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NORTH WALES SOCIAL CARE AND WELL-BEING
SERVICES IMPROVEMENT COLLABORATIVE

North Wales Learning Disability Strategy

Consultation report

August 2018



Contact us

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Introduction

An Equality Impact Assessment was undertaken to identify potential inequalities arising from the development and delivery of the North Wales Learning Disability Strategy. The information gained through this process has been used to develop the North Wales Learning Disability Strategy.

This report provides details of the consultation undertaken as part of the Equality Impact Assessment and provides evidence of how we are meeting the requirements of the public sector equality duty.

Background

Support for people with learning disabilities is a priority in the [North Wales Regional Plan \(Area Plan\)](#) based on what people told us was important to them as part of the [population assessment](#) produced by the [Regional Partnership Board](#).

The Social Services and Well-being (Wales) Act 2014 includes a statutory duty for Regional Partnership Boards to prioritise the integration of services in relation to people with learning disabilities (Welsh Government, 2015).

The Learning Disability Strategy sets out how we will work towards integrated learning disability services in North Wales. It has been developed jointly by the six North Wales councils and Betsi Cadwaladr University Health Board (BCUHB) supported by Public Health Wales.

Actions and plans developed to implement the strategy will need an Equality Impact Assessment to assess their potential impact.

Public sector equality duty

The Equality Act 2010 introduced a new public sector duty which requires all public bodies to tackle discrimination, advance equality of opportunity and promote good relations. The table below outlines the duties of public bodies.

| Public bodies must have due regard to the need to: | Having due regard for advancing equality means: |
|---|--|
| Eliminate discrimination, harassment, victimisation and any other conduct that is prohibited under the Act. | Removing or minimising discrimination, harassment or victimisation suffered by people due to their protected characteristic. |
| Advance equality of opportunity between people who share a protected characteristic and those who do not. | Taking steps to meet the needs of people from protected groups where these are different from the needs of other people. |

| | |
|---|--|
| Foster good relations between people who share a protected characteristic and those who do not. | Taking steps to build communities where people feel confident that they belong and are comfortable mixing and interacting with others. |
|---|--|

Councils in Wales also have specific legal duties set out in the Equality Act 2010 (Wales) regulations 2011 including assessing the impact of relevant policies and plans – the Equality Impact Assessment.

In order to establish a sound basis for the Learning Disability Strategy we have:

- reviewed the performance measurement and population indicator data recommended in the data catalogue provided by Welsh Government, along with other relevant local, regional and national data
- consulted as widely as possible across the North Wales region including with the general public, colleagues and people with protected characteristics;
- reviewed relevant research and consultation literature including legislation, strategies, commissioning plans, needs assessments and consultation reports.

Details of the local, regional and national data, the literature review and a summary of the consultation findings is provided in the [population assessment report](#) and the [regional plan consultation report](#).

This report sets out the additional consultation carried out for the Learning Disability Strategy:

- who we have consulted with;
- how we have consulted; and
- the consultation feedback.

Consultation principles

A key part of the Equality Impact Assessment is consulting with people who may be affected by the Learning Disability Strategy and in particular people with protected characteristics. The protected characteristics are:

- Age
- Disability
- Gender reassignment
- Marriage and civil partnership
- Pregnancy and maternity
- Race
- Religion and belief
- Sex
- Sexual orientation
- Welsh language

Case law has provided a set of consultation principles which describe the legal expectation on public bodies in the development of strategies, plans and services. These are known as the Gunning Principles:

1. Consultation must take place when the proposal is still at a formative stage.
2. Sufficient reasons must be put forward for the proposal to allow for intelligent consideration and response.
3. Adequate time must be given for consideration and response.
4. The product of the consultation must be conscientiously taken into account.

Local councils in North Wales have a regional citizen engagement policy (Isle of Anglesey County Council et al., 2016) This is based on the national principles for public engagement in Wales and principles of co-production which informed our consultation plan.

Consultation and engagement

A significant amount of consultation and engagement had taken place with children, young people and adults with learning disabilities and their parents/carers for the population assessment and regional plan. This included work undertaken by the North Wales Learning Disability Participation Group which includes representatives from self-advocacy groups across North Wales. This work has been used to inform the development of the strategy alongside the additional consultation and engagement work that took place specifically to inform the strategy.

Consultation process

We developed a draft set of themes for the strategy based on the engagement findings so far which we consulted on with the North Wales Learning Disability Participation Group and the regional provider network. These were then shared widely as part of the consultation along with a vision for learning disability services in North Wales (developed as part of regional work by Mobius in 2008). We asked people the following questions.

Consultation questions

1. Do you think these are the right areas to look at?
2. What do you think works well at the moment?
3. What do you think needs to be improved? Please include your ideas for improving services and ways to make the most of the resources already in our communities, including people with learning disabilities, friends and family, community groups, voluntary organisations and professionals.

We also produced an easy read version of the questionnaire in consultation with the Learning Disability Participation Group.

The timetable for the development of the Learning Disability Strategy was as follows.

| Month | Actions |
|----------------------------|--|
| January 2017 | Initial visioning event (Going Forward Together). |
| September 2017 | Scoping of capacity to develop the strategy. |
| October 2017 to March 2018 | Project plan agreed. Baseline data collected to inform the strategy. |
| April to July 2018 | Engagement and co-production with people who use services, carers, providers, front-line staff and other stakeholders. |
| August to September 2018 | Revise the strategy, agree priorities and draft action plans. |
| October to December 2018 | Consult on revised strategy and produce the final draft. Final draft strategy to appropriate boards and committees for approval. |
| January 2019 | Put the strategy into action. |

Consultation methods

The consultation methods we used were:

- Online questionnaire and easy read questionnaire circulated widely to staff, partner organisations, the citizen's panel, service users and other members of the public.
- Discussion groups and interviews with children, young people and adults with learning disabilities, parents/carers and parents with learning disabilities. This element was led by the North Wales Citizen's Panel.
- Consultation events for service providers and local authority and health staff.

Promotion plan

Details of the consultation including an online questionnaire and easy read version of the questionnaire were made available on our website

www.northwalescollaborative.wales/. We promoted the link through the Learning Disability Partnership members (representing the six local authorities and health) and to people on the learning disability strategy mailing list which included members of the regional provider forum. Initial emails were sent out on 23 April 2018 with a reminder on 11 June 2018. A press release was sent out through each of the six local authorities and health board.

North Wales Citizens Panel Citizen Panel shared the survey through Facebook, the website (www.laisygogledd.wales/), letters and phone calls and face to face meetings. The majority of responses came from fact to face meetings.

In addition the link to the online survey was sent to the county voluntary councils below, asking them to circulate it to their networks:

- Mantell Gwynedd (Gwynedd)
- Medrwn Mon (Anglesey)
- CVSC (Conwy)
- DVSC (Denbighshire)
- FLVC (Flintshire)
- AVOW (Wrexham)

To help reach people with protected characteristics the link was circulated by the North Wales Regional Equality Network to their members with a request to circulate widely.

Information was sent to members of the:

- Regional Partnership Board
- North Wales Leadership Group,
- North Wales Adult Social Services Heads (NWASH),
- North Wales Heads of Children's Services (NWHoCS)
- North Wales Citizen's Panel

Presentations on the strategy were given at the following meetings:

- North Wales Learning Disability Partnership
- North Wales Managers of Services for Disabled Children
- North Wales Regional Event for Self-Advocacy Groups
- BCUHB Strategy, Partnerships & Population Health Committee
- BCUHB Stakeholder Reference Group
- Conwy COG4 Partnership Group
- North Wales Adult Services Heads (NWASH)
- North Wales Heads of Children's Services (NWHoCS)
- North Wales Leadership Group
- Regional Partnership Board

We also attended a meeting of a regional network for parents with learning disabilities.

Social Care Wales circulated to the third sector representatives on the regional population assessment leads network and Learning Disability Wales have shared details on their Facebook pages.

Consultation and engagement review

There were 175 responses in total to the consultation and around 200 views of the regional plan page on the website.

Table 1 below shows the breakdown by members of the public and representatives of the organisations and table 2 shows the number of people with different protected characteristics who took part in the survey.

Table 1 and table 2 show that the majority of responses were from people with a learning disability including parents with a learning difficulty. We reached people in all age groups, people who have a disability or long standing illness/health condition and carers, Welsh and English speakers. We had responses from women and men although there were not as many responses from men. We also had a small number of responses from people with different marital statuses, ethnic identity, sexuality and gender identity. We did not get many responses from people with protected characteristics of national identity (other than from the UK and Ireland) or religion. We did make sure the survey and reminders were sent to groups and networks of people with these protected characteristics. We will also make the people responsible for implementing the strategy aware of these gaps in the consultation so they can take any additional action needed to eliminate potential discrimination.

Please note, the tables below only reflect the answers given to the equality questionnaire. For a full picture of the engagement with people with protected characteristics these figures should be considered alongside the list of organisations who responded to the consultation as well as [organisations](#) who responded to the regional plan consultation and the [organisations and service user groups](#) who responded to the more in-depth engagement carried out for the population assessment that informed the regional plan.

We used this data to monitor the responses while the consultation was open and encouraged groups representing under-represented groups to share the survey and take part.

Table 1: Number of responses by members of the public and organisations

| Type of response | Number | % of responses |
|--|--------|----------------|
| Person with a learning disability | 70 | |
| Representative of an organisation | 65 | |
| Parent or carer of a person with a learning disability | 30 | |
| North Wales Citizen Panel Member | 60 | |
| Parent with learning difficulties | <5 | |
| Total | 175 | |

Some people may have ticked more than one box. Numbers have been rounded to the nearest 5 to prevent disclosure of personal information and may not sum.

Table 2.1: Age

| Age | Number |
|--------------------------|---------------|
| 0-24 | <5 |
| 25-34 | 5 |
| 35-44 | 20 |
| 45-54 | 40 |
| 55-64 | 20 |
| 65 and over | 5 |
| Prefer not to say | 15 |
| No information available | 75 |
| Total | 175 |

Numbers have been rounded to the nearest 5 to prevent disclosure of personal information and may not sum.

Table 2.2: Sex

| Sex | Number |
|--------------------------|---------------|
| Female | 70 |
| Male | 30 |
| Prefer not to say | <5 |
| No information available | 75 |
| Total | 175 |

Table 2.3: Ethnic identity

| Ethnic identity | Number |
|--------------------------|---------------|
| White | 100 |
| Black or mixed heritage | <5 |
| Prefer not to say | <5 |
| No information available | 75 |
| Total | 175 |

Table 2.4: Preferred language

| Preferred language | Number |
|---------------------------|---------------|
| Spoken English | 80 |
| Spoken Welsh | 10 |
| Spoken English and Welsh | 15 |
| No information available | 75 |
| Total | 175 |
| Written English | 90 |
| Written Welsh | 5 |
| Spoken English and Welsh | 10 |
| No information available | 75 |
| Total | 175 |

Table 2.5: Disability

| Disability | Number |
|--|---------------|
| Learning disability / difficulty | 70 |
| Long standing illness/health condition | 15 |
| Physical impairment | <5 |
| Mental health condition | <5 |
| Sensory impairment | <5 |
| Total number of people | 75 |

The total above does not sum as some people had more than one disability.

Table 2.6: Religion

| Religion | Number |
|--------------------------|---------------|
| Christian | 45 |
| None | 30 |
| Other | <5 |
| Prefer not to say | 25 |
| No information available | 75 |
| Total | 175 |

Table 2.7: Sexuality

| Sexuality | Number |
|--------------------------|---------------|
| Heterosexual / straight | 85 |
| Lesbian, Gay, Bisexual | <5 |
| Prefer not to say | 15 |
| No information available | 75 |
| Total | 175 |

Table 2.8: Carers

| Carer | Number |
|--------------------------|---------------|
| Yes | 35 |
| 1-19 hours | 15 |
| 20-49 hours | 10 |
| 50 hours or more | 10 |
| No | 60 |
| Prefer not to say | 10 |
| No information available | 75 |
| Total | 135 |

Table 2.9: Marital status

| Marital status | Number |
|--|---------------|
| Married or in a same sex civil partnership | 60 |
| Single | 10 |
| Divorced or legally separated | 5 |
| Widowed | <5 |
| Prefer not to say | 20 |
| No information available | 75 |
| Total | 175 |

Organisations represented in the online survey

Below is a list of organisations whose staff took part in the online consultation. We also held engagement events for providers and local authority and health staff so more individuals and organisations took part in the consultation than are listed here. In addition the draft strategy was shared widely to provide a further opportunity for individuals and partner organisations to influence and shape the strategy.

Local authorities and health

- Betsi Cadwaladr University Health Board
- Isle of Anglesey County Council
- Gwynedd Council
- Conwy County Borough Council
- Denbighshire County Council
- Flintshire County Council
- Wrexham County Borough Council

Responses from health staff included the Community Learning Disability Team, Learning Disability Nurses, Occupational Therapy, children's learning disability services, in-patient services for people with learning disabilities.

Responses from local authority staff were mainly from within social services departments, from both children's and adults' services.

Service user groups and organisations

- AVOW (County Voluntary Council)
- Cartrefi Cymru Coop (Not for profit domiciliary care agency)
- Centre of Sign-Sight-Sound (Supporting people with a sensory loss)
- Clwyd Alyn Housing Association (Housing provider)
- Community Transport Association (Supporting inclusive and accessible community transport across Wales)
- Conwy Connect (An independent voluntary organisation working on Conwy county promoting the rights of adults with a learning disability to have equal choices and opportunities)
- Grange Residential Care Ltd (Residential care home for adults with learning disability and/or Autism Spectrum Disorder (ASD) in St Asaph.
- Flintshire Learning Disability Planning Partnership (a group including service user representatives, advocacy, service user providers and parents)
- Home Instead Senior Care (Health care provider)
- Job Centre Plus (Delivering a service with the aim of supporting people into work or coaching them to understand the services that are available for people who have disabilities and health conditions).

- Lifeways (Supported Living Provider for adults with learning disability/mental health).
- Mencap (Support individuals with a learning disability).
- MHC (Social Care) UK Limited (Provide residential services for people with learning disabilities, autism, and co morbid diagnosis and people with functional mental health)
- NWAAA Self Advocacy Groups
- Potens (Private limited company providing support to younger adults in Wales, England and Northern Ireland. We support adults with learning disabilities and mental health issues.
- PSS (Shared Lives Adult Placement)
- Stand North Wales CIC (Parents support)
- Voyage Care (Provide support to individuals)

Consultation findings

Consultation survey

Research methods

The survey was carried out between 23 April 2018 and 20 July 2018, see above for details of how it was promoted and who took part. The answers to the open ended questions were coded using the Catma software. In the analysis we have tried to give a sense of how often themes were mentioned by saying whether comments were by one person, a few people or by many people. This is not to say that just because one person raised an issue that it's not important and it may also reflect the views of many other people, which we can check and investigate further.

Potentially identifying information such as names of people and organisations has been removed from the quotes used.

Findings

Overall 93% of respondents agreed with the themes for the strategy. Comments in support of the themes include:

“The areas are perfect, they cover many aspects of daily living and are concise”

“They are all important to make me happy”

Suggestions for additional themes or expanding the themes included:

- The need for real voice, choice and control with a focus on rights and equality. One person said we need to go beyond questionnaires or consultation towards a truly co-produced strategy and co-produced services.
- More inclusion and integration of people with learning disabilities into the wider community. Including the need for staff training about specific learning difficulties and an awareness that not all disabilities are visible.
- Advocacy support for individuals.
- Support for people with profound and multiple learning disabilities, complex health needs and/or challenging behaviour.
- Support for people who also have other needs such mental health needs, who have autism or involvement in the criminal justice system and forensic needs.
- Carer breaks (respite) – including for people with profound and multiple learning disabilities; jointly commissioning breaks for people with challenging behaviours and additional health needs; and, access for people with learning disabilities to

holidays without their parents. Need to consider the impact on carers of providing care and support.

- Having enough money to live on.
- Early intervention, for example “listen when a family is crying out for help before it reaches crisis point’.
- Early years and having the right start in life.
- The importance of transport.
- The needs of older people with learning disabilities and older carers.

There were 7 people with learning disabilities (4%) who commented that they were not sure that some of the things were important to them including being healthy, being safe, a good place to live and the right support. Other things that were important to people were the way they were treated, for example support workers that understood that they ‘like a clean house’.

Services that work well

- The support people receive from family and providers was the most often listed as something that works well, for example, “being supported by people who know me, my routines and my behaviours” and “I get good help from my advocate and the support workers that come and see me”.
- In addition to good support workers other staff were mentioned for example “I have a good social worker” and “some places work well where you have good staff teams”.
- Some people mentioned joint working between local authority colleagues, co-located teams and multi-agency teams, social services working well with third sector organisations.
- People’s work was also mentioned as working well for example “I am supported in my work at [name of workplace]. I really like it there” “I work in [name of workplace] 2 days a week. This is very good for me as I am learning basic living skills”.
- Carer breaks (respite) for example “Respite has also been an important factor for us as a family and [name of provider] have been a major part in this and have provided us with support we could only dream of”.
- A few people mentioned support budgets, direct payment and person centred approaches as working well.
- Good education was mentioned by a couple of people, including a residential college.
- Charities that provide activities such as swimming.

- The acute liaison service with additional comments that it needs to be used and improved.

A couple of people also said that nothing works well at the moment.

What needs to be improved

The feedback on what needs to be improved is broken down by theme below. In addition to this there were issues that can prevent people from experiencing good outcomes under all of the themes, which are:

- **Support for carers:** Carer breaks (respite) was mentioned by many people in the consultation. Some of the specific issues include a lack of short breaks for families, respite provision for people with more complex needs such as challenging behaviour and autism and regular and predictable respite that is open all year round. Someone also mentioned the need for safe places and activities in the community where support workers can take young people with complex needs to give families a break. For example “There is a lack of short breaks for families and without this we have seen many families going into crisis resulting in out of county placements that are far away” and “without regular breaks families cannot survive”. People mentioned the importance of considering the impact on families, including the needs of siblings of children with learning disabilities. Also the importance of listening to parents and supporting parents/carers to building resilience and develop coping mechanisms. People also mentioned the needs of older carers, for example:

“Something needs to be done about the huge number of elderly carers to: a. Ensure that they are physically fit enough to continue caring b. To gradually introduce their adult sons/daughters to services so that it won't be such a shock for them when their parents are no longer able to care. To estimate the likely cost of providing services to this group of clients in the future.”

- **Funding:** having enough funding available for services, for example “Budget cuts are hitting statutory services and this will impact on individuals, groups and families” and “The government needs to fund services for vulnerable people!”. A few people mentioned the need to work together and consider merging budgets to try and address these issues and one person mentioned the issue that providers and direct payment recipients may have to pay back pay for sleep-ins. Another person mentioned that we need to make better use of technology.
- **Transport:** people mentioned how important transport was to them for inclusion in activities including having someone who can drive them, bus passes and subsidised transport. People also mentioned the orange wallet system that helps people with using public transport. One person said: “I miss out on evening activities as none of my family drive so I rely on taxis which are expensive”.

- **Access to information:** A few people mentioned the need for more information about the services that are available, details of who is able to access support from them and availability of services in Welsh. One person suggested sharing information about offers available at local facilities such as the leisure centre or theatre.
- **Workforce development:** Some people talked about the importance of training and support for staff, particularly support workers. Also the importance of training the wider workforce, such as training for GPs about the needs of people with learning disabilities and how to access community teams. Some of the feedback and suggestions included:

“Often support workers are low paid and are not given training and support”

“Thorough inspections and better recruitment for services who provide care for people with complex needs, people need to be free from abuse, services must act on staff poor practices.”

“Most [staff] have no understanding of impact on people’s lives, assuming because they can do something everyone can.”

“Ask individuals and their families to input into training for professionals - especially for decision-makers.”

“Adequate training for support staff: up to date information about the needs and rights of people who have a learning disability; respect for people with learning disabilities; mental capacity act and making choices/decisions; communication/ learning/wishes and feelings of people - identifying the needs of each individual and adapting approach; losing labels and 'seeing' the person; enabling as opposed to doing for; people with learning disabilities trained to deliver training; limiting the use of support staff mobile phones while they are working; encouraging support staff to join in with activities rather than just taking a person to a venue and sitting on the side-lines, observing.”

“Good supportive management style for the service provider is important as is regular audit/ supervision interviews”

Many people mentioned the importance of **joint working between health and social care** and other partners to provide good services and to address funding issues. A few also suggested better information sharing systems between health and social care. Comments included:

“Maybe it would help if health and social care budgets were merged for some services to stop health and social care fighting over who pays for what.”

“I find that a lot of the work the community nurses are doing now is focused around assessment for funding and funding applications, this takes time away from nursing interventions and a lot of the hands on work that used to be done by community nurses. It would be good to have a specific role or link nurse for

completing health funding applications, and this to be separate from the community nursing role to free up the role for doing specific health interventions.”

“There needs to be more understanding of what other areas can provide and look at replicating that in the local area.”

“working across teams and organisations e.g. CAMHS and disability services, child and adult disability.”

“I think all local authorities should all be working in the same way so... you know you are giving information that is up to date and consistent.”

“Managerially, Betsi Cadwaladr University Health Board and Social Services need to work better together, shared targets etc”

We also asked people for **ideas to improve services that would make the most of resources already in our communities**, including people with learning disabilities, friends and family, community groups, voluntary organisations and professionals. There was a lot of support for the idea that we should ‘help each other’ as well as for the improving inclusion within the wider community, for example,

“We need to access all services from all sectors, community groups and voluntary organisations”

“Clearly there is a need to reduce the number of organisational services and to get more community-based activities that people with learning disabilities attend / contribute”

“It should be remembered that the biggest steps need to be taken by society, not by the individual. A simple example of this is as follows - a person sits at the doorstep of a building, sitting in a wheelchair. The 'problem' is not the person. The problem is the lack of a ramp.”

“I believe that the contribution of individuals to communities is important as well as taking action, whether they are small or large towards greater independence.”

But there were also some concerns about the pressures this could put on people. For example,

“What things could people do to help each other? People could share experiences of Direct Payments, form co-operatives, pool Direct Payments etc. However, at [over 60] years of age I have had enough and am very disillusioned. I just want to retire and be my son’s mum – not his care manager! The SS&WB Act talks a lot about co-production and using “natural

supports". Whilst I am not against these things you can't rely on the good will of volunteers. Families like ours have spent years fighting for services for our sons/daughters. We can't be expected to have the time and energy to form co-operatives or social enterprises or charities to set up alternative services for our sons/daughters. Generally speaking I think that Adult Social Care is an inefficient bureaucratic organisation which is not really focussed on the best interests of people with learning disabilities (although there are individuals working within Adult Social Care who are really dedicated and doing their best for people.) I think we need an alternative model of support."

"Voluntary groups are always trying to find money to support their work and this can often fall on a small group of volunteers ~ could some work together and share the load?"

A good place to live

A few people mentioned where they live as one of the things that is working well. For example,

"I have a good life with my adult placement, I have my own room and a dog and a proper family"

"I live in a supported living house we have a support worker with us at all times so we know that we are safe, we enjoy living together in a girls house and going out together."

Another person said advocacy was important in helping them find a place that suited them. For example,

"I got a lot of help from advocacy to move house because I wasn't happy and I didn't feel safe in my old house so I moved to a better flat, I got to choose my flat and I decorated it and put what furniture I wanted in it."

People wanted to have more choice about who they live with. Some people said that having pets was important to them.

One person suggested that,

"Local Authority and Health need to be looking at purchasing pre-built houses to accommodate individuals with a learning disability that is in their county whilst staying away from the typical 'learning disability community'"

A few people said that their needs to be more investment in accommodation and accommodation-related support particularly for young people.

Out of county

A few people mentioned issues with out of county placements. One person said there were problems with timely decision making and that some of their cases had been to panel 4 or 5 times. Another that,

“We hit a lot of housing issues due to certain counties refusing to place people from out of county. If a person wants to live in a particular place they should be able to.”

Something to do

A few people mentioned the importance of having something meaningful to do, not just something to do. Making a difference was really important to a number of the people we spoke to. For example:

“I like to go to meetings to tell people what is important to other people in other counties.

“I like to help people in the shop, I think people need more jobs.”

“I like making a difference to people and talking to people.”

Many people mentioned their jobs as something that works well. Work was often mentioned by people as important because it's a chance to spend time with friends and people they get on well with.

There were a lot of different leisure activities that people mentioned as important to them including: volunteering, snooker, tennis, wheelchair basketball, ten pin bowling, playing pool, Men's Sheds, magazines, star wars figures, art and art classes, cinema, shopping, watching TV and films, swimming, colouring, computer games, newspapers, ironing, watching and playing football, music, theatre, dancing, going out every night, sports clubs, buzz club, curry night, going out for meals, walking and holidays. A few people mentioned that there need to be more leisure activities and opportunities for people with learning disabilities, more integrated community-based activities and mixed groups.

There were some concerns about day services and suggestions that we should move to a more inclusive and integrated model, for example:

“I do not believe that the "day service" model is sustainable, it is institutionalised and focuses on containment rather than community integration. We should be focusing on liaising with private sector companies as employers for individuals - giving individuals purpose and reducing social stigma.”

“Why do we still have day centres where people sit around drawing and painting when they could be integrated into society as a positive member of the community?”

“More access to supported employment and movement from that to paid employment.”

There were other concerns about a lack of jobs and suitable activities, for example:

“I think I’m going to struggle to find work when [work placement] closes.”

Some suggestions included:

“Leading by example, coming from both Health and Social Services by employing people with learning disabilities”.

“More collaboration with Disability Advisers in Jobcentre as we have access to the benefits of the people who access all our services and as a requirement to receive benefits we have an obligation to meet the carers and the people with health conditions and disabilities (where possible of course) to ensure they are informed of their rights and provision available to them.”

Children, young people and families

People spoke about the importance of disabled children attending sessions with their friends and including children in existing local groups in the community such as leisure centres or theatres. Need to encourage local groups to support children with learning disabilities and understand that not every disabled child will need one to one support. Need a wider range of activities and also to better share information about the activities available.

Education

A couple of people mentioned issues with the process of statementing, requesting a statement and delays. One person said we needed to review residential schools to see if we are “getting value for money, appropriate support and quality support”. Another said that educational settings need to provide ‘consistency, routine and structure’. And another that,

“I think everyone with a need should have access to laptops in school as a given extended time automatically for exams and if a one to one support is recommended by professionals then it should be implanted without question by the place of learning.”

Friends, family and relationships

Many people said that friends, family and relationships were important to them. People also talked about good relationships with staff and work colleagues. A few people also mentioned that having pets was important to them. For example,

“I think family is important, I live with an adult placement with other people and she is lovely and helps me a lot.”

“My boyfriend is important to me”

When asked what needs to happen a few people mentioned being involved in the community and more support to access community activities as well as meeting friends and partners. For example,

“I would like a relationship, to get married and live with my husband”

“People need to be supported to maintain and develop relationships with friends and partners in a way that puts their own interests first and not the needs of their parents/carers and support workers first.”

“We live in an area where more can be done to access the outdoors we need more accessibility to outside organisations and with this I believe people with learning disabilities will gain trust friendships”

“More support for friendships and relationships - why can't someone pop in to a friend's shared house for a coffee? Why do they always have to do things with the people they live with?”

“Individuals should be encouraged to work based on their ability. They need to be empowered by friends and family to become citizens within their own community.”

Being safe

People commented on the importance of safeguarding vulnerable people so that they can feel safe when accessing their communities. This includes treating people with respect so they don't feel looked down on. One suggestion was having more police on the beat so that they can get to know their community and community members can get to know them. Another person said that more help is needed for people when they get teased for having a disability, they said “me and my girlfriend used to get teased a lot but now we just ignore them”.

Being healthy

People highlighted the need to look at the mental health needs as well as the physical health needs of people with learning disabilities and the need to reduce stigma around mental health. A few people commented that people may not think about mental health when they think of 'being healthy'.

Some people mentioned the need for improving support for people with learning disabilities in hospitals. For example,

“Improvement is needed in hospital settings when people with a learning disability are admitted onto general wards.”

“Learning disability acute liaison nurses need to be available in hospitals at all times to support people. Not just Monday to Friday between the hours of 9am and 5pm. An effective system to flag people with learning disabilities who may need extra support/reasonable adjustments when they arrive at hospital needs to be introduced.”

“Responsibility and awareness needs to be shifted into the community - in an ideal world, we wouldn't need learning disability nurses.”

“Sometimes in our experience health professionals are excellent and are willing to work collaboratively with providers (who after all know the individuals we support best). I would single out GP practices, District Nurses and Ambulance staff here. However, hospital staff often seem too busy or just unwilling to take the time to listen and develop an understanding of how people communicate, what their general needs are, and how our staff can assist them in providing the best possible service.”

One person highlighted the need to improve acute health services and highlighted the need to use the resources developed by the Paul Ridd foundation to improve care in hospitals.

One person mentioned the need for better communication between medical professionals, health visitors, midwife and patient and their family. Another mentioned the need for more consistency when young people move to adult services and gave the example of different CHC funding guidance. A few people mentioned difficulties accessing services and getting doctor's appointments, for example:

“I would like for hospital letters to be easier to read as they are complicated”

“Access to GP appointments – I have to ring at 8 o'clock in the morning for an appointment”

One person mentioned the need to improve services between acute services and community services, including the need for additional Occupational Therapists,

“The link between inpatient and community needs to be bridged better with more services in the community to aid in managing and support people to reduce placement break downs and to better care for people in placement and in their own homes.”

Another person mentioned the need to be aware of sensory loss,

“Many, many people with a Learning Disability also have a sensory loss which is often overlooked, whether that be because of the tests that are performed or because their carer simply misses the loss and puts issues with communication down to the Learning Disability. We need to ensure that more people are able to access the tests, making sure the tests are explained fully, and that carers are made aware of the signs of a sensory loss, and the prevalence within the Learning Disability Community.”

Children, young people and families

People commented that access to mental health needed to be quicker for children with learning disabilities and also more support for their parents.

The right support

People highlighted the importance of having the right support with changes in life and transition but also said that this theme needs to cover more than that. This includes supporting people to be independent, to have choices, good communication and being treated well by support workers. One person reiterated a point from the ‘Going Forward Together’ Event that a key principle is ‘delivering the right care at the right time by the right people’.

Good support was often mentioned as something that works well for people. A few people mentioned how important it was to be independent, have choices about the support they receive and have the right amount of support.

“If I could choose my hours to have support so I can have a social life”

“Would be better if we had more support workers so we could do more and gain more independence.”

“[it’s important to me] to make my own decisions, to be treated as an individual, to live independently as long as possible”

People talked about the importance of people being nice to each other, being treated with respect and also being supported by people that they know and work well with. Example of where this isn’t working well include:

“[Support worker] is a nice man but doesn't work well for me.”

“I'm not happy with my support workers I don't like them being rude.”

Good communication and team work and helping each other were also very important to people. For example,

“listen, teamwork, explain things clearer”

“We also need to ensure that the communication needs of people are met at all times, and that parents and/or carers are not the sole people able to assist with communication.”

One person mentioned the importance of helping people to understand what the right support is, for example:

“Do people have choices in their support in order to differentiate between good and less good?”

There were ideas about how to improve the support available, including:

“We need to look at how resources can be better utilised, for example, transportation to events and staffing ratios.”

“Providers need to liaise with each other, get together, re-unite individuals.”

“Thinking outside the box and even working with staff from another shared house to enable people to do something they would otherwise not be able to do.”

“We need more services for these high-end individuals to prevent them from having to go out of county/ a long way from home for support, as often the families want to support them within their homes and in the community but feel unable to due to without increased support and without feeling more able to integrate in the community”.

“We also inform groups of holiday dates and he is always offered a service within the time frame that it can't be utilised, and are never offered a last minute cancellation, when we have asked. Kids don't show up and there is no consequence for those parents. Aware can be for health reasons, but if the LA is paying for a service for 10 kids and only 5 show, call parents and see if they are local. Even an hour can save a parent's sanity.”

“A "state of the art safe house" facility, NOT a hospital, in times of crisis or emergency for people on the spectrum. A place where they feel supported and understood, NOT a place where they feel they are being punished for some unknown crime.”

“Good support that is known and trusted by the individual that can help them to grow by teaching some basic skills towards greater independence. This involves the service member being there from the interview stage and selecting the appropriate candidate. It also means consistency whereby the support is not chopped and changed to suit the providing agency. By consistency it allows the individuals chance to build a trusting relationship which is important for the well-being of the individual.”

There were also concerns about people who may not be eligible for services or who fall between services eligibility criteria, for example, between learning disability services and mental health.

“Some individuals do not meet the 'formal' threshold for services and can potentially miss out on receiving assessment and services if their IQ is deemed not to identify them as having a learning disability.”

Children, young people and families

Parents mentioned challenges around waiting for assessments, the time taken and needing to wait for a certain age for an assessment. Parents also said they needed better support and understanding from professionals while waiting for an assessment. For example “not try to blame the parents about their child’s behaviour while waiting for an assessment... they sent me on parenting courses and making me believe it was all my fault”.

For parents with a learning disability, one person said that it’s important that they get to have their say too.

Suggestions for improving services included:

“We need more services that are going to support children and their families with complex needs and there needs to be more understanding of what other areas can provide and look at replicating that in the local area”

Support budgets, direct payments and person-centred support

These were mentioned as working well by a few people who took part in the survey, for example,

“Direct payments present an opportunity for people on the margins of society to take back control of the support they need and exercise genuine choice over the life decisions that the majority of us take for granted. Some people are benefitting from these opportunities and in turn, are shaping the types of support that they need.”

There were also some concerns about Direct Payments including comments that people need much more support to use them and difficulties finding a direct payment worker. One person gave an example of the difficulties they had had with direct payments:

“Son currently gets Direct Payments and we employ his PSAs ourselves. We have been doing this for 3 years. We had no support from Social Services apart from the DP Support provided by [name of provider]. This support was inadequate. Running and managing a service for my son is akin to running a

small care company. There was too much work and too many responsibilities. So we decided to give up last July and asked for extra funding to buy in a service from a Provider. Social Services agreed to this but more or less left it up to us to find the Provider and arrange a TUPE transfer. In the end there was only one Provider who could offer a service and we are still struggling with the TUPE transfer. So we have been struggling for 10 months with not enough staff because a part-time member of staff left and we were unable to replace her and the situation still is not resolved... People with severe learning disabilities and their families need a lot more support to use Direct Payments. The DP set-up also needs to be sustainable as parents will not be able to do all the management of staff themselves for ever. Maybe having an organisation (e.g. a co-operative) to be the employer would be better”

Support with changes in life and transition

A few people mentioned the importance of good transition from children's to adults' services. Comments included:

“More consistency across health services when young people move to adult services e.g. CHC funding guidance is different”

“Looking at the needs as a whole of the children growing up within mainstream and special schools before they enter adult services should be a priority to assist with the needs and services for the future, adult services can then develop their services according to the needs locally.”

A few people mentioned the needs of older carers and supporting people to be ready for changes, for example,

“Important to discuss realistic future care plans with carers for their loved ones sooner rather than later.”

“Earlier planning and interventions required, but also creativity around service provision in order for people to continue to live in what are often loving environments - shared care, downsizing accommodation, extra care where the parent and person can continue to live together with their differing and changing needs and outcomes being well accounted for.”

Conclusion

Overall the vast majority of people consulted were supportive of the themes. Based on the feedback received we have amended them to clarify what we mean by ‘right support’, add ‘family’ to the ‘friends and relationships’ theme, change ‘something to do’ to ‘something meaningful to do’, include a separate ‘early years’ theme and make sure that a lifespan approach and the needs of people with profound and multiple learning disabilities are included throughout the strategy. The other findings and

ideas for improving support will be incorporated into the strategy and action plans. This report will also be made publically available so that the details can be used to inform other work.

‘Going Forward Together’ Event

The event was an initial staff/partner engagement session on ‘Developing our Learning Disability Strategy’ that took place on 17 January 2017 involving 28 staff from across BCUHB and the six local authorities. The event was facilitated by BCUHB to inform the development of this strategy. The discussions looked at current strengths and challenges and what needed to change.

The event identified the following key themes for the development of a strategy:

- Joint working through a shared vision/shared values
- Service user and co-production
- Leadership, governance and accountability
- Commissioning
- Staffing (including links to North Wales Workforce Development Strategy)
- Staff involvement in the development of the strategy

The guiding principles discussed were:

- Shared responsibility to implement the legislation.
- Person first, learning disability second.
- Right support at the right time to the right people in the right place.
- No-one to experience delays in support due to disagreements between services. Shared responsibility to ‘fix it’.

The key observations and actions were:

- The staff that attended understood the need to work together to build a robust strategy for learning disabilities – they all contributed to the whole event with very few delegates having to leave early.
- The overall consensus was that a shared vision and values would need to be developed to underpin the strategy. This work commenced during the session but would be further enhanced
- The core capabilities of the Learning Disabilities service was not as easy to describe by the delegates and therefore some further analysis/discussion would lead to a better understanding of the current state.
- It was acknowledged that this was a starting point and further continuous engagement would be required in order to develop the Learning Disability Strategy for North Wales.
- Involving people with lived experience was agreed as a critical next step.

- Programme of work to be developed following the lessons learnt from the Mental Health strategy development.
- Agreement that the LD Partnership Group was key but work was required on Terms of reference and membership.

Provider forum

The first North Wales provider forum was held on 9 April 2018 and around 60 people attended from across the region. The full report is available at

<https://www.northwalescollaborative.wales/learning-disability-provider-forum-9-april-2018-event-feedback/>.

Based on the feedback from the day the themes for the strategy were updated before they went out to wider consultation. Other findings included more detailed definitions of the themes, principles and values (including Welsh language and culture, advocacy and self-advocacy) and the barriers faced (including transport issues). There was discussion about the wide range of people who needed to be involved in the development of the strategy which informed the project's communication and consultation promotion plans.

Staff engagement event

The local authority and health staff event was held on 18 July 2018 and over 100 people attended from across the region. The full report is available at:

<https://www.northwalescollaborative.wales/learning-disability-strategy-local-authority-and-health-staff-event/>

Event findings

The event provided more information about what needed to be included under each of the strategy themes as well as ideas for actions under each theme. Overall findings were:

- Make sure we include people with profound and multiple learning disabilities in the strategy – consider a 'sub-strategy' focussing on this group. Also include people currently living in a 'hospital environment' and people who need support due to pre-offending behaviour or offending behaviour.
- Continue to promote and develop [Dewis Cymru](#) as a source of information about the services and support available in local communities.

The event highlighted importance of:

- Working together, joint commissioning and planning, pooling resources and sharing skills and good practice across North Wales. Shared responsibility and addressing of shortfalls when things change.

- Culture change - raising awareness and building friendships and relationships within an inclusive community to make the most of the assets, resources and skills available.
- Taking a person-centred approach.
- Workforce development. Suggestions included a clear pen portrait / skills for staff providing support and training for the wider workforce, including GPs and healthcare assistants, about reasonable adjustments and preventative measures.
- Making links between the different themes, for example, having the right support is key to good outcomes in all of the themes and all the themes contribute to good health.

References

Isle of Anglesey County Council, Gwynedd Council, Conwy County Borough Council, Denbighshire County Council, Flintshire County Council and Wrexham Council 2016. North Wales Regional Citizen Engagement Policy. NWASH.

Welsh Government 2015. Social Services and Well-being (Wales) Act 2014: Part 9 Code of Practice (Partnership Arrangements).