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NORTH WALES SOCIAL CARE AND WELL-BEING
SERVICES IMPROVEMENT COLLABORATIVE

North Wales Learning Disability Provider Forum: Event feedback

9 April 2018 at The Optic, St Asaph

About the event

This was the first meeting of a regional learning disability provider forum in North Wales. The aims were to:

- agree how the forum will work, who needs to be involved and what we will focus on;
- introduce the Learning Disability Strategy being written jointly between the health board and the six local authorities in North Wales; and,
- find out how best to involve service providers in co-producing the strategy.

The invite went to members of the Learning Disability Partnership to circulate to their local provider networks; the Learning Disability Strategy mailing list; Children and Young People's Residential Care providers and Independent Fostering Agency providers. The event was advertised on the [Regional Partnership Board website](#) and in the [Learning Disability Strategy Newsletter](#).

There were 57 people who attended representing around 30 different organisations from across North Wales including third and independent sector providers, health and local authority staff and parents/carers. A full list of attendees and apologies is included in [appendix 1](#). Simultaneous translation was provided by Sandra Williams.

Agenda for the day

1pm Registration and refreshments

1.30 Welcome and introduction

2.00 Learning Disability Strategy (group discussion)

2.45 Planning the forum and involvement in the strategy (group discussion)

3.20 Conclusions and next steps

3.30 Close

Introduction

Neil Ayling, Chief Officer for Flintshire County Council Social Services introduced the event. He spoke about the background to the event, building on the good work already taking place in North Wales and delivering on what people have told us is needed in the regional population assessment. These findings are in line with the Social Services and Well-being (Wales) Act 2014 and the Regional Partnership Boards priority to integrate services for people with learning disabilities.

The first aim of the Regional Partnership Board's work-stream is to write a regional, integrated (joint between health and social care) learning disability strategy. The timeline for the strategy is below. The provider forum event was held at the start of the engagement phase for the project.



The vision for the strategy is taken from a [report](#) commissioned by the [North Wales Social Care and Well-being Improvement Collaborative](#) from [Mobius UK](#) in 2008.

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.

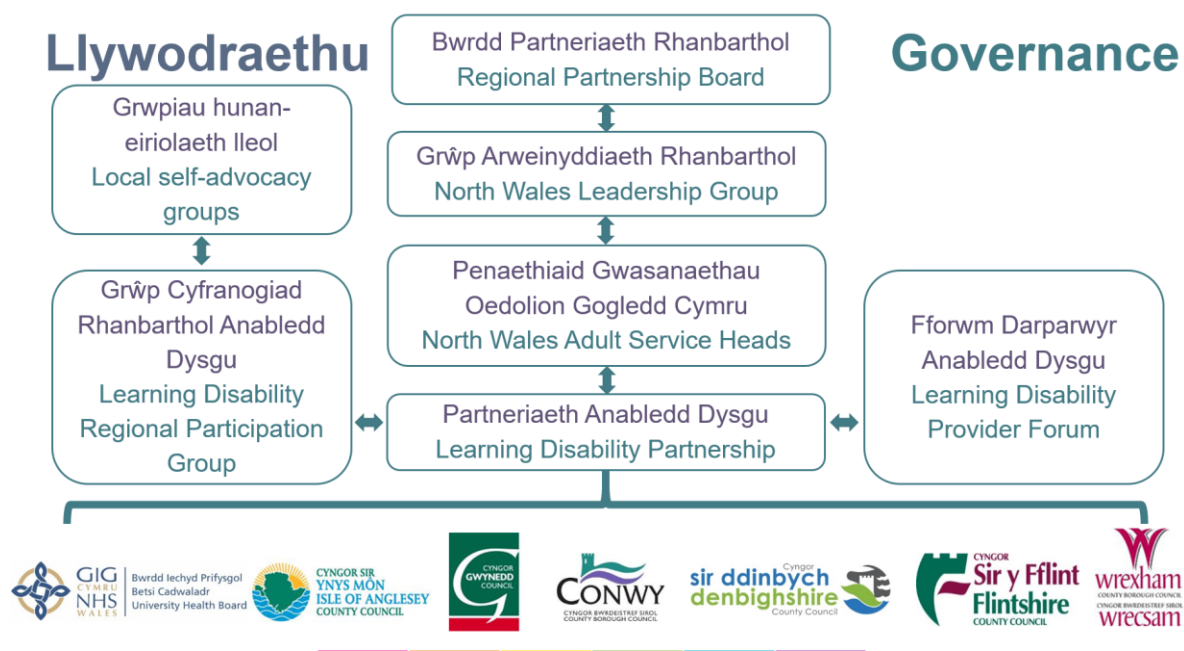
An initial workshop on the strategy held in January 2017 also highlighted the following values as important in developing the strategy.

- Agreed single vision.
- Shared responsibility to deliver 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 [population assessment](#) highlighted the following findings which will inform the strategy.

- There are around 650 children and 2,800 adults (including around 300 age over 65) with learning disabilities on local council registers in North Wales. The actual number of people with learning disabilities may be higher.
- The number of children and young people is expected to remain around the same (because the overall population is likely to stay the same or reduce slightly) although we think the number of children with more complex needs may increase due to improvements in health care.
- The number of people with learning disabilities needing support is increasing and people with learning disabilities are living longer. These trends are likely to continue. There are also an increasing number of older carers (including parents and family) providing care and support for people with learning disabilities.
- People with learning disabilities tend to experience worse health, have greater need of health care and are more at risk of dying early compared to the general population. For example: 6% of women with learning disabilities had a cervical smear test compared with 71% of women eligible overall.
- People have told us the things that matter are: having something to do, having a good place to live, being healthy, friends and relationships, being safe.

Governance of the project will be as below. There will be other opportunities to feed into this strategy in addition to these groups.



Group discussions

On each table the group discussed the learning disability strategy and then how they thought the provider forum should be structured.

Learning disability strategy

1. What else needs to be considered in the strategy?

Themes

Need more detail on the proposed themes – what do they mean and what will this look like in practice.

- **Something to do:** Have employment as a separate theme. Involve business and encourage them to offer real, paid work opportunities. Support people with learning disabilities to achieve self-worth, meet with others and be involved within the community / workplace. Have higher expectations of people with learning disabilities.
- **Friends and relationships:** People with learning disabilities may not always want to mix/socialise with others with learning disabilities. Challenge the idea of 'learning disability only' events and encourage engagement with the wider community. Recognise that people can inspire one another.
- **Being healthy:** Provide training for carers, care providers and all health professionals in the specific needs of people with learning disabilities. Basic awareness training for all staff who come into contact with people with learning disabilities. Tailored support for those with learning disabilities and ensure that information, for example on having a blood test, is appropriate. Have formal follow-up processes for when an appointment is missed. Examine current practice to see if it is appropriate. Explicitly recognise that better health should include better mental health. Cover health risks.

Other suggested themes included:

- **Transition** (support around change and planning for the future): including from children to adult services and leaving home. Include a focus on training, skills, lifelong learning and self-development. Make sure support is there as long as people need it – no cliff edge.
- **Support for carers and carer breaks.** Establish structured carers forums to share experiences. Important for parents, carers, family to have an input, they provide a great deal of support. Recognise the challenges of an ageing carer population.
- **Autism** (recommend it should be a separate theme).
- **Financial support:** PIP, planning for future. Benefits v salary. Advice and support. Direct payments – Citizen Directed Support.
- **Transport:** accessibility and availability, transport training.

- **Advocacy:** giving people a voice, including self-advocacy.

Principles and values

- Focus on what's right for the individual and not what the service can do or how we think we can improve. Plan for the long term. Support should be flexible and meet people's changing needs so we don't provide too much or too little.
- Promote the Welsh language and culture - absolutely central.
- Services should be more integrated and less fragmented, avoiding duplication and silo working. They should 'pull together' in the same direction to achieve the same goal.
- The strategy should be broader than learning disability support services, including the wider community and business / education to raise awareness of the needs of people with learning disabilities and the particular challenges that they face.
- The strategy needs to be accessible to everyone (not just easy read). Everyone who works in services needs to be able to use this strategy – it should be straightforward and practical with an outcome focus.

Other issues to consider

- Existing provision, how well it's meeting current demand and how consistent it is across North Wales.
- What's worked well and what hasn't. Focus on prevention and understand what is preventing us from doing this well at the moment.
- Need better response to crisis.
- Access to information, including about the services available.
- Approach to commissioning, recognising your market, being flexible.
- The barriers (including societal restrictions) to accessing activities in different counties.
- Community integration – using voluntary organisations more. Create a central place or hub to locate / access what is available in the community.
- Develop more active support. Include positive risk.
- Staff training and skills analysis: train staff to meet the needs of the individual, involve service users in training, use train the trainer more.
- Housing: need to engage private landlords and housing associations in developing support packages along with family, friends and services. Service users want to know they can live in their home for the rest of their life (as much as anyone can know this). Look at various options for carer breaks, such as hotels.
- Supporting people who are not known to services

- How the strategy and processes are managed across the region. Accurate management information should be used to identify where there are failures in the support network.
- Use of technology – where do we need to increase this?
- Dietary needs and nutrition
- Self-esteem and independence
- Funding: will there be the resources available to deliver the strategy? Differences in funding can have an impact on how values are applied and resources and staff are not always available. Acknowledge this will always be an issue – if money is tight then it is even more important that we work together and work more efficiently.

2. Who else should we include?

The groups mentioned:

- People with learning disabilities
- Direct support workers
- Parent providers / carers
- The third sector, voluntary sector, board members of charitable organisations
- Local authority members
- Health professionals - Learning Disability nurses, Acute Learning Disability Services staff, GPs and other primary care staff, A&E staff, hospital staff.
- Benefits staff, DWP
- Jobcentre+ (linked to the 'Disability Confident Employers' initiative)
- Advocates
- Housing – housing associations, housing departments, private landlords
- Commissioners – key people from contracts, procurement and so on
- Schools and education (including Further and Higher Education and work with young people to help change attitudes about people with learning disabilities)
- Hard to reach groups
- Wider statutory services – Police, PCSOs, emergency services and so on
- Employers and businesses - Business Wales, Trade Associations. Some employers are good at supporting people with learning disabilities and we need to contact and engage those employers who are not involved.
- Press (as part of raising awareness)

Other points raised:

- Providers can feel uncomfortable sharing good practice when they may be competitively tendering against others in the future.
- Mapping out the services available – who, where and what they are offering, improve access to Dewis and facilitate knowledge sharing and case studies.
- Need to think creatively in all areas and develop novel solutions.

Suggestions for how to reach people: Easy Read; selling the benefits; encouraging involvement; work with 6th Form Heads to encourage students to become involved in learning disability projects and to learn more about people's needs; address prejudice; work with nursing tutors/trainers; and, engage research students to undertake related research projects and publish their findings.

3. How would you like to be involved?

- Online questionnaire. Note the pressure of work can make it difficult to respond to online questionnaires. An alternative is to send in an existing relevant report.
- Each county's provider forum. Put the strategy as a regular agenda item. Could be provider led not LA led? The forums are set up differently in each county - review the effectiveness of each provider group.
- Regional forum – but ensure that a record / minutes are published.
- Virtual Groups.
- Opportunities to share practice, views and learn from each other.
- Gather the views of direct support staff through team meetings.
- Overarching authority to share information and provide feedback. Identify how the information is shared up and down the system. Share information about how people can be involved in the strategy and how we will keep people informed about progress.
- Identify key areas and use key people to progress work and develop action plans to put ideas into practice. Include SMART outcomes and report on what has / hasn't been achieved and why. Set up action focussed 'Action Team / Groups' to oversee plans, monitor outcomes and target specific areas of challenge, for example, a group about improving smear test uptake.

Regional provider forum

Overall the groups felt a regional provider forum would be helpful if it had a clear purpose. Suggestions for agenda items included:

- 'Trending' topics including statistics, management information, keeping up with current ideas, emerging themes, current/future changes to legislation, changes in funding, local initiatives, governance changes, such as CSSIW to CIW and RISCA
- Share information and good practice, problem solving, bring issues, share challenges and seek advice.
- Feed into strategy development, give a provider perspective and hold the strategy to account
- Update on strategy implementation
- Base the agenda on the strategy – could focus on one theme each meeting
- Challenge and act as a 'pressure group'

- Forum for two-way dialogue
- Shaping and alignment
- Co-production
- Look at what's being offered and what has been delivered
- Networking
- Must be outcome focussed
- Identify training needs
- Keep it live

The options for the regional provider forum discussed were:

1. A forum open to all providers (like the 9 April 2018 event)

- *Advantages:* Inclusivity and opportunity to hear a wide range of views and ideas. Provides a forum to keep people updated and informed about progress on the strategy. Can include all providers including parents and could be useful to have commissioners and key service representatives at the event also (like today).
- *Disadvantages:* Inconsistent attendance. Difficulties following up actions and getting commitment. Having a group too large for open discussion.

2. A forum made up of representatives from local providers

- *Advantages:* easier to contribute to, agree and take forward actions with a smaller group and have more open discussions.
- *Disadvantages:* representatives may not represent everyone's views and promote their own agenda, they may not have the right knowledge and experience. Would need a clear process for feeding messages back and forward with plenty of notice so representatives can get a broad view.

3. A combination of options 1 and 2 – regular meetings of representatives with an annual event involving a wider group.

- *Advantages:* Would include a wide range of views

4. Any other ideas

- Standing agenda item on local provider groups that could feed into the larger group
- Having a 'strategic group' with sub-groups or action groups to undertake targeted pieces of work with a clear focus with fluid membership so that members join and participate in line with their expertise. Need the right people at the right time. Keep a clear link to the strategy and strategic objectives.. Would meet as often as required.
- The annual event should include people affected by learning disability to share their experiences and achievements.

- Hold regional provider meetings in the morning and then an all Wales event in the afternoon.

Overall there was a broad consensus that we should have strategic local forums, operational groups and theme-based groups that feed into a broader structure. Membership of the wider group could include everyone with an interest in the agenda. These groups could meet quarterly, with the regional group meeting every six months.

Conclusions

Based on the feedback on the day the themes for the strategy have been updated before going out to wider consultation as follows.

Our 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.

We think the strategy needs to look at how health and social care services can work better together and focus on the areas people have told us matters to them:

- having something to do
- having a good place to live
- having the right support through changes in life
- friends and relationships
- being healthy
- being safe

Other issues we think we need to look at in-depth in the strategy are:

- the needs of people profound and multiple learning disabilities and complex needs
- the needs of parents and carers
- the needs of older people with learning disabilities and older carers

The other findings will be used to inform the strategy including 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).

A wide range of people needed to be involved in the development of the strategy. The suggestions made will be incorporated into the project's communication and engagement plan. Newsletters with project updates will be published every two months on the [Regional Partnership Board website](#), along with feedback from this event.

The consultation on the strategy will run between April and July 2018 and we agreed to take the findings back to the provider forum in the autumn. Following the meeting an idea was raised for a regional conference which could be held around April 2019 to launch the strategy and would combine a large inclusive conference with workshops on specific themes.

For more information please contact Sarah Bartlett, sarah.bartlett@denbighshire.gov.uk, 01824 712038.

Appendix 1: Event attendance

Name	Organisation
Dorothy MacPhail	Allied Healthcare Bangor
Gavin Jones	Allied Healthcare Dolgellau
Rhys Astley	Anheddau
Sion Milner	Anheddau
Alan Dowey	BCUHB
Dr Jess York	BCUHB
Ffion Marshall	BCUHB
Joanne Carribine	BCUHB
Kirsty Watson	BCUHB
Lesley Singleton	BCUHB
Sian George	BCUHB
Stewart White	Bevris Support
Mandy Tilston-Viney	Cartrefi Cymru Cooperative Ltd
Ann Hipkiss	Castell Ventures
Rona Lewis	Coleg Meirion Dwyfor
Eleri Saunders Davies	Coleg Meirion Dwyfor
Catherine Thornton	Conwy Connect
Claire Lister	Conwy County Borough Council
Fiona Dennison	Conwy County Borough Council
Fiona Stevenson	Conwy County Borough Council
Angharad Tucker	Coptions Ltd
Cllr Arwel Roberts	Denbighshire County Council
Jeni Andrews	Denbighshire County Council
Jane Hulme	Erlas Victorian Walled Garden
Michael Jones	Flintshire County Council
Neil Ayling	Flintshire County Council
Bethan Evans	Gwynedd Council
Olwen Ellis Jones	Gwynedd Council
Beverley Wilkinson	Home Instead Senior Care
Greg Price	Just ONE
Jacqui Caldwell	LD Wales and other organisations
Kelly Jones	Mencap Cymru
Kathryn Taylor	MHC UK Ltd
Bethan Jones Edwards	NWSCWIC
John Williams	NWSCWIC
Sarah Bartlett	NWSCWIC
Deborah Clarke	Royal Mencap Society
Adelyn Ellis	Seren Ffestiniog Cyf
Rhianwen Jones	The Grange, St Asaph
Maria Cross	The National Autistic Society
Robert Bell	The National Autistic Society
Rod Waterfield	Waterfield Skills Centre

Alison Hay	Wrexham County Borough Council
Jennie Lewis	Gwynedd Learning Disability Transformation Group
Sharon Jones	Allied
Toni King	Allied
Nichaela Jones	BCUHB
Anna Edwards	BCUHB
Sarah Thomas	Centre of Sign Sight Sound
Roger Wilkinson	Home Instead
Helen Jones	Just One
Carol Davies	Procure Wales Limited
Matt Coniton	Prospects
Sarah Zielonka	PSS
Tracy Davies	Tyddyn Mon
Neil Lynch	Tyddyn Mon

Apologies

Jane Roberts	Anheddau
Sharon Burke	Anheddau Cyf
Elaine BaileyJohn	Autism Initiatives
Patricia King	BCUHB
Neil Ryder	Cartref Ni
Tracy Peers	Cartref Ni
Jane McDonald	Conwy County Borough Council
Paul Mazurek	Denbighshire County Council
Lisa Williams	DVSC
Matt Thomas	Flintshire County Council
Warwick Allan	Home Instead Senior Care
Annette Hewitson	Lifeways
Dewi Ward	Mencap Cymru
Helen Gilbert	MHC UK Ltd
Helga Uckermann	NWAAA
Kathy Slinn	NWAAA
Maria Bell	NWSCWIC
Trevor Hughes	Plas Garnedd Care Ltd
Sarah Prescott	Procure Wales Limited
Frances Adams	Prospects
Tina James	Prospects
Linda Jones	Seren Ffestiniog Cyf
Audra West	The Moorlands
Lorna Laws	The Moorlands
Angela Godsmark	Voyage Care
Karen Flynn	Wrexham County Borough Council
Heather Henry	Wrexham County Borough Council
Julie Trematick	Wrexham County Borough Council