

North Wales Together

Seamless Services for People with Learning Disabilities

Evidence Review

October 2019

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1 Introduction

The Institute of Public Care at Oxford Brookes University has compiled this evidence review for Flintshire County Council to help inform the implementation of the North Wales Together: Seamless Services for People with Learning Disabilities programme.

North Wales Together is a partnership of six local authorities/three sub regions: Conwy and Denbighshire; Flintshire and Wrexham; Gwynedd and Anglesey, and Betsi Cadwaladr University Health Board. Flintshire is the contracting local authority for this programme.

The programme is based on the *North Wales Learning Disability Strategy* which was written by health and social care services together with people with learning disabilities and their families/carers. The strategy is based around what people have said matters most to them:

- Having a good place to live
- Having something meaningful to do
- Friends, family and relationships
- Being safe
- Being healthy
- Having the right support

The strategy promotes the principles of the Social Services and Well-being (Wales) Act 2014.

- **Voice and control:** putting the individual and their needs at the centre of their care and giving them a voice in and control over reaching the outcomes that help them achieve well-being.
- **Prevention and early intervention:** increasing preventative services within the community to minimise the escalation of critical need.
- **Well-being:** supporting people to achieve their own well-being and measuring the success of care and support.
- **Co-production:** encouraging individuals to become more involved in the design and delivery of services.

The North Wales vision is that:

“People with learning disabilities will have a better quality of life; living locally where they feel ‘safe and well’, where they are valued and included in their communities and have access to effective personal support that promotes independence, choice and control”.

To achieve the vision and provide services based on what matters to people there are five planned workstreams:

- Integrated Structures
- Workforce Development
- Assistive Technology
- Commissioning & Procurement and,
- Community and Culture Change

The purpose of this evidence review is to identify policy guidance and best practice to inform the development of the programme / new service models. This is a piece of desk-based research and sources include both academic research reports as well as a range of policy and guidance documents and best practice examples produced by government and other professional bodies with expertise in these areas.

The programme manager has requested specific areas for investigation as follows:

Commissioning and procurement

- What is current thinking about how to commission housing and support for people with learning disabilities and complex needs, including commissioning across regions and sub regions and dealing with ‘ordinary residence’ criteria?

Workforce development

- What are some key methods and learning content which can be used to maximise the skill bases of providers locally in relation to people with complex needs?

Assistive technology

- Why are direct payments important and what are the ways in which families can be supported to set up and manage their direct payments (or other arrangements such as individual service funds), as the best way to achieve good outcomes?

Integrated structures and pooled budgets

- What are key principles for integrating health and social care and examples of good practice including the use of pooled budgets?

Community and culture change

- How can NWT increase the use of and recruitment (of carers) to Shared Lives, for all ages and in particular for young people with learning disabilities from age 16?
- What are the ways in which other areas/countries have enabled people with more severe levels of need to access employment?
- What models and approaches are there to ensure that advocacy is available to ensure the voice of people with profound and multiple learning disabilities is heard?

2 Findings

2.1 Commissioning and procurement

Key question:

What is current thinking about how to commission housing and support for people with learning disabilities and complex needs, including commissioning across regions and sub regions and dealing with 'ordinary residence' criteria?

Recent guidance from the National Commissioning Board Wales (2019) aims to support health and social care commissioners who are grappling with the difficult issues involved in meeting the growing accommodation and support needs of people with learning disabilities including those with complex needs. Challenges include shrinking budgets, the need to commission across regions and sub regions and joint commissioning using a mix of funding sources.

It takes as its starting point, a quote from Simon Duffy, Director of the Centre for Welfare Reform:

“Our aspiration should be to help people find real homes without trying to fit people into service models – the hospital, the hostel, the group home or individual flat. (Rather) each person should be treated as an individual and work with them to help them get the housing and support option that is right for them.” (p3)

Key housing principles (LGA, ADASS, NHS England, 2016) designed by people with a learning disability include:

- a choice about who they live with, and the location and community in which they live
- housing that works for them and meets their needs
- to be offered settled accommodation
- to be able to remain in their home even if their care and support needs to change
- ensure that choice about housing is offered early in planning for people

From this perspective **housing options** might include:

- Home ownership / shared ownership
- Accommodation via a local authority waiting list for general needs
- Private sector rented accommodation
- Specially commissioned accommodation provided by specialist housing providers
- Shared accommodation with carers eg Shared Lives

For more detail see LGA, ADASS, NHS England (2016), Appendix 3, *Typologies of models of accommodation*. p70).

Some helpful general points made in the National Commissioning Board (2019) guidance are:

Develop relationships between social care commissioning and housing strategy:

There needs to be join up with local authority housing strategy teams, so that future accommodation and support needs and types of provision for people with learning disability including complex needs are included in the Programme Development Plan (PDP). This will then allow Registered Social Landlords (RSLs) to access Social Housing grant from Welsh Government.

Provide resources and training for commissioners, providers, senior managers, elected members, social workers **about the different housing and support options that are available**, the evidence base behind them and the impact of each on rights, choice, control and inclusion. See National Development Team for Inclusion(NDTI) paper: www.ndti.org.uk/resources/publications/housing-choices-discussion-paper-4

Innovative and progressive procurement and strategic commissioning are essential ingredients for getting the right mix of housing and support provision. What this means and how to do it are explained in parts five and six of the guidance.

Regional Partnership Boards are advised to put in place **integrated and collaborative commissioning arrangements** including the use of pooled budgets, to facilitate provision of support and accommodation for people with learning disabilities especially for those with complex needs where joint working between health, social care, housing and other partners, as well as cross regionally is essential for good outcomes and value for money solutions.

In terms of some of the technical issues that crop up with commissioning across regions and sub regions, such as how to deal with ordinary residence criteria, a useful source of advice is the LGA (2018) Ordinary residence guide which is aimed at supporting partners to understand and apply the concepts of ordinary residence – in particular, recognising that many of the people supported have experienced complex care and support arrangements, over a number of years, in different geographical areas and where guidance and policy may have changed during this time.

Two other sources that may be helpful in the Welsh context are from Luke Clements Professor of Law and Social Justice at the School of Law, Leeds University (2017). and a Welsh Government, Law Wales briefing (2016)

Good practice examples**Advance Housing: redevelopment of supported housing including accommodation designed for people with complex needs**

Coombe End was a freehold property owned by Advance, a housing association, previously purchased with NHS capital grant with a 100% legal charge back to NHS England.

The property was a registered care home that was no longer fit for purpose. After negotiations with Gloucestershire County Council, the CCG, NHS Property Services and NHS England, it was agreed that the existing property would be demolished and a block of eight purpose-built one bedroom flats would be developed on this site.

Three of the flats were built to a design specification that would enable someone with complex needs to take up the tenancy. A lift was included to make sure the development was accessible. There is also space for a staff member to sleep at the development and this staff team provides the 24 hour support. People are able to choose their individualised support if they do not want to use the background support provider.

The advantages of the scheme are:

- Everyone can have their own front door but can meet with others so do not feel isolated
- People living there have a tenancy with Advance and the support is provided by their chosen support provider so there is a clear separation between the housing and the support.
- The development is an 'ordinary' development of flats, close to amenities and transport links, and fits in with the neighbourhood
- It has meant the re-use of a site where there was an established provision for people with a learning disability so relationships locally are good
- The flats designed for people with complex needs offer flexibility for future use

From: ADASS, LGA and NHS England (2016) Annex B which includes various examples of housing models for settled and short-term accommodation.

In **Torfaen County Borough Council** the housing strategy officer and the learning disability team have worked closely together to identify the range of accommodation needs of the people supported by the team. On the basis of the information gathered, they have developed a range of accommodation options with bespoke, individualised support packages. This has included people with lower level needs right through to people with complex needs. They have worked with a Registered Social Landlord who has responded by developing housing options based on the needs of the people.

National Commissioning Board Wales (2019) p30 and p25

Swansea Accommodation Group

A monthly meeting takes place with Swansea City Council adult social care, procurement colleagues. Supporting People Commissioner, Registered Social Landlord partners and housing strategy.

The purpose of the meeting is to review current and future accommodation requirements for people with a learning disability within the local authority in order to effectively plan accommodation provision when required. The presence of a representative from housing strategy means that where Social Housing Grant is required this can be essentially allocated live within the PDP providing there is sufficient Social Housing Grant available. This allows for enhanced levels of delivery, rents at a more sustainable level, and accommodation needs for the next three years can be determined and planned on a rolling basis.

National Commissioning Board Wales (2019) p35

Torfaen County Council currently provide a range of options for people with additional support needs

Blaenavon

- 5 x 1 bed bungalows for people with complex care these units are allocated through ABUHB – 24hr 2:1 support
- 4 x 1 bed flats on a new build scheme for people with low level need, these units are allocated through social care panel

Pontypool – all of these units are on 1 scheme

- 4 x 1 bed flats for people with complex care allocated through ABUHB 24hr 2:1 support in place
- 3 x 1 bed shared unit for people with complex learning disability 24 hr support
- 2 x 1 bed flats for people with physical disabilities allocated through social care panel – able to access support from the above units

Cwmbran

- 9 x 1 bed flats for people with low level learning disability allocated by social care panel – originally 24hr support however now reduced to floating support. This scheme is adjacent to an extra care independent living scheme and can therefore access services there also
- 16 x 1 bed flats split into
 - 4 x 1 bed for people with autism – this area has communal facilities and 24 hrs support on site
 - 8 x 1 bed physical disabilities independent living
 - 4 x 1 bed flats for people with low level learning disabilities floating support available from above package if required

In planning

- 6 x 1 bed flats, these units will be utilised by social care for any person requiring a package of care: physically disabled, learning disability, mental health etc. – 24 hr care / support package will be available
- 2 x 1 bed fully accessible flat
- 4 x 1 bed flats general needs

Closer to Home (C2H) was an innovative informal collaboration between health, social services and the third sector in the Western Bay area of South West Wales that aimed to address these problems by supporting people with a learning disability who have behaviours that challenge to live in their own homes in local communities.

This collaboration was established in 2012 between the four statutory commissioners: Abertawe Bro Morgannwg University (ABMU) Health Board, Swansea, Neath Port Talbot and Bridgend local authorities.

There are variations on the Closer to Home approach across Wales that operate on a regional basis and are at different stages of development. However, an evaluation of the Western Bay Closer to Home project has been carried out by Abertawe Bro Morgannwg University Health Board and the project continues.

See National Commissioning Board (2019) p53 for full details of this innovative case study

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/>

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>

2.2 Workforce Development

Key question

What are some key methods and learning content which can be used to maximise the skill bases of providers locally in relation to people with complex needs?

The Health and Social Care workforce within North Wales is currently facing some key challenges. The top two areas for concern described in the North Wales Workforce Strategy (2018-2021) are that:

- Most people entering the sector need to develop skills and gain qualifications
- There are high levels of workforce turnover and at least a quarter of the workforce leaving the sector each year to take up employment elsewhere.

Recruitment and retention are clearly high priorities. Equally important is the need to skill up staff in order to deliver the principles identified within the Social Services & Wellbeing (Wales) Act. The health and social care workforce needs to be equipped and able to deliver services that are outcome focussed and person centred, moving away from traditional based approaches to ones that are self-directed, co-produced and deliver personal outcomes. The North Wales Strategy is committed to supporting staff to be confident, well equipped and committed to transforming services in the ways set out in the Social Services and Wellbeing (Wales) Act.

“Make sure the workforce has the knowledge, skills and values to be able to deliver outcomes focussed, flexible care and support at home” (Social Care Wales, 2017, p8)

Providers (private, public and voluntary and community sector) who work with people with learning disabilities including complex needs, need to establish a skills and knowledge base amongst their staff that includes:

- Active listening
- Understanding and promoting wellbeing
- What Matters conversations
- Strength based approaches
- Advocacy (assessing the need)
- Difficult conversations
- Understanding and working with risk
- Information advice and assistance
- Increased knowledge of community resources
- Commissioning and contracting skills
- Multi-disciplinary working

Resources for commissioners and providers to help upskill the workforce

A good place to start is the **Social Care Wales website** which has a section on learning and development that includes National Occupational Standards (NOS), qualifications, Continuous Professional Development (CPD), best practice guides, an employers toolkit and a learners charter.

In relation to people with complex needs, the website has a learning resource called ‘positive approaches’ that may be helpful in assisting social care workers should they be faced with difficult situations. It provides practical examples of a range of positive and proactive approaches and ways of working that support safe practice, for example, Positive Behaviour Support (PBS) and Person Centred Active Support (PCAS). It is suggested that it can be used for discussions either in group situations such as team meetings or training sessions or between managers or mentors and social care workers.

The Skills for Health, Health Education England and Skills for Care (2016) *Learning Disabilities Core Skills Education and Training Framework* outlines what it is that a whole variety of different employees, across both health and social care, need to learn about to successfully enable people with learning disabilities to reach their fullest potential and live meaningful lives. It covers nineteen different topic areas that are of key importance to people with a learning disability. It gives the desired learning outcomes for each topic and links to key references and documents that will be valuable to those planning training or curriculum content.

In respect of people with complex needs there are useful sections on: supporting people (children, young people and adults) with Profound and Multiple Learning Disabilities (PMLD), supporting people (children, young people and adults) with a learning disability and at risk of behaviours that challenge; supporting people (children, young people and adults) with a learning disability and a mental health condition.

Skills for Care also produce regular electronic news bulletins on training opportunities, new resources and best practice in working with people with learning disabilities. For example a recent edition (see website) highlights a pilot project to test a peer review process for PBS training and information about a **learning disability nursing associates training grant**.

In England, Skills for Health, Skills for Care and Health Education England have joined forces as part of the Transforming Care Programme to offer a comprehensive range of support in workforce planning, capability and development (see website). Their guidance suggests that a planned and structured approach is the best way to maximise and improve the skill base of providers in local areas in relation to people with learning disabilities and complex needs. The following key steps are recommended and templates and frameworks are provided to help with the tasks:

- Identify what skills the workforce needs to work with all levels of need including complex
- Carry out a learning needs analysis to identify gaps
- Formulate learning outcomes and minimum standards for the delivery of education and training-related core skills
- Decide who delivers education and training to different groups of staff
- Follow guidance on recruiting and retaining staff
- Offer leadership training
- Consider how to improve access to healthcare for people with learning disabilities (includes what training and information the wider workforce needs)
- Produce a workforce planning guide for providers

Upskilling the workforce is obviously important but in order to bring about the cultural change necessary to implement new ways of working with people with learning disabilities and complex needs, the values attitudes and behaviours of organisations and staff need to transform. IPC offers guidance on how to do this in its 2018 publication: *Transforming Care Partnerships: Desired Behaviours and Cultures*, covering the following key themes:

- Person-centred and asset based
- Co-production
- Collaboration
- Positive behaviour support
- Commissioning / Market Shaping
- Practice leadership
- Strategic leadership

Examples of best practice

The Institute of Public Care is working with local authorities in Wales to run learning sets for team managers and leaders of adult and children's learning disability teams. The learning sets explore *how* staff can work alongside people with learning disabilities, their families and carers – *how* to promote wellbeing and personal outcomes through the care and support pathway including the undertaking of assessment and reviews for all people with a learning disability inclusive of those that are considered to have complex needs. The learning sets cover the following areas:

- Introduction to the programme
- Understanding and enabling personal outcomes
- How to develop strength based practice and approaches
- How to promote and support independence
- Understanding and working with risk
- Constructive partnership working

Positive Behaviour Support (PBS) is an effective and ethical way of supporting people with learning disabilities who are at risk of behaviour that challenges. PBS is a framework for developing an understanding of behaviour that challenges rather than a single therapeutic approach, treatment or philosophy. It is based on an assessment of the broad social, physical and individual context in which the behaviour occurs, and uses this information to develop interventions. The overall goal of PBS is to improve the person's quality of life and of those around them, thus reducing the likelihood of challenging behaviour occurring in the first place (IPC 2017)

NICE guidance (2018) on Positive Behaviour Support recommends that staff providing direct support to children, young people and adults with a [learning disability](#) and [behaviour that challenges](#) have the 'direct contact' level competencies of the Positive Behavioural Support Academy's [Positive behaviour support competence framework](#).

United Response has produced a positive behaviour support guide to help organisations embed this way of working. They believe that “all behaviour is a form of communication that can tell us important things about the quality of a person's life. We believe that people we support have the right to have their behaviour recognised and responded to in a respectful, positive, person centred and professional way” (p1).

Gloucestershire Local Early Intervention Service (IPC 2018)

This is a small team of behaviour specialists based in Gloucestershire Community Council who work with children, adolescents, and young adults (0 to 25 years of age) who present with challenging behaviour. The team works closely with other services across health, education and social care. The aim is to provide support which enables

individuals to lead a normal life and reduce reliance on specialist services. The team works within a Positive Behavioural Support framework.

How does it work?

The service aims to equip those stakeholders (family, staff, members of their circle of support) with the skills they need to ensure a good quality of life for the individual by identifying the function(s) and working proactively to adapt the environment and teach skills to reduce the dependence on behaviours that challenge.

Once a referral has been made, the first stage is a Functional Assessment to understand the cause of behaviours. Then a PBS plan will be developed with stakeholders.

The help provided will be individually tailored to the need but can include:

- Consultation
- Training
- Support to deliver interventions
- Modelling of how to deliver interventions

2.3 Assistive technology

Key question:

Why are direct payments important and what are the ways in which families can be supported to set up and manage their direct payment (or other arrangements such as individual service funds) as the best way to achieve good outcomes?

Direct Payments (DP) are one way in which people with learning disabilities and their families can put into practice the concept of Citizen Directed Support (CDS). As defined by Simon Duffy (2018)¹, CDS is:

“a new way of organising support to people with disabilities and families in order to better respect their human rights and advance their citizenship. Citizen directed support works by shifting control to the person and to those close to them and ensuring they can shape the support they need to fit their lives”. (p9)

Direct Payments are seen as essential to the implementation of the Social Services and Well-being (Wales) Act 2014. The explanatory memorandum to the regulations that accompany the Act (Welsh Government 2015) underlines this:

“Direct Payments are crucial to achieving the Welsh Government’s aim of improving the well-being of people who need care and support to achieve their well-being outcomes and carers who need support to achieve their well-being outcomes. They provide the mechanism to increase independence, choice and control, and are an enabler of co-production in care planning which affords individuals the freedom to plan flexible and innovative ways to maximise their well-being outcomes.”

Being able to control the money available to them has been a big step forward in enabling people with learning disabilities to meet their needs and fulfil their aspirations. NICE guidance suggests that local authorities and health boards:

- Ensure that a range of funding arrangements are available, including direct payments, personal budgets or individual service funds, depending on children, young people and adults' needs and preferences.
- Offer people a choice of funding arrangements and support people to use these budgets, where they wish to, by:
 - telling them how each element of their support will be funded
 - telling them how much money is available and how much control they have over how the money is spent
 - giving them and their families and carers information about different ways of managing their budgets, and how these may affect their carer
 - supporting them to try out different mechanisms for managing their budget
 - offering information, advice and support to people who pay for or arrange their own care and support, as well as to those whose care and support is publicly funded
 - offering information about benefits entitlement
 - ensuring that carers' needs are taken fully into account

In practice, there are a number of other factors to ensure that the money results in the best outcomes for the individual, namely:

- individuals know what they are entitled to early on
- the individual participates fully in planning and setting goals (with the help of an advocate if needed), alongside family and professionals
- All resources and assets are taken into account, not just the direct payment
- There is freedom for the individual to use resources flexibly and creatively
- There is a wide range of provision available locally to meet needs and support aspirations (including for example social enterprises, co-operatives, user led services)
- There is provision of information, advice and assistance in accessing care, support and other opportunities

A number of organisations have sprung up to help develop the right environment and support families through these steps to maximise the potential for good outcomes.

Good practice examples

Community Catalysts is a Community Interest Company established in 2010 who support the development of small, self organising enterprises to provide highly personalised, flexible care and support to people in their community, which can be paid for through direct payments. The aim of the organisation is to build and strengthen what is already there and working well in a community and to harness the talents and imaginations of local communities so that people have real choice of services and supports to help them live the life they want.

For example, Community Catalysts has been working with Rotherham Council since 2017 on a 2 year project which aimed to make connections between people with a learning disability and their local community. The local Catalyst, Harry has supported the development of new community enterprises to increase the choice for people who need some help to live a good life. Due to the success of the programme the contract has now been extended from February 2019 to November 2020. Harry will continue to support the council to develop new customer pathways for people so that they have a wider choice and can use the community enterprises available. In addition he will work with other agencies to support people with a learning disability to recognise their talents and set up their own groups and ventures.

Independent Service Funds are an alternative way of managing personal budgets that can ease the administrative burden on people with learning disabilities and their families, see example below.

Individual Service Funds (ISFs) provide flexible support because the service provider holds the personal budget as a 'managed account' and works with the person to design, develop and manage the best possible support, altering it with minimal fuss when changes are needed.

New Key provides support to people living in supported living accommodation in Bristol, Torquay, Totnes and Kingskerswell. People who use the service include people with physical disabilities, autism or learning difficulties. New Key helps people to live independently and assists them to live the lives they want. They support people to achieve outcomes in managing their own money, making friendships, finding work, managing their home, finding and attending local groups, exercising and cooking skills.

The following case example illustrates their flexible approach to care and support using an ISF to improve health and wellbeing outcomes:

"A person with high anxiety that we support requires support throughout the day to mitigate falls risks, provide reassurance and ensure his safety. He regularly has Reiki sessions from the same practitioner, who he trusts and relates well to, he has had this treatment regularly for two years and it has a hugely calming effect for him. Instead of paying £15 per hour for the support worker to be there when this happens, the ISF is used to fund a DBS for the Reiki therapist, and potentially any training (e.g. first aid) and she fulfils the support function whilst giving him Reiki, she charges £10 per hour and usually does two hours a session. We are able to use the ISF to fund two or three sessions a week saving £10 support costs per session. (Based on 2 sessions a week over 52 weeks this would deliver a saving of approximately £1040 per annum)"

Dosh is a national organisation that supports people with a learning disability to be able to manage their money. They can provide financial advocacy, appointeeship for benefits and account management for self-directed support budgets. They believe that everyone should have personalised support to use their money in the way they want and for the things they enjoy.

“We can create a bespoke package of support that does exactly what you want. This could include support with benefits, budgeting, bills, banking, direct payments and much more”

Salvere is a non profit making community interest company who enable people to self manage their care and support at home. Their services include support planning coordination, direct payment employer support, a brokerage system, an e market place and peer support. Staff consist of a mixture of ex social workers, ex brokerage workers, family carers and people who use services.

In Lancashire Salvere completed 6000 plans in 18 months. On average it took 2 weeks to complete support plans with people. There was an increase in the use of direct payments and 90% of people use community support

Wandsworth and Penderels Trust

Penderels Trust is a national organisation based in Coventry that provides direct payments support services to a number of councils in London and in other areas of the country. In Wandsworth they provide most aspects of direct payments support for people in the locality, including general help and information, specialist employment support and quarterly peer support meetings. A separate payroll service is also commissioned and provided by ‘Payroll Masters’. The council is looking into developing a pre-paid card system but already offers people two different types of direct payment:

- A ‘standard’ direct payment – where the service user has their own account and is personally responsible for their direct payment.
- An ‘assisted’ direct payment account – where the payroll provider holds the direct payment and the support service assists with all aspects of using it.

Penderels are making significant efforts to build good working relationships with local voluntary organisations and charities and run monthly meetings to share information and best practice with local organisations.

The Wiltshire Centre for Independent Living is a highly respected organisation set up in 2005 by a group of disabled people to support disabled people living in Wiltshire to have choice and control to live independent lives. Their vision is for all disabled people to be able to live independently through individual choice, control and equal rights. Their mission is to provide the support required to achieve this.

They provide a range of services, including support to families and individuals to manage personal budgets and direct payments.

Imagineer Community Interest Company can help with support brokerage as well as setting up direct payments. They follow the seven 'Good Help' principles:

- Power sharing
- Enabling conversations
- Tailoring
- Scaffolding
- Role modelling and peer support
- Opportunity making
- Transparency

The National Brokerage Network works in accordance with the Social Model of Disability and the Principles of Independent Living. It aims to promote empowerment to all disabled and disadvantaged people by supporting the individual to gain control of their lives and control the choices and decisions they make about the things important to them. They describe brokerage as:

- Not another industry – just a new way lots of people can be more creative
- Not a narrowly defined planning role – but working alongside people to make change happen
- Not provided by a special group – an activity many people can do in many ways
- Brokerage is not the answer to every problem – but it is a better way of thinking about how we can be allies and help change to happen as people take control over their own lives.

2.4 Integrated structures and pooled budgets

Key question:

What are key principles for integrating health and social care and examples of good practice including the use of pooled budgets?

Put simply, there are a number of enablers that can enhance integration between health and social care so that people with learning disabilities experience seamless services that meet their needs and help them to achieve their aspirations. The Institute of Public Care (2018) has summarised them as follows:

1. **Leadership and accountability** – a clear vision and shared commitment to improving local people's health and wellbeing using approaches which focus on what is the best outcome for citizens and communities. Governance arrangements that transcend organisational boundaries, are collaborative, and where decisions are taken at the most appropriate local level.
2. **Delivering integrated care** - Services and the system are designed around the individual and the outcomes important to them and developed with people who use or provide services and their communities; everyone – leaders, practitioners and citizens – is committed to making changes and taking responsibility for their own contribution to improving health and wellbeing.

- 3. Shared systems** - common information and technology, at individual and population level, shared between all relevant agencies and individuals and use of digital technologies; long-term payment and commissioning models, including jointly identifying and sharing risk; integrated workforce planning and development, based on the needs and assets of the community, and supporting multidisciplinary approaches.

A good source of practical advice and guidance on what these principles might look like in practice can be found on the Social Care Institute for Excellence website, section called: *Integrated care research and practice (2018)* which covers the following topic areas:

- Prevention and self care
- Multi disciplinary teams
- Assessment and care planning
- Community based integrated services
- Care and support in crisis
- Transitions of care

Key messages about pooled budgets from recent Welsh guidance (ADSS Cymru, 2019) include:

- Health Act flexibilities enable partnerships and pooled budgets to be put in place without requiring organisational re-structuring
- Formal partnership agreements are useful mechanisms for making integration happen
- Partnerships need to agree joint priorities and targets, what resources are needed, the types of services required and what outcomes are to be met. Only then should they start to set up pooled budget arrangements
- Partnership agreements must be in writing and there are legal requirements in terms of what they must include
- A partnership must have proper accountability arrangements and should be proportionate to the size and scope of the partnership
- Staff from different organisations that will be working with a pooled budget need to understand each other's roles, working practices, culture etc.
- There may be a need for training to ensure consistent attitudes, values, behaviours as well as core competencies are in place across organisational boundaries

See Appendix One for a summary of the advice notes.

Good practice examples

Integrated Service for Children with Additional Needs (ISCAN), Gwent (IPC 2019)

The Gwent ISCAN service covers the whole of the region and provides a single point of access to services for children and young people aged 0-18 years who have two or more developmental needs and those with suspected Autistic Spectrum Disorder (ASD) or Attention Deficit Hyperactivity Disorder (ADHD).

The service is headed up by an Integrated Children's Services Manager, who is also the Head of Occupational Therapy services and manages the Neurodevelopmental Service (which includes ASD and ADHD services), the Child and Adolescent Learning Disability Service and the continuing healthcare elements of these services. What is immediately striking is the broad spectrum of roles included within the ISCAN service which support both health and social care needs.

The weekly multi agency panel comprises paediatricians, consultant psychiatrists, members of the neuro developmental team, representatives from across therapy services, educational psychology, care co-ordination and social services. Together they consider incoming referrals and decide on the best pathways to provide optimum care and support for children and families. The result is a streamlined and rapid process that avoids duplication, ensures professionals consider the child's needs holistically and provides a transparent and managed allocation of resources.

More recently a new care co-ordination team has been added to the service and is available to children who have multi-agency complex needs. The function of the team is to provide the family with a single point of contact, co-ordinate services involved with the child and facilitate integrated assessment and planning (IAP) in the most complex cases.

Integrated assessment and planning has resulted in:

- Fewer children waiting on multiple statutory agency waiting lists
- More children receiving an integrated assessment and planning service
- Earlier intervention on a multi-agency basis
- Improved relationships with families who are in receipt of a co-ordinated and integrated assessment process
- More effective use of scarce agency resources as planning is not done in silos but on a shared and agreed basis
- More empowered families resulting in greater resilience

Conwy County Borough Council – All Age Disability Service (IPC, 2019)

Four years ago, in response to the Social Services and Wellbeing Act (2014), Conwy Council restructured its provision for people with disabilities as part of their Social Services Transformation Programme. Three new teams were created: children and young adults under 25, adults over 25, early intervention and prevention and community support services working within one integrated disability service. In addition, closer links have been made to the local health services with the aim of providing equality of access to support and resources across the age range based on assessed need.

Key benefits of being part of an all age service include:

- Greater profile for children's service, equality of access and resources across the age range
- Skills and knowledge transfer between children and adult teams, flexible workforce and greater shared understanding of legislation, policy and practice across the whole lifespan
- Children and families can access Community Support services including sessional workers who are registered for domiciliary care
- Children can access the Early Intervention and Prevention team which includes a Progression Service that works with a person to identify what is important to them and develops plans to achieve their personal outcomes eg learning to travel independently
- Young people can keep the same social workers and support workers when they transfer to the adults service, providing consistency for individuals at key points in their lives e.g. moving from school to college
- Creative use of direct payments – families can access a pool of (all age) direct payment workers to deliver tailored support eg early morning help to get children ready for school; accompanying a young person on the bus to college (instead of expensive taxi) to build confidence and independence
- Investment in children and families early on benefits adult services ('spend to save') – more likely they will be able to stay living with family/progress to independent living rather than expensive residential placements

Integrating Health and Social Care: North East Lincolnshire Case Study (LGA, 2018)

The NHS and local government in North East Lincolnshire have been working together for more than ten years with a common aim to improve health and care outcomes for their population.

North East Lincolnshire has been operating pooled budget arrangements under a Section 75 agreement for a considerable time. Initially a three year rolling renewal was in operation. This then became an annual negotiation which considers factors such as inflation, efficiency pressures, needs, and any new statutory requirements. The discussion results in an 'agreed value' and the CCG commits to managing within that value. There is no formal risk/ benefit sharing agreement beyond this. The CCG can request a change to the 'agreed value' should this be necessary. Because the Council has representatives on the Boards of the integrated care providers, they are aware of any pressures that may be arising and need to be factored in. A high level of transparency between the Council and CCG underpins this unusually informal approach that has worked well for eleven years, illustrating the maturity of the relationship and ability to make financial decisions based on what is 'best for the system' rather than organisational self-interest.

In the past two years, the Council and CCG moved away from the national 'client/contractor' split by appointing a joint director of adult services (DASS). This role is broader than the traditional DASS role and includes oversight of some housing functions and the housing related support programme. The DASS is employed by the Council but is located within the CCG and has oversight of all

adult services commissioning functions. This has enabled further development of the relationship between health services and Council functions and the exploration of new opportunities to join up commissioning, for example the CAMHS pathway and development of the extra care housing strategy. The DASS is a key member of the Council's housing delivery board, and as such, is able to influence the delivery of specialist and supported housing.

2.5 Community and culture change

2.5.1 Shared Lives

Key questions:

How can NWT increase the use of and recruitment (of carers) to Shared Lives, for all ages and in particular for young people with learning disabilities from age 16?

Shared Lives is a form of social care placement where care and support are provided within the Shared Lives carer's own home. Shared Lives schemes may offer long term, short term, emergency or respite overnight accommodation, and may offer daytime support for people who do not live with the Shared Lives carer. Around 1,000 people in Wales receive care and support from Shared Lives carers. Person Shaped Services (PSS) who have produced a UK guide to Shared Lives emphasise that it is a concept more than a specific form of service (PSS, 2019)

Shared Lives carers are not required to register with Social Care Wales, but as part of the social care workforce they are required to have completed the general induction framework requirements and are encouraged to have at least the level 2 qualification in Health and Social Care.

Shared Lives schemes are required to apply for registration with Care Inspectorate Wales. The provision of accommodation is regulated under the 2019 Adult Placement Scheme regulations, and the associated statutory guidance (Welsh Government 2019). It is the schemes themselves that are regulated, not the individual Shared Lives carers. The provision of daytime support without accommodation is not covered by these regulations. By contrast, in England it is the care and support provided by Shared Lives carers that is regulated by the Care Quality Commission and not the accommodation itself. In England, the term 'adult' is qualified to include young people aged 16 and 17 (Legislation.gov.uk 2019).

An interesting point to note is that according to the Care Inspectorate Wales website, only three local authority run Shared Lives schemes came up as registered Adult Placement schemes. Shared Lives Cymru, however, list Shared Lives schemes offering accommodation in 21 of the 22 local authority areas, mostly via third sector providers.

In long term placements, the person living with a Shared Lives carer may consider this their own home, but they do not have a tenancy agreement or legal rights and responsibilities as tenants.

Parents with learning disabilities and their child/ren

Parents with learning disabilities are more likely than any other group of parents to have their children taken into care and adopted. A significant contributing reason is the lack of appropriate care and support for the parent in their parenting role. A parent with learning disabilities may need appropriate care and support within their own home, or a placement with their baby or child that provides both accommodation and care and support. Such placements may involve an assessment of the parent's ability to provide safe and good-enough parenting, with support.

If someone is already within a Shared Lives placement before becoming a parent, the hope would be that the Shared Lives carer would be willing to allow the placement to continue.

Where someone is living independently before becoming a parent and is now judged as needing a placement alongside their baby either for support or assessment, the options are limited to Shared Lives, mother and baby unit and/or specialist fostering service. The options available depend on whether or not the baby (or the parent, if aged under 18) is a looked after child. If the child is not looked after, the parent is over 18 and the parent requires significant care and support to carry out their parenting, then a Shared Lives placement is the only way to provide a placement within a family home.

Young people aged 16 or 17

A young person aged 16 or 17 is, by definition, not an adult. This creates regulatory difficulties in Wales because overnight accommodation via Shared Lives schemes is provided under the Adult Placement Service regulations.

There are different circumstances in which a young person aged 16 or 17 might benefit from a Shared Lives placement:

- the young person is already a looked after child. They want to continue to live in a family setting as an adult. Their current foster carer is unable to commit to providing a placement after their 18th birthday under the 'When I'm Ready' regulations (Welsh Government 2016). Moving to a Shared Lives placement now would save the young person either having to move on their 18th birthday or moving twice (once now to another foster carer who can offer a post-18 placement, and again just before their 25th birthday when the 'When I'm Ready' regulations cease to apply)
- the young person lives at home and receives respite care. They want to continue receiving respite as an adult. By changing respite placement now, they are able to settle with their new carers so not all changes in their life happen at the same time.
- the young person lives at home and either receives respite care or no overnight care. However, they will need a full time placement as an adult. Being able to begin overnight placements with their future Shared Lives carer well before their 18th birthday would ease transition.
- the young person lives in residential care such as an education placement, hospital placement or children's home, the current placement may not be the best or least restrictive way to provide care and support, and they will need a full time placement as an adult.

Technically, it would be possible for a Shared Lives provider to offer more than one form of service. The service from age 18 would be provided and regulated under the Adult

Placement Service regulations. The service at age 16 or 17 could be provided under Fostering Service regulations where the young person is already a looked after child or needs the protection of being a looked after child. This would mean the Shared Lives carer needing to become an approved foster carer. The service at age 16 or 17 could alternatively be provided as a form of supported lodgings (an unregulated service).

Day support

Shared Lives schemes may offer daytime care and support for people who do not live with the Shared Lives carer. In England, this type of support in the Shared Lives carer's home (when not part of an Adult Placement) is not classed as domiciliary care. The regulations in Wales are not clear on this point.

Long term placement

Shared Lives carers provide care and support to someone within their own home. The ethos is of 'joining the family'. This type of placement is appropriate where someone does not wish or is unable to live with their own family, but they want to live in a family setting. It is not appropriate for people who want to live independently or have their own tenancy.

Recruitment

Shared Lives Plus provides guidance on recruitment (see further information on p32). However more is known about what works for recruiting foster carers. While they are distinct services, the motivations, key characteristics of suitable carers and successful recruitment strategies will be similar. The Fostering Network's recruitment and retention research project provides cutting edge resources that could form the basis for Shared Lives carer recruitment materials and retention practices (see further information on p32).

Importantly, different strategies will be needed depending on the type of Shared Lives service requiring more carers. As the types of service are similar to the range of services provided by foster carers, examples of targeted strategies are available from The Fostering Network's project.

Good practice examples

Shared Lives Care Leavers: Shared Lives Plus has been awarded up to £365k to extend the national Shared Lives model, providing an alternative to foster care for young people with additional needs. Piloting six to eight schemes in different parts of England, young disabled people with on-going social care needs can move to a Shared Lives home from the age of 16. <https://innovationcsc.co.uk/projects/shared-lives-care-leavers/>

This report by PSS presents a way to demonstrate the **social impact of Shared Lives** services, and includes examples of how different schemes are contributing to different outcomes and impacts

http://www.psspeople.com/wp-content/uploads/2017/04/Impact-Report_Shared-Lives-and-TRIO.pdf

The Care and Social Services Inspectorate Wales 2017 **Shared Lives Powys inspection report** highlights good practice that demonstrates that the service went beyond minimum requirements:

“We found that compatibility was highly profiled and that people visited, stayed overnight and were offered a trial period before finally moving in with their host families. We saw that throughout this period the registered manager offered support to both the person moving in and the carer, and we were informed by one carer that “Richard is excellent, I keep him informed of events, he is so helpful”.

Four people placed by SLP were spoken with and all expressed great satisfaction with the service. Two people told us of their outings with members of the carer’s own family, which were regular, and much anticipated, and of the various places they went each week. We were informed that in one of houses visited, good relationships had been forged with neighbours and the people using the service and one carer stated that “We are like one big family, there is always someone coming or going!” People told us of their interests, one attended a centre daily, another enjoyed dancing in a club. We also spoke with one person who preferred to remain indoors and this was respected although daily walks were encouraged. One person enjoyed travelling and regularly went out for the day on the bus, visiting friends and relatives. We were informed of holidays and events such as Christmas, Easter, and in some cases visits and overnight stays with family. People using the service enjoy a high degree of belonging and attachment and are cared for by robustly vetted and well supported carers.

People can be confident that they will be cared for by carers who are properly trained to care for them. This is because carers told us that they are offered training frequently and that they are kept informed of any forthcoming events, although one carer thought the venues were always too far away. In addition, they have all received training in specialist topics pertaining to the people living with them, if, and/or as necessary, such as epilepsy, and positive behaviour management. Both carers were highly satisfied with the support they received, one stating that the service received from SLP was “Brilliant. Richard Gwynn [service manager] comes every 6 weeks, if I have any problems, he’s there. He is more like a friend now”.

https://gov.wales/docs/cssiw/report/inspection_reports/16288_6_e.pdf:

2.5.2 Employment of people with learning disabilities who are further from the job market

What are the ways in which other areas/countries have enabled people with more severe levels of need to access employment?

Most employment and employability schemes target people with learning disabilities who are closest to the job market. Despite this, the best estimate available (given the lack of data collection) is that fewer than 6% of those known to social services have even one hour a week of paid employment (Hatton, 2018) and fewer than 1% work for 16+ hours a week. My Life My Choice (2019), an Oxford self-advocacy organisation, has begun a ‘1% Mark’ as part of their ‘Walk it Like You Talk It’ campaign to recognise

organisations where at least 1% of their employees have learning disabilities. This leaves much work to be done, even with those who are closest to the job market. For those who are further from the job market, nothing is known about their employment rate but it can be presumed they are under-represented.

In everyday life, 'employment', 'work' and 'job' usually mean the worker is paid at least the national minimum wage. For people with learning disabilities, it cannot be assumed that this is happening. Schemes set up to support people with learning disabilities into work, and social enterprises set up to create work may use these terms while not paying their workers with learning disabilities or making a token payment that may or may not cover their expenses for working. In some parts of the UK, people with learning disabilities pay to be able to 'go to work'. It is important to become familiar with what is happening in work opportunities, work placements and social enterprises in North Wales, and not to assume that everyone described as having a job is being paid.

It is challenging to find reliable data on outcomes for people with learning disabilities who participate in schemes that are designed to support them into work. While there are many stories of people gaining employment, too often on closer inspection the outcome is unpaid work rather than paid work.

The desire for a meaningful life is as strong and valid for people further from the job market as for those closer to the job market. There is no legal, practical or rights-based justification for investing in the ambitions of some people with learning disabilities and not others. Employment of those further from the job market has been achieved elsewhere (see best practice examples below), making it a realistic goal. Paid employment is not the only work-related route to a meaningful life. Those further from the job market may actively choose other work-related routes to a meaningful life, and this should not be seen as a lesser goal than actively choosing the goal of (supported) paid employment. Equally, they may actively choose non-work-related ways to have a meaningful role within their communities, such as involvement in community activities or what is describe in the following section as 'serious leisure'.

Although most work-related schemes currently target those close to the job market, current approaches and use of resources are generally delivering poor results in terms of sustained paid employment. This is not an issue particular to North Wales, and suggests more evidence is needed for 'what works' before making new investments into schemes that have the stated aim of increasing employment and employability. It may be that by investing the futures of those further from the job market will create new approaches which will go on to improve outcomes for those closer to the job market.

While aspirations abound across the UK, real life examples of people with more severe learning disabilities, complex needs, profound and multiple learning disabilities or significantly challenging behaviour securing and maintaining paid employment are thin on the ground.

Best practice examples

One of the most common routes would appear to be a family member creating a **microenterprise** for their family member, and operating the microenterprise in conjunction with that family member, for example <https://www.bittyandbeauscoffee.com/> and <https://johnscrazysocks.com/>

In the **Basque country**, social innovation is further advanced than in Wales. Chris Bolton of the Wales Audit Office recently visited there as part of a Churchill Fellowship and was impressed by the employment practices of one of the Mondragon Corporation sets of enterprises <https://www.gureak.com/en/who-we-are>

My Life My Choice have produced a series of videos of members talking about their paid work <https://vimeo.com/showcase/4803565>

Project Search began in the United States. It provides supported internships for people who feel able to work and study full time, and a successful outcome is defined as:

- employment in an integrated setting
- year-round work of 16+ hours a week
- work that is paid at minimum wage or higher

The 2014 evaluation of Project Search showed around 36% of graduates from Project Search achieved these outcomes, with another 11% meeting the other criteria for success but securing fewer than 16 hours a week of work. Younger graduates and those with lower levels of impairment were more likely to achieve these outcomes. These percentages represent very high outcomes compared to other models for supported employment or employment preparation. However anyone unable to sustain at least 16 hours a week would either not have entered the programme or would not have graduated; this would be the case for many people with learning disabilities who are further from employment.

The 2016 Mencap report, **Raising Our Sights**, address work and day opportunities for people with profound and multiple learning disabilities. See Paragraphs 99 to 104: https://www.mencap.org.uk/sites/default/files/2016-06/Raising_our_Sights_report.pdf

Employers Guide to Employing Someone with Learning Disabilities. Contains case studies. <https://www.mentalhealth.org.uk/file/4330/download?token=JalbsQhC>

Examples of services leading to meaningful community lives, other than paid employment <http://www.psspeople.com/wp-content/uploads/2017/06/Day-Opportunities.pdf>

NDTI run a programme called **Preparing for Adult Life**, which brings together case studies and information on all topics, including employment <https://www.preparingforadulthood.org.uk/downloads/employment>

On 3rd December, a two year action research project called **The Bridge** (lead partner: Barod Community Interest Company) will be releasing research findings and fact sheets around people with learning disabilities starting their own businesses.

2.5.3 Voice, choice, control and advocacy for people with profound and multiple learning disabilities

What models and approaches are there to ensure that advocacy is available to ensure the voice of people with profound and multiple learning disabilities is heard?

Voice, choice and control are central to human rights, complying with the Mental Capacity Act, including the making of Best Interests decision) and are explicitly written into the Social Services and Well-being (Wales) Act. The principles of voice, choice and control apply to anyone using social care, including people with profound and multiple learning disabilities. However in practice, people with profound and multiple learning disabilities are at high risk of having little or no voice, choice or control.

The challenge is four-fold.

- The first is **attitudes and assumptions** about the ability of someone with profound and multiple learning disabilities to express a choice or have control in their life in a meaningful way. Where someone cannot use words, it may be assumed they have no voice, cannot make a choice and therefore require others to take control of their lives. Even in 2019, many of the people involved in the life or community of someone with profound and multiple learning disabilities may interact with that person as if they were not fully and equally human. Naturally, this has a negative impact on people's emotional wellbeing and reduces their motivation to try to communicate as well as opportunities to develop an adequate means for communicating with others.
- The second is **time**. Where someone needs support to exercise their voice, choice and control, it is much quicker to make decisions on their behalf. Most health, social care and support services, including social work and general medical practices, operate under time constraints. Commissioning therefore needs to permit adequate staff time and staffing levels to allow them to provide adequate and person-centred support.
- The third is **lack of understanding** of what it means to have voice, choice and control where someone lacks legal capacity to make a decision or where they require substantial support to become legally capable of making a decision. If, even with support, the person lacks legal capacity, then a Best Interests decision needs to be made on their behalf. 'Best interests' does not refer to what someone else thinks would be in the person's best interests, but the best understanding of what the person would have chosen for themselves if they could make that decision. This requires time and creativity to enable someone to have as much input as possible into decisions ranging from what to eat for breakfast to where they live and who supports them. Somewhat confusingly, the term 'supported decision making' can be used to refer to support to achieve legal capacity and also support to be as involved as possible where a Best Interest decision needs to be made by a substitute decision maker.
- The fourth is **technology and skill**. While there are ways to facilitate someone's ability to form and express an opinion that can be understood by someone who knows them well, this area of work is under-developed across the world. Academics who specialise in carrying out research with people with profound and multiple learning disabilities are grappling with this issue just as much as parent-carers and public services. It takes two to communicate. Difficulties in communication mean

both the person with profound and multiple learning disabilities **and** those around them need to learn communication skills. Some people with profound and multiple learning disabilities have developed language skills but not communication skills; others do not understand language (Sheehy and Nind, 2005). The approaches used to improve communication will depend on someone's potential for understanding language. For information about communication, a good place to start is an internet search on 'augmented and alternative communication' (AAC) and 'Total Communication' (while more usually associated with d/Deaf people's communication, it has also been applied to communication by and with people with profound and multiple learning disabilities). Much of the cutting edge work in early years settings on communication and learning, particularly the use of technology, needs to be transferred to work with older people with profound and multiple learning disabilities. For information about the skills needed to involve someone as much as possible in the world around them, key phrases are 'active support' and 'intensive interaction'. Active Support focuses on the overall support provided. There is research evidence for its effectiveness in improving outcomes (for example <https://www.nationalelfservice.net/learning-disabilities/challenging-behaviour/person-centred-active-support-increased-choice-making-opportunities-for-people-with-learning-disabilities/>) Intensive interaction focuses on developing communication where someone has little or no language or speech. In addition, 'mediated lives' is a helpful concept for professionals as most people with profound and multiple learning disabilities will rely on someone who knows them well to mediate their engagement with the wider world.

Best practice examples

General

This report includes examples to illustrate most of the sections and many of its recommendations for improving life and services for children and adults with profound and multiple learning disabilities http://www.complexneeds.org.uk/modules/Module-4.2-Safeguarding---privacy,-dignity-and-personal-care/All/downloads/m14p050c/valuing_people_with_pmlid.pdf

Attitudes

One University has employed a person with profound and multiple learning disabilities to co-deliver a two day elective course to social work students. The main aim was to challenge attitudes and assumptions about people with profound and multiple learning disabilities. The experience for students, lecturers and the co-trainer was positive. The main learning point for students was that the co-trainer was a fellow human with his own personality and skills to share, rather than someone incapable of communicating and needing care. The experience is written in the following paper: Nicki Ward, Christian Raphael, Matthew Clark & Vicki Raphael (2016) Involving People with Profound and Multiple Learning Disabilities in Social Work Education: Building Inclusive Practice, *Social Work Education*, 35:8. 918-932, DOI: [10.1080/02615479.2016.1239705](https://doi.org/10.1080/02615479.2016.1239705)

Mental Capacity, Best Interest decisions and supported decision making

The legal status of supported decision making in the United States is different from its status in England and Wales. However the principles and practical approaches are transferable. This website provides examples and case studies from the United States <http://supportmydecision.org/>

This contains an example of a 'balance sheet' that can be used when making a Best Interest decision about someone's living and support arrangements. This example shows how prior support of the person to be as involved as possible in making the decision meant their wishes could be included in the balance sheet

<https://www.suffolk.gov.uk/assets/Adult-social-care-and-health/mental-capacity-and-deprivation-of-liberty-safeguards/2013-09-25-Best-Interests-Guidance-Balance-Sheet-Approach.pdf>

Active Support

The Association for Real Change carried out a three year action research project which is written up in this report. It has examples of using Active Support, and discusses some of the challenges as well as the benefits

<https://arcuk.org.uk/activesupport/files/2015/05/CAOL-Project-Publication.pdf>

This link takes you to a suite of examples across different service settings of organisations putting person centre and active support into practice

<https://www.drivingupquality.org.uk/site/driv/templates/general.aspx?pageid=47&cc=gb>

This is an evaluation of a project run by Mencap Lambeth. The project made real changes to people's involvement, and there is enough detail in the evaluation report for North Wales Together to think how to apply the learning to a North Wales context

<https://www.simplestuffworks.com/wp-content/uploads/2016/10/Carousel-Project.pdf>

Previous Barod research found a North Wales family whose adult son with complex needs went to the village pub with a support worker. The pub landlord had made sure he and his staff learned some of the signs the young man used, so they could welcome him as warmly as they welcomed any other customer.

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United Response (no date) *Positive Behaviour Support Guidance for Developing Effective Positive Behaviour Support Plans*

Available at:

<https://www.unitedresponse.org.uk/Handlers/Download.ashx?IDMF=5212082f-e5ac-4aef-9f15-a42e913370e6>

Wandsworth and Penderels Trust website:

<https://www.penderelstrust.org.uk/directpaymentsupport.php>

Welsh Government (2015) *Explanatory Memorandum to the Care and Support (Direct Payment) (Wales) Regulations*. Available at:

<http://www.senedd.assembly.wales/documents/s85203/CLA5-08-19%20-%20Paper%208.pdf>

Welsh Government (2019) *Statutory Guidance: Adult Placement Services*. Available at:

<https://gov.wales/sites/default/files/publications/2019-04/guidance-for-providers-and-responsible-individuals-of-adult-placement-services.pdf>

Welsh Government (2016) *When I'm Ready Good Practice Guide*. Available at:

<https://gov.wales/sites/default/files/publications/2019-05/when-i-am-ready-good-practice-guide-march-2016.pdf>

Wiltshire Centre for Independent Living website: <https://www.wiltshirecil.org.uk/>

Further Information and resources: Shared Lives

Protocol for providing services to 16 and 17 year olds in England

<https://sharedlivesplus.org.uk/wp-content/uploads/2019/04/2.12.-Transition-and-mixed-child-Shared-Lives-arrangements.doc>

Research showing the advantages (financial and personal) to Shared Lives compared to other service models <https://www.thinklocalactpersonal.org.uk/innovations-in-community-centred-support/directory/Community-alternative-to-residential-care/>

Regulation of Shared Lives in England

https://www.cqc.org.uk/sites/default/files/documents/20130725_100998_v2_00_supporting_information_-_shared_lives_schemes_for_external_publication.pdf

Shared Lives Plus's guidance on recruiting Shared Lives carers

<https://sharedlivesplus.org.uk/wp-content/uploads/2019/04/7.07.-Recruitment-of-Shared-Lives-carers.docx>

Shared Lives Plus report on Wales for 2017-2018 <https://sharedlivesplus.org.uk/wp-content/uploads/2019/04/Shared-Lives-in-Wales-2017-18-English.pdf> and

<https://sharedlivesplus.org.uk/wp-content/uploads/2019/04/Shared-Lives-in-Wales-2017-18-Welsh.pdf>

The Fostering Network's work on recruitment and retention

<https://www.thefosteringnetwork.org.uk/policy-practice/recruitment-and-retention/recruitment-and-retention-research>

Working with 16 and 17 year olds in England: <https://sharedlivesplus.org.uk/wp-content/uploads/2019/04/External-Frequently-asked-questions-when-working-with-under-18-year-olds.pdf>

Further Information and Resources: Employment

The British Association for Supported Employment (BASE) has an online knowledge base <https://www.base-uk.org/knowledge-base>

While IPS (Individual Placement and Support) is a form of supported employment targeting people with severe mental health problems, it is worth exploring whether it can be adapted for people with learning disabilities who are further from the job market <https://www.centreformentalhealth.org.uk/what-ips>

Leisure can be defined as 'casual' and 'serious'. 'Casual leisure' is done for personal pleasure, requires no ongoing commitment and has no goals beyond being enjoyable. For those without work, it can easily become a way of killing time. 'Serious leisure' requires commitment, has goals, involves building a body of expertise and becoming part of a network or community of people committed to the same leisure activity. For those without work, it can become central to their life and take the place of work.

Research studies (helpfully summarised by Ian Patterson and Shane Pegg in their 2008 paper* have shown that serious leisure provides many of the community and personal

benefits associated with paid employment or formal volunteering. A good, if dry, place to start thinking about developing and supporting 'serious leisure' opportunities for people with profound and multiple learning disabilities is found here <https://www.seriousleisure.net/>

* Ian Patterson & Shane Pegg (2009) Serious leisure and people with intellectual disabilities: benefits and opportunities, *Leisure Studies*, 28:4, 387-402, DOI: [10.1080/02614360903071688](https://doi.org/10.1080/02614360903071688)

Further Information and Resources: Voice, Choice, Control and Advocacy

Attitudes

This report is from New Zealand, but just as relevant to North Wales <http://www.donaldbeasley.org.nz/assets/Uploads/publications/article-19-research-full-report.pdf>

As part of the Valuing People programme in England, Mencap and the Foundation for People with Learning Disabilities set up a PMLD Network. This is their report http://www.complexneeds.org.uk/modules/Module-4.2-Safeguarding---privacy,-dignity-and-personal-care/All/downloads/m14p050c/valuing_people_with_pmld.pdf

Time

The Learning Disability Wales guide to commissioning, if followed, would mean services were commissioned that allowed time for people with profound and multiple learning disabilities to receive the kind of support that allows them voice, choice and control. <https://www.ldw.org.uk/wp-content/uploads/2019/03/Guidance.pdf>

Mental capacity, Best Interest decisions and supported decision making

SCIE provides resources about the Mental Capacity Act. This is a good starting point <https://www.scie.org.uk/mca/introduction>

This gives more information about Best Interest decisions, but neglects discussion of the need or ways to support someone to be as involved as possible in a Best Interest decision about their life <https://www.qcs.co.uk/best-interests-work/>. That gap is filled by this Scottish guide which provides advice and examples of supported decision making in the context of the United Nations Declaration of the Rights of Persons with Disabilities https://www.mwcscot.org.uk/sites/default/files/2019-06/mwc_sdm_draft_gp_guide_10_post_board_jw_final.pdf

Communication

This site provides a good overview of the software and hardware available that may support voice, choice and control for people with profound and multiple learning difficulties <http://www.inclusive.co.uk/articles/computers-for-people-with-profound-and-multiple-learning-difficulties-a232#>

This provides a good overview of alternative and augmented communication (AAC)
<https://communicationmatters.org.uk/>

This is a very practical piece of research comparing a low tech and a high tech communication aids <https://www.isaac-online.org/wordpress/wp-content/uploads/A-comparison-of-PECS-and-an-iPad-powerpoint.pdf>

This is a practical resource pack on using Total Communication with people with learning disabilities
<https://www.eastsussex.gov.uk/media/3428/totalcommunicationresourcepackopt.pdf>

This article explains the background and idea of Intensive Interaction <http://www.intellectualdisability.info/how-to-guides/articles/intensive-interaction-using-body-language-to-communicate> while this article explains more of the practical application

Support to be involved

This handbook about Active Support explains the ideas behind the method, and describes how to use Active Support
<https://arcuk.org.uk/publications/files/2011/11/Active-Support-Handbook.pdf>

The United Response guide to Active Support targets front line staff. It is equally useful for parent-carers. The format could be used to produce a simple North Wales guide to sit alongside 'Safe Place' training for members of the community and staff in public services who run ordinary community facilities such as the pub, leisure centre and local shops or cafes. <https://www.unitedresponse.org.uk/active-support-guide>

This is a helpful Australian video based online training course. The first four modules focus on people who provide day to day care and support to someone with profound and multiple learning disabilities and/or challenging behaviour, or who work in a setting designed to provide a service to people with learning disabilities. The fifth (final) module focuses on organisational leadership required to create a culture where staff are enabled to use Active Support <http://www.activesupportresource.net.au/>

This pdf of a PowerPoint provides an excellent overview of Active Support for service managers, elected members and other strategic leaders
<http://www.reinventingquality.org/docs/Stancliffe07-2.pdf>

This article applies Intensive Interaction to improving communication with autistic people with severe learning disabilities. While it focuses on children, the principles apply to people of all ages. <https://www.icommunicatetherapy.com/child-speech-language/autism-spectrum-disorder-asd-children/intensive-interaction-autism/>

Intensive Interaction can be applied in the classroom
<http://www.hillside.lancsnfl.ac.uk/wp-content/uploads/2013/05/Intensive-Interaction.pdf>

Appendix One

Integration and pooled budgets Summary of ADSS (2019) Cymru Advice Notes

Advice note 1 – An Introduction to Integration

The Social Services and Well-being (Wales) Act 2014 provides Welsh Ministers with powers to direct the creation of formal partnerships and pooled budgets, both this Act and A Healthier Wales, provide considerable scope for RPBs to develop their own approaches to integrating services where appropriate to deliver seamless care. (Also see, Guidance Note 5: Pooled funds, on the SCW website).

There is excellent work in the Gwent Region on developments to improve both integrated working and decision making concerning the funding of complex packages of care.

The development of formal partnerships and pooled budgets were introduced with the Health Act 1999. These arrangements were designed to be very flexible and became known as 'Health Act Flexibilities' enabling partners (local authorities and health boards) to design their own partnership arrangements for the integrated commissioning and delivery of services. These arrangements could be applied to a single service or to a range of services. They have the immediate advantage of enabling partners to create new organisational arrangements without major restructuring of organisations.

The development of formal partnerships and pooled budgets are designed to support safe and effective integration, providing appropriate protections to users, carers, staff, managers and organisations. They provide for effective governance arrangements and, where RPBs are developing integrated services outside of a formal partnership, they will need to scrutinise the governance arrangements to satisfy themselves that they are legally robust.

Useful annexes – 'steps to integration' and 'enablers and barriers' to integration.

Advice note 2 – Policy and Legislation

Promoting integration outside of any formal partnership agreement has a number of disadvantages. There is often nothing that binds the individual public bodies to follow a locally agreed plan along with a business delivery process. Unless we can evidence the supposed resources, staff and contracts for services in that plan and secure that plan through joint management of it within formal agreed governance, it is of little value.

RPBs can take many steps towards improving integration, building upon their population needs analysis and their Area Plans. They can work together to identify opportunities for integration. The advantage of a formal partnership arrangement is that it should reduce unnecessary bureaucracy by operating with one system rather than imposing the requirements of integration with two or more systems continuing to operate.

Advice Note 3 - Practicalities of Partnerships

A Part 9 (or Section 33) Agreement, is a written agreement that must comply with certain statutory directions on content and which, therefore, forces the partners to agree joint priorities and targets, what resources are needed, the types of services required and what outcomes are to be met. They will of course also need to agree how the partnership arrangement is jointly overseen and controlled. (see Advice Note 4 on Governance).

The partners can then bring together different funding streams so that providers and their service users do not need to apply separately to different funds or services, ensuring monitoring arrangements are less bureaucratic.

The Partnership Regulations state that for use of any of the flexibilities under Section 33 of the NHS (Wales) Act 2006, the partners' agreement must be in writing and specify:

- The agreed aims, objectives and outcomes of the partnership;
- The contributions to be made by each of the partners and how these may be varied;
- The NHS functions and health related functions of local authorities which are subject of these arrangements;
- The persons the service is for and the kinds of arrangements they can expect;
- The staff, goods and services or accommodation that are also to be provided in support of the arrangements;
- The duration of the arrangement and provision for review or termination of the arrangements;
- How the arrangements are to be monitored, and in the case of pooled fund arrangements, how they are to be managed.

Advice note 4 - Governance

The principal legislation involving governance of local authority relationships with NHS bodies (or vice versa) is consolidated in the National Health Service (Wales) Act 2006 and set out in Partnership Regulations, (The National Health Service Bodies and Local Authorities Partnership Arrangements (Wales) Regulations 2000). This prescribes functions of NHS bodies and local authorities which may be subject to partnership arrangements.

The partners must establish proper accountability arrangements and lay these open to appropriate external scrutiny. Such arrangements will be properly documented and open to review and revision from time to time.

The scale of governance arrangements should be proportionate to the level of investment in the partnership. Partners must decide what form of governance best meets the local needs and circumstances; the arrangements should be proportionate to the size of the partnership.

An early action is to establish an appropriate governance group that provides transparent, accountable, timely decision-making and fits with individual partners scheme of delegation.

Organisations will continue to be accountable for their functions that are part of the partnership arrangements. It is therefore crucial that from the outset, they should be clear about the aims and objectives that are intended to be achieved by the partnership.

The establishment of a Partnership Board or Management Group would, in the first instance, need to decide how best to secure the operational interface necessary to manage the partnership arrangements. For example, a Board or Group could be charged with:

- Setting the strategic direction for joint working by partners and bodies
- Committing partner bodies to working together to deliver common objectives
Confirming budget decisions to support joint planning and funding
- Monitoring the effectiveness of joint planning and working arrangements at local and scheme / project levels.

Local partners will need to be clear about what decisions the Partnership Board or Management Group is able to make on their behalf. The amount of delegation to the board will need to be judged in the context of the Partnership Agreement. Once agreement has been reached, and the lead partner has taken on the functions, it will agree a protocol with the partners setting out the arrangements. The protocol should be in writing and cover:

- What the decision-making process is, and the rights of the board to make a decision?
- Whether liabilities will be shared and if so, how that will be affected?
- What insurance and indemnity arrangements have been made?

It will be the responsibility of the board / management group to scrutinise management, financial and performance data to check whether the joint working/use of pooled budgets are achieving the desired outcomes.

Advice note 5 – workforce implications

The success of partnership arrangements will depend on the enthusiasm of skilled and trained staff in working together. “Partnership staff should be familiar with the partner organisations and have a wide range of contacts within them. Partnership staff will also need to understand the organisational context of those with whom they work” (Audit Commission, 1998)

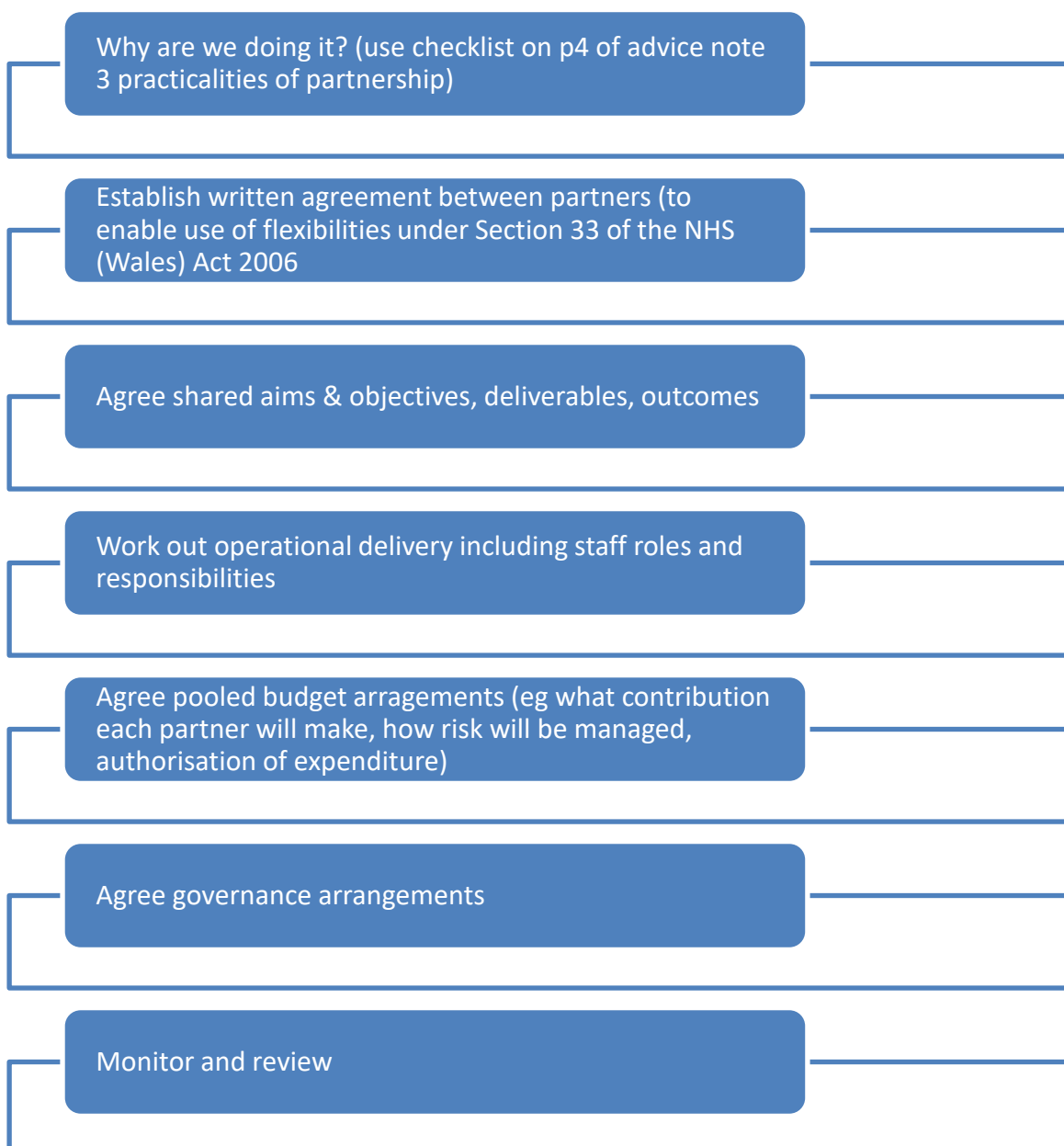
The Partnership Regulations require that prior to entering into partnership arrangements, there should be consultation with all of the relevant stakeholders, i.e. those affected by the proposed establishment of partnership arrangements. Staff groups and organisations are key stakeholders. It is important to consult and work with staff from the earliest possible opportunity to consider and develop the arrangement.

Where there is a pooled fund, depending on the terms of the local agreement and level of delegation, nominated staff from the partner bodies will be able to access the fund to purchase services and goods. The eligibility criteria for use of the pooled fund will have been agreed in order to set it up and the normal assessments will take place. The possibility of staff being able to use joint assessment records, undertake joint assessments, and, in some cases, establish ‘trusted assessment’, where one person

assesses on behalf of other service areas, is likely to arise, at least for some of the services. This will have significance for training, education, and the development of core competencies, as well as the need for clarity in accountabilities for fulfilling tasks

For all staff involved in partnerships, the focus must be on the development of core competencies with related training programmes, jointly developed and linked to professional training.

Suggested process flowchart



Key messages

- Health Act flexibilities enable partnerships and pooled budgets to be put in place without requiring organisational re-structuring
- Formal partnership agreements are useful mechanisms for making integration happen
- Partnerships need to agree joint priorities and targets, what resources are needed, the types of services required and what outcomes are to be met. Only then should they start to set up pooled budget arrangements
- Partnership agreements must be in writing and there are legal requirements in terms of what they must include
- A partnership must have proper accountability arrangements and should be proportionate to the size and scope of the partnership
- Staff from different organisations that will be working with a pooled budget need to understand each other's roles, working practices, culture etc.
- There may be a need for training to ensure consistent attitudes, values, behaviours as well as core competencies are in place across organisational boundaries