that challenges.

Who: PBS practitioners, PBS coaches, PBS leads, SALT, psychologist. Strong links to early years settings (pre-school, nursery, childminders etc), primary and secondary schools, parent carer support groups.

Activities: Train families, schools and pre-school settings in positive behaviour support. Be a place for other professionals to sign post to when there are emerging behaviour issues causing concern. Provide functional assessment of behaviours that challenge and work with families, early years settings and schools to implement evidence-informed interventions to prevent, reduce or stop behaviours.

Desired Outcomes: Reduce behaviours that challenge.
Prevent isolation and exclusion due to behaviours that challenge.
Reduce the risk of family breakdown.
Increase the quality of life of children and young people who display behaviours that challenge.
Increase the quality of life of their families.

PBS Short-term intervention

Short-term intervention should be something that children, young people and adults with learning disabilities can access at any time across their life-span. This might include intensive desensitisation or skills building interventions that enable someone to access universal services or engage/contribute to their community. It might be supporting their communication needs or teaching skills to maximise independence and reduce behaviours that challenge. It may be increasing knowledge to support someone to stay safe and engage in adult relationships.

Aim: To meet the immediate health/therapeutic need to reduce or stop behaviours that challenge; or to teach a skill that will empower the child, young person or adult with a

¹⁹ NICE (2015) 'Guideline: Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges.'

learning disability to communicate more effectively, be more independent; or to empower a young person, adult or family to access universal services and/or contribute to their community.

Who: PBS/ABA Lead, PBS coaches, PBS practitioners, LD/MH nurse, OT, Physio, SALT, psychologist, strong links to sexual health practitioner.

Activities: Teach skills such as managing medication or cooking healthy meals. Provide desensitisation programmes. Provide hospital liaison services if someone is suffering a health crisis. Provide support to people with learning disabilities to increase their knowledge around sexual health and relationships. Provide support with end of life care. Provide counselling for people with learning disabilities and their families. Deliver evidence informed interventions that increase resilience, reduce risky behaviours, develop self-esteem and empower people to advocate for themselves. Via community connectors assist and empower people with learning disabilities and their family carers to contribute to their communities.

Desired Outcomes: To reduce or stop behaviours that challenge.
To increase the independence of children, young people or adults with learning disabilities.
To enable people with learning disabilities to get their health needs met.
To increase the resilience of people with learning disabilities and their families.

PBS Crisis Intervention in the Community

One important requirement of services is that they are able to 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. 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.²⁰ This should take the form of a crisis intervention team.²¹

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 and/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.²²

²⁰ Mansell, J. (2007) 'Services for people with learning disabilities and challenging behaviour or mental health needs' Department of Health.

²¹ <http://www.challengingbehaviour.org.uk/learning-disability-assets/southlondonandmaudsleyhnsfoundationtrust0316.pdf>

²² Transforming Care (2015) 'Building the Right Support'

For all inpatient provision (secure or not) children admitted to hospital should be placed in an environment suitable for their age and must have access to education.²³

Aim : To provide crisis support in the community for any child, young person or adult 7 days a week, 24 hours a day regardless of their place of residence.

Who: PBS practitioners, PBS coaches, PBS leads, LD and MH nursing access to counselling and/or post trauma support for staff working in the crisis intervention team, staff working in support services and families. Close links to G.P.s, psychiatrist, children and adult mental health services.

Activities: Provide rapid and flexible support in the person's place of residence when family or paid carers are struggling to cope with a sudden escalation in behaviour. PBS practitioners providing support in the person's place of residence should enable family or paid carers to have a break from trying to manage the behaviour. This will enable parent carers to meet the needs of other family members (such as other children) who may be distressed by the behaviour. It will also give them space to attend to their own physical and psychological needs. The crisis team should support family or paid carers to de-escalate and stabilise the behaviour. The crisis team should provide access to post trauma support for families and paid carers. The crisis team should provide access to rapid and flexible clinical input.

Desired Outcomes: To keep people with learning disabilities safe.
To keep family carers and paid carers safe.
To prevent placement breakdown and people being admitted to hospital.

PBS Long-term Support in the Community

The impact that disability, autism or mental health conditions have on some people mean that they will require long-term PBS support if they are to remain in the community. The complexity of the issues they face and the level of risk that their families and paid carers have to manage on a daily basis means that living a life in the community can only be sustained if their circle of support has ongoing input from the PBS team.

Aim: To provide ongoing behaviour support to families or services supporting children, young people or adults with complex behaviour issues in order to maintain stability and resilience and prevent family and/or placement breakdown.

Who: PBS practitioners, PBS coaches, PBS leads, LD and MH nursing, specialist providers who are PBS trained, psychologist, psychiatrist, social worker.

Activities: Provide full functional assessments that result in evidence-based formulations. 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 families and paid carers empowering them to successfully implement the guidelines.

²³ Transforming Care (2015) 'Building the Right Support

Desired Outcomes: To prevent family and/or placement breakdown.
To increase the resilience of family and paid carers.
To enable people with learning disabilities whose behaviour challenges to live good lives in their community.

Key Culture Change

That family and/or placement breakdown is not inevitable. That positive behaviour support works and is most effective the earlier in a person's journey it is used.

Commissioners must work together across the system to create all age positive behaviour support teams.

9. Question: How do you know you are improving well-being?

Answer: Measure outcomes

For more than a decade commissioners have focussed on driving the price for services down to maximise the amount of care a person can get at the lowest possible cost. It is now widely recognised that extending this approach further is unsustainable as it threatens the existence of those providers who deliver local services. In response, there has been a recent move by local authorities across the UK towards an approach which looks at how the full range of services contribute to achieving outcomes both at an individual and strategic level. This is often referred to as 'outcome-based commissioning'.

There is much debate within the NHS and adult social care currently as to whether there are sufficient resources within the system to fund a sustainable model of care and support. This leads commissioners to be very careful about how every pound is spent. It is in part this approach to value for money that has also led to councils looking at an outcome-based model of social care. It is very important that the resources available are spent in the best possible way, and advocates argue that one impact of outcome-based commissioning is that it can lead to a more cost-effective and sustainable model of social care²⁴.

The National Outcomes Framework²⁵ and the Social Services and Well-being (Wales) Act 2014 provide guidance on the outcomes that should be measured and the national outcome indicators that should tell commissioners whether good outcomes are being achieved. It is important that commissioners recognise the link between What Matters conversations and the national outcomes framework (see example below).

²⁴ IPC (2016) 'Outcome-based commissioning in domiciliary care' SSIA / National Commissioning Board for Wales

²⁵ The full version of the National Outcomes Framework can be found at:
<http://gov.wales/docs/dhss/publications/160610frameworken.pdf>

National Well-being domains (Some Examples)	National Outcome Statements	What Matters Conversations The outcomes identified are unique to the individual. Examples include:
Physical and mental health and emotional well-being	<ul style="list-style-type: none"> I am healthy and active and do things to keep myself healthy 	What matters to me is going to the gym 3 times a week and cooking healthy meals.
Domestic, family and personal relationships	<ul style="list-style-type: none"> I belong I contribute to and enjoy safe and healthy relationships 	What matters to me is seeing my friends regularly.
Contribution made to society	<ul style="list-style-type: none"> I engage and make a contribution to my community I feel valued in society 	What matters to me is being part of the self-advocacy group and helping others.

The full list of domains is included on pages 9 and 10.

Measuring outcomes for those who are unable to self-report

It can be difficult to apply the national outcome indicators to the learning disability population because not all people with learning disabilities can self-report.

When an individual is unable to self-report efforts must be made at their review to gather opinions from their circle of support. This will involve asking family members, paid carers, other professionals, friends and advocates to rate the degree to which the outcome statements are true for the person.

Key Culture Change

Measuring outcomes is the only way to know whether people with learning disabilities and their families are living good lives in their community.

Commissioners must measure outcomes by ensuring that it is built into provider contract reviews and individual person reviews. They must collate and aggregate this data and use it for strategic monitoring and planning.

Further work on measuring outcomes

The Institute of Public Care has developed proposals for measuring outcomes on behalf of the National Commissioning Board. These proposals will be subject to further scrutiny and development. The NCB will work with stakeholders to co-produce more detailed guidance on the development of an approach to measure outcomes.