



North Wales **Together**  
Gogledd Cymru **Gyda'n Gilydd**

*Seamless services for people with Learning Disabilities*  
*Gwasanaethau ddi-dori i bobl ag Anableddau Dysgu*

# Children and Young People Event Evaluation Report





Photo taken by permission of the volunteers from the Denbigh Children's Centre

#### SOME QUOTES FROM THE DAY

Find out about me!

Being helped to make my own decisions!

Someone I can trust!

Happy, smiling faces, jokes, good sense of humour

**BEING ALLOWED TO GROW UP!**

My needs, wants, likes, dislikes and preferences are understood!

**Event:** Children's Event  
**Date:** Thursday 17<sup>th</sup> October, 2019  
**Venue:** Conwy Business Centre, Llandudno Junction  
**Attendees:** Registered via Eventbrite: 110  
Attended on the day: 120

## 1. Introduction

The following report provides a brief overview of the background, and format of the Childrens and Young People's event and an analysis of the feedback received from participants.

## 2. Background:

- 2.1 Following the launch event for the Learning Disability Transformation Programme in June 2019, and in discussion with the Heads of Childrens Services, it was agreed to run a further event with a specific focus on children and young people with learning disabilities.
- 2.2 In the shift to a preventative health and social care framework, getting it right for children and young people is of critical importance. The event was thus aimed at families and the people and services who work with children and families in order to provide them with the opportunity to find out more about the Learning Disability Transformation Programme; to get involved and to explore in more detail the issues highlighted in relation to children and young people in the ***North Wales Learning Disability Strategy***.
- 2.3 By also involving both the Children's Transformation Project and the ALN Transformation Project, the event provided a further opportunity for participants to find out more about these programmes and to explore areas of synergy.

## 3. Co-production of the event

- 3.1 To ensure the format and the content of the event would address the interests and concerns of all stakeholders, the event was co-produced by the Learning Disability Transformation Team, The Children Transformation Team, Flintshire Children's Services, Denbigh and Conwy Children and Adolescent Learning Disability Service (CALDS) and Angelsey Childrens disability Service. This helped to ensure that the day included 'something for everyone', families, young people and professionals.
- 3.2 A key focus of the day was the inclusion of 9 young people from the Denbighshire and Conwy CALDS Children's Centre who helped out as volunteers. Their presence and active involvement at the event, elevated the discussions on the day and highlighted the fundamental importance of tackling

the issues and barriers that prevent children and young people with learning disabilities from achieving their full potential in North Wales.

3.3 Including the young people, and working together to organise the event, also highlighted that co-production is at the heart of the Learning Disability Transformation Project and that we can achieve more when we work together in equal partnership.

#### 4. Attendance and representation on the day

4.1 110 individuals registered for the event and on the day the event was attended 120 people with a good mix of parents, children with learning disabilities, health and social care professionals.

4.2 It was noted however, by many attendees that colleagues from education were under-represented on the day.

#### 5. Format

5.1 The event was structured around a number of presentations in the morning followed by four interactive workshops. It was jointly compered by Kathryn Whitfield, Programme Manager for North Wales Together and Fon Roberts, Head of Children's Services, Anglesey County Council.

5.2 In the morning, participants heard from the following:

- A welcome video made by the volunteers from the Denbigh Children's Centre/ CALDS team and introduced by one of the young people, Scott Parry
- Opening remarks and setting the scene from Nicola Stubbins, Director of Social Services, Denbighshire County Council and host for the Children's Transformation Project and Sally Holland, the Children's Commissioner for Wales.
- Overview of the Learning Disability Transformation Programme and a short video about the programme by Kathryn Whitfield and Fon Roberts
- An overview of the Children's Transformation Project from Sharon Hinchcliffe, Programme Manager.
- A joint input on ***being person centred – a journey through transition*** jointly presented by Annemarie McNally (parent) and Mark John-Williams (Link officer for Wrexham)
- Introduction to Measuring the Mountain (<http://mtm.wales/>) from Katie Cooke.
- And accessible music workshop videos presented by Scott Parry.

**The following videos can be found on our website by clicking on the following <https://northwalestogether.org/videos/>**

- Welcome Video from the Young People (Denbigh Children's Centre/ CALDS)
- Welcome video from Sally Holland, Children's Commissioner for Wales
- Shane the Sheepdog Video

The Musaic Minds Videos made by the Denbigh Children’s Centre can be found on their YouTube channel:

<https://www.youtube.com/channel/UC5GPdAOst-dTKrJZbKG0XhQ>

5.3 During the break participants had the opportunity to reflect on and record their feedback on 4 key questions on a **Talking Wall**:

- How can we help people before, during and after they have been told their child has a learning disability?
- How can we help give young people good skills while they are growing up?
- How can we help make short breaks better for everyone?
- How can we help make the change between being a child and being an adult easier for everyone?

5.4 Following the lunch break, during which participants were entertained by a series of Musaic Mind Videos created by the team and young people from CALDS, everyone had the opportunity to attend 2 of the following 4 workshops:

- Person Centred Planning - Supporting Children, young people and their families, to plan for and achieve a good life
- ALN and the new Individual Development Plan
- Good Support
- Assistive Technology

## 6. Key findings and feedback: The Talking Wall

6.1 The full record of all the feedback from the Talking Wall can be found in **Appendix 2**. The following highlights key messages and themes for each topic in the table below:

Topic	Key themes/ messages
How can we help people before, during and after they have been told their child has a learning disability?	<ul style="list-style-type: none"> <li>• <b>Communication and language:</b> the fundamental importance of professionals actively listening to parents, being honest and open and a having an understanding of the potential impact of a diagnosis. Being sensitive to cultural differences and Welsh language.</li> <li>• <b>Tiered support on offer pre and post-diagnosis:</b> as well as education for parents. Strong theme was the importance and role that <b>peer support groups</b> could play as well as having educational workshops in the community. And quick access to specialist support when needed.</li> </ul>

Topic	Key themes/ messages
	<ul style="list-style-type: none"> <li>• The feedback made it clear that people don't always want to use specialist services but do need help to find out what support and information is there in the community.</li> </ul>
Short breaks	<ul style="list-style-type: none"> <li>• <b>More availability</b>, variety and flexibility needed especially to prevent crisis escalation.</li> <li>• <b>Simplify the system</b> for accessing short breaks.</li> <li>• <b>Co-produce</b> options with families</li> </ul>
Skills for young people	<ul style="list-style-type: none"> <li>• <b>Start earlier</b> and be creative and holistic in approach – many people highlighted the importance of teaching young people skills to enable them to be independent. E.g., budgeting, cleaning, cooking and link this to transition to becoming an adult and living independently in the community.</li> <li>• <b>Co-produce individual skills</b> plans with young people and use peer mentoring approaches e.g., buddy up with young person from mainstream school</li> <li>• Take <b>positive risks</b> so that young people are challenged to reach their potential.</li> <li>• <b>Explore the use of different media</b> to support skills development as this can be more engaging/accessible.</li> </ul>
The change from being a young person to an adult	<ul style="list-style-type: none"> <li>• <b>Start planning earlier</b> with a focus on both the child and the parents/carers/families. This needs to include preparing in the case where the young person may not meet the thresholds for adult LD services especially health e.g., IQ and include adult services – more reach down and up between adults and children's.</li> <li>• <b>Create a dedicated transition service</b> that works with <i>all young people and their families</i> to make sure no-one falls off the edge of a cliff. i.e., services should not just disappear when a child reaches 18</li> <li>• <b>As per above, ensure there is a core focus on transition for children with more complex needs</b> as the transition can be particularly complicated.</li> <li>• <b>Early planning</b> can enable more young people to stay at home/ in their community versus going to residential college/ placements. This must involve the family in</li> </ul>

Topic	Key themes/ messages
	co-producing the plan and setting realistic expectations around service provision.

## 7. Key findings and messages: the workshops

7.1 Feedback was not provided by the Person Centred Planning Workshop as its focus was more practical than consultative in nature.

### I. ALN Tribunal Act and the role of the Individual Development Plan workshop.

- The workshop provided people with an overview of The Additional Learning Needs and Education Tribunal (Wales) Act 2018 with a specific focus on the key role of the new Individual Development Plan (IDP).
- In small groups discussion took place on people's view of the strength, weakness, challenges and opportunities that the Act and the IPD would bring.
- Overall people in the workshop felt that the Act and the IDP provided an opportunity for a refreshed and more coherent approach to how agencies work together with a focus on achieving the outcomes that matter to young people.
- Concerns were raised in relation to the current capacity of 'universal provision' to adequately meet the needs of children not eligible for an IDP AND the management of expectations at key transition points e.g., education to adult social services.

**Key messages are highlighted below (See Appendix 3 for full feedback)**

<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>• One plan that has the child at the centre and what is important to them i.e., their personal profile</li> <li>• That it is portable and moves with the child versus current system of multiple plans</li> <li>• Tool to promote better inter-agency working and coordination, key information all in one place</li> <li>• Makes it clear who is involved in supporting the child, their role and their responsibilities.</li> </ul>	<p><b>Weaknesses</b></p> <ul style="list-style-type: none"> <li>• In terms of the act, concerns were raised about universal provision as it currently exists and its capacity to meet the educational and support needs of children not eligible for an IDP. There are variations across the schools in this respect e.g., postcode lottery.</li> <li>• Concerns raised that some children currently in scope in the current system, will become ineligible for an IDP</li> <li>• Whilst welcome, there were also concerns about the capacity of the current system to deliver fully on the act without new resources. Feeling that the current system is stretched with families having the battle for resources. Will the IPD just be an overlay on this?</li> <li>• Potential to raise expectations of families that services cannot meet i.e., support packages and thereby lead to an increase in tribunal cases.</li> </ul>
<p><b>Opportunities</b></p> <ul style="list-style-type: none"> <li>• Improve multi-agency working with children and families at the centre.</li> <li>• Develop more consistency between schools and services in and between counties</li> <li>• Have a longer term, more aspirational plan for children within a co-productive approach</li> <li>• Increasing eligibility to 25 provides an opportunity to align services</li> <li>• Develop a more wide spread offer of education – day centres etc. so young person can gain qualifications in a work place – thus allowing the IDP to cover up to 25.</li> </ul>	<p><b>Challenges</b></p> <ul style="list-style-type: none"> <li>• The parents are driving this at present. This needs to change. IDP should be done all together not separately. Capacity issue for services.</li> <li>• Transition from children to adult's health services not in line with Act and does not factor in eligibility requirements for access the health LD services and funding.</li> <li>• Advocacy – thin on the ground, detective work, funded by LA / conflict of interest, quality of existing services</li> <li>• To get all relevant persons at the review / paperwork in on time/ time to undertake reviews</li> <li>• May challenge relationships between parents / placements re. expectations when transitioning from education to social services.</li> </ul>



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## II. Assistive Technology workshop:

- The key message from the workshop is that assistive technology should be a core part of the support options available but at present it is an afterthought or an add-on.
- People liked the equipment and the apps they saw in the workshop and could recognise the potential. They had an awareness of Assistive Technology but mainly in relation to traditional solutions.
- Concerns were raised around the reliability and affordability and they would like the opportunity to try equipment before they buy it.

## III. Good support workshop

- This workshop was interactive in nature and discussions in small groups took place around 3 key questions:
  - What does good support look like?
  - What is currently working well?
  - What's not working well? (full feedback can be seen in Appendix 4)

What would make things work even better? <b>Topic</b>	<b>Key messages/ learning</b>
<b>What does good support look like?</b>	<ul style="list-style-type: none"> <li>• Puts the person at the centre ('has to work for me')</li> <li>• Outcome focussed</li> <li>• Consistent and reliable</li> <li>• Allows for positive risk taking</li> </ul>
<b>What is working well?</b>	<ul style="list-style-type: none"> <li>• Lifespan approaches to service models e.g., 3 social work teams are now 0-25 years.</li> <li>• Co-location of children's health and social services teams</li> <li>• Pooling of direct payments and having them coordinated in one place</li> </ul>
<b>What is not working well</b>	<ul style="list-style-type: none"> <li>• Eligibility for health LD service is based on IQ rather than assessed need.</li> <li>• Lack of consistency and coordination between health, education and social services.</li> <li>• Bounce culture between services both in terms of accessibility, eligibility and funding</li> <li>• Short term funding/ investment</li> <li>• Direct payments i.e., charging policy; recruitment of PAs big issue, capacity of individuals and families to act as an employer.</li> <li>• Big gap in relation to LGBT and service provision meeting their needs.</li> <li>• Big jump in culture and support levels from children's to adults – need to focus more on early preparation for this change and helping families and young people manage expectations.</li> <li>• Staff shortages/ recruitment issues.</li> </ul>
<b>What would make it even better</b>	<ul style="list-style-type: none"> <li>• If all service models were consistent e.g., lifespan in approach making the transition from children to adults more seamless</li> <li>• Integrated approaches between children's health and social work services.</li> <li>• More honest and open communication between services and families especially in relation to managing expectations.</li> <li>• Re-align services so that <i>eligibility</i> is based on need versus IQ.</li> <li>• Coordinating posts/ roles valued by families and young people – help to navigate system.</li> <li>• Young people <b><i>being allowed to grow up</i></b>; take positive risks and be challenged so as to reach their potential.</li> </ul>

## **8. Conclusion**

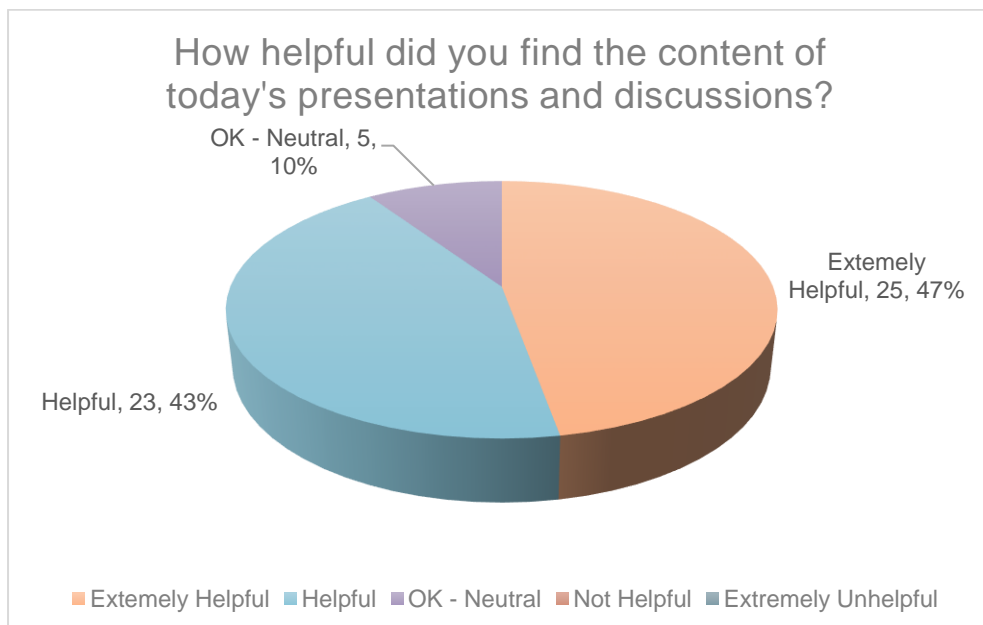
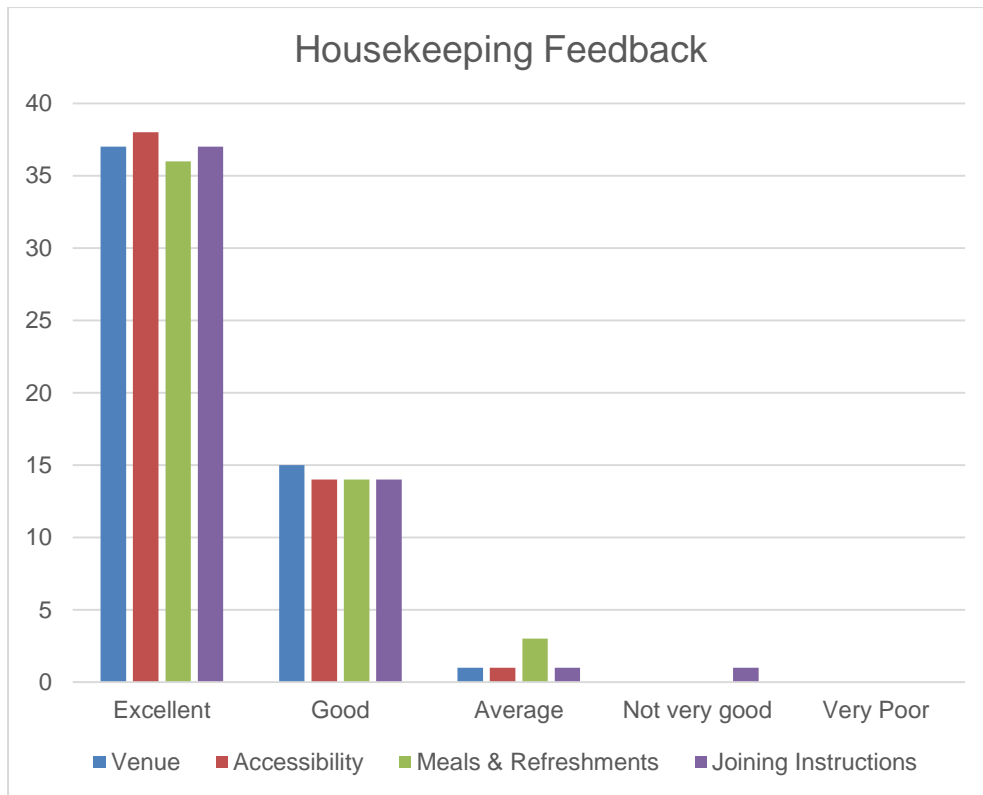
- 8.1 **Feedback from the event suggests it was a success**, attended by many people from Health and Social Services from across the region. Some areas were more highly represented than others.
- 8.2 It was noted throughout the day that there was a lack of representation from education services. It would be useful to assess if this was down to not receiving an invitation or lack of engagement. The invitation went to all senior managers in children's with a request for it to be cascaded, so we can't assess how effective the cascade was.
- 8.3 Feedback has been very good with the majority of delegates confirming it was a useful day, where their knowledge had increased. Many delegates also cited the value of these regional events to network across region and find out what others are doing.
- 8.4 Many people commended on the feedback sheets that they absolutely loved the young people's input into the day and having them involved. It had an inclusive feel and reminded everyone why we are trying to improve services.
- 8.5 Overall feedback for the workshops was very positive, however many cited they were over too soon and more time for discussions would have been valuable.
- 8.6 Another learning point is having more presentations/ presenters in Welsh and more Welsh discussions in the workshop. There was also no Welsh evaluation form, which was down to last minute changes to the form and no time for translation, therefore is a learning point for the team.

## **9. What happens next?**

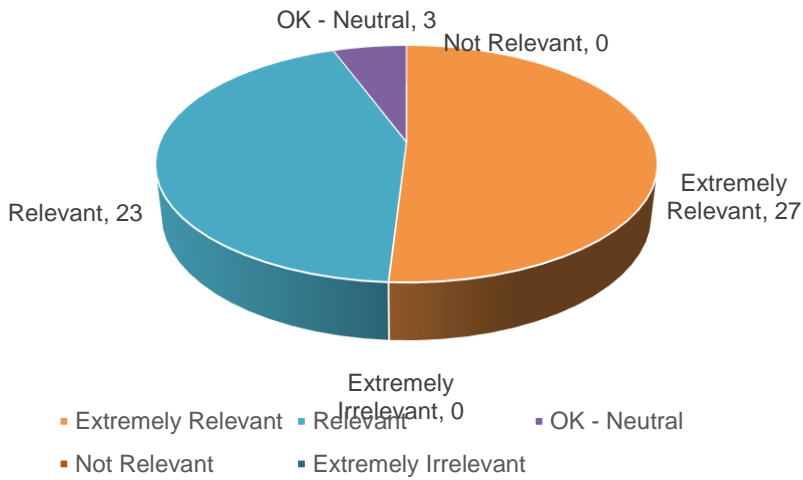
- 9.1 The Programme Team is currently agreeing delivery priorities with all its partners. The feedback from the event will be used to inform these priorities and also provide an evidence base.
- 9.2 The Learning Disability Transformation Team will also be working closely together with the Heads of Children's Services, the ALN Transformation and Children and Young People's Transformation Teams to address and find solutions for those issues that are cross-cutting in nature including:
- Pre and post diagnostic support and education for families in the community
  - Improving the transition from children's to adult services in general, for those with PMLD, and in light of the pending ALN Tribunal Act.
  - Better engagement in the transformation agenda from education
- 9.3 This report will be made widely available to participants and other stakeholder in a bi-lingual format and in easy read.

## 10. Evaluation Responses

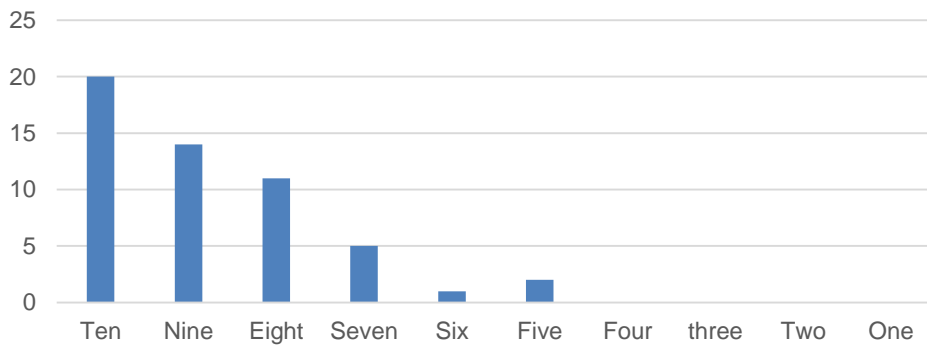
Evaluation forms completed: 53



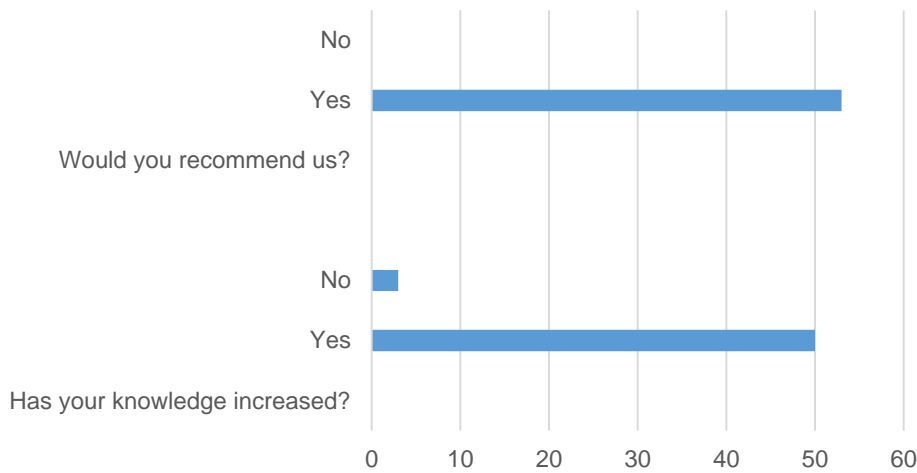
### How relevant was the content to your work?



### How would you rate your overall experience of the Children's event? (10 highest)



### Has your knowledge increased and would you recommend us?



## Appendix 1

### Written Feedback

Here are some of the comments on the feedback forms.

#### 1. What has been the most valuable part of today's programme?

- Networking / Connecting with others/ Networking across region
- The young people being involved/ Young people and parents presence and participation
- Videos and sharing of experiences
- Learning about the strategy
- Learning about different services
- As a parent it was useful to meet and talk to people providing services and working on the front line and learn of the challenges that they face. It was good to be heard – I hope that this results in some actions
- Learning about assistive technology
- ALN legislation information group
- Have collected some stories for measuring the mountain
- Listening to people and doing what is best for the child

#### 2. What message have you taken away from the event?

- The importance of early person centred planning/ real PCP is needed to support young people/ Putting the person at the centre of their care
- The importance of working together to support young people with LD
- What "good" support looks like?
- Learnt a lot about work which is on-going
- Integration of services
- The importance of listening to the child's needs and wants
- Importance of creativity
- Consistency is key
- Positive forward thinking
- The messages from all the social care sector seem to be very similar – people have to be at the heart of everything
- Importance of seamless services/ Co-working across services is very important – good to hear what is going on across counties
- Services criteria/eligibility and the frustration it causes for families
- Listening to young people and their families, respect them, their individual needs and wants
- It was good to acknowledge that things are not where they should be. We now need actions in finding and implementing solutions.
- Health and education don't link and this worries me

#### 3. Is there anything else we can do or ask someone to do?

- We would like more activities that are access for young people with LD
- Work with community groups so they can involve & enable people to be a part of their community
- Draw on other establishments resources & expertise e.g. universities
- Early support to manage behaviours i.e. 'hands on' support
- Out of office hours – crisis service/ A crisis service for the hours other than 9-5 Mon- Fri for advice and 'hands-on' help and support for behaviours and the management of them.
- Integrated crisis pathway for breakdown situations and impending crisis situations
- Recognise the different challenges for people with PMLD and don't lose them under the umbrella of LD. See the core and essential service standards for people with PMLD (at PMLD link online)
- Support for parents to understand the needs and potential of their child whilst coming to terms with diagnosis
- Look at how we can provide support for vulnerable children who do not fall into 'labelled services'
- Adult services to offer long term solutions not just short bursts of input – sticking a plaster on is not good enough
- Adult services talk to child services!
- Have more links with the theatre and music world
- Look at all the things we can do already without extra funding
- Change the language, e.g. 'service user' = person we support etc.
- We need to think about inequality of access to services due to language barriers in North Wales (other languages in addition to Welsh e.g. Polish etc.)
- Work better & improve communication between agencies/ better communication between children's services and adults services

**4. Is there anything you would like noted for future events/ anything we can improve on?**

- Really good day bringing diverse people together. Loved hearing family stories. I really hope we are able to make positive changes in the next few years.
- To consider the complex needs cohort. Not all with SLF are ambulant and verbal.
- I feel that Education would benefit from attending future events
- We could have invited more children and young people from other counties
- We need to ensure key stakeholders are present
- More time for the workshops
- Invite more parents and make the events more available to all
- Education services need to be on-board and present at events
- More parents sharing experiences
- Can we have an update with regards to improvements
- Would have been great to hear more children/young people talking about what matters to them

- Would have been more useful to have more gadgets on show in the assistive technology workshop
- The welcome from the young people was fantastic – more of this please!!
- Workshops felt a bit rushed
- Would have been great to see other services having stalls at the event
- More workshops
- More presentations could be delivered in Welsh
- Lack of Welsh in the workshops
- We could work with all disabilities
- Less text book/more real.
- More content around complex needs



## Appendix 2: Feedback from the Wall

How can we help people before, during and after they have been told their child has a learning disability?

- Psychoeducation – develop YP skills in looking after their own emotional wellbeing – what does LD mean for children/for carers/parents – How parents/carers can look after themselves
- Family hubs
- Listen, have awareness
- Parents feel empowered to be the parent their child needs
- Give parents opportunity to process and meet soon afterwards to answer any questions
- Diagnosis itself should not be traumatic, it should be a gentle process of understanding
- Provide specialist advice post diagnosis – often left with nothing
- Easier, quicker referral process to LD services such as Derwen/SCS
- Awareness of services out there
- Listen to family and individuals
- Increased social services presence for pre-school children, not just at times of crisis
- Offer access to groups after diagnosis
- Listen and let people know how they can speak and share with other parents
- Sensitive communication
- Link to families who have gone through this for support, informally & formally, e.g. buddies/family groups
- Increased resources in pre-school services
- Counselling, time to talk
- Provision of information
- Provide a contact for when they need – helpline
- Meet with other families
- Genetic counselling to be invested in for parents/children
- Family support & skills workshops/training for parents & cares which involves service users
- Speak the family language
- Co-location of staff & family workers, therapy groups etc.
- Friendly buildings so families see staff and staff see families
- Give parents an equal seat at the table and listen to the parent=expert
- Access to parent support groups
- Access to counselling
- Get to know them – be aware of their stage of understanding and what is important to them
- Support with the specific things they ask for, when they ask
- Honest & open
- Understand the family culture
- More robust post-diagnostic support from health, particularly re neurodevelopmental diagnosis

- Seamless! Respecting their journey
- Put them in touch with other families who have been through same/similar situation – parent support groups
- Don't be dismissive
- More robust support from all agencies

How can we help give young people good skills while they are growing up?

- Time, patience and opportunity to be creative
- More early intervention focused on skills
- More resources so not having to focus on crisis
- Working with other agencies
- Include 'independent living skills' as part of their care plan/personal plan
- Include budgeting, opening a bank account, cleaning, keeping a space/home
- Link training in with community support/transition service for 1yr-6mths from 18+ to help with Independent Living and any pitfalls/obstacles
- Create own 1 page profile which is 'live' and changes
- Integrated services, early intervention, pro-active
- Encourage having own voice
- Ongoing services involving parents – intensive in initial years, then all issues in school & parents are less involved
- Not be too risk adverse
- Be creative about housing & support options
- Start planning early
- Help them keep their friendships
- Follow their interests
- Reduce our insistence on sitting at tables
- Be flexible and creative with our support – one size doesn't fit all
- Seamless
- Learn for life, love and interest, not a standard curriculum
- Use different media for learning, video etc. much more accessible for many people
- Linguistically appropriate services
- Flexible
- Include them in all decisions, give them a voice and act upon their wishes
- Peer support from YP in mainstream schools
- Have individualised skill plans
- Practical skills in schools
- Promote and respect the attachment/relationship between child & parents
- Positive risk taking to meet peoples potential
- Focus on practical skills for independent living
- Accept their differences – they are not all the same
- Involvement in community activities to build a circle
- Not being risk adverse

How can we help make the change between being a child and being an adult easier for everyone?

- Early planning led by Young person
- Greater planning & links with 'older' youngsters to get ideas
- Have a more seamless service earlier on i.e. from 14 onwards
- Transition for complex health needs liaison between children's ward & adult A&E & GP to build up relationships as parents are 'left' at 16-19
- Children with mild or no LD LD diagnosis receive service but get nothing once in adult services
- Don't see my child/adult as a £ sign
- Ensure health are able to complete timely assessment
- Budgetary skills
- One page profile by young person which is 'live'
- Loose the focus on segregated 'special colleges' and think about developments in local communities
- Improve information about services & decision making processes for children and parents
- Support positive risk – let people live their lives
- Clear pathways – graduated approach – time to make sure its gone/going well
- Break down barriers within health directorate – service in health is 14-15 (agreed with twice over)
- Having a PA
- Early preparation – preparing young people & also their parents/carers/families
- Better co-working between children & adults services
- A service/team specifically for transition?
- Preparation needs to be graduated & well planned with clients and families supported & involved at all steps
- Better co working between services – transition teams?
- Start early – concentrate on the child, not money
- Schools need to enable children more to develop skills so transition to adult life is more prepared for
- More integrated communication
- Starting the transition earlier
- Transition team in place?
- Designated transition service for all children as well as those with LD, looking at all the community services listed; GP, optician, housing etc for a period of 6 months-1year, guiding them through
- Services should not just disappear when a child/YP passes a chronological age – seamless changes would be more beneficial
- No false promises
- Complex children coming through, families need specialist workshops and knowledge
- A named family assistant who liaises with family & other professionals & facilities
- Better joint working between adult & children's services with clearly identified time scales to prevent rushed and poorly planned transition
- More resources so adult/children's services can work together early on
- Years ago children/adults were on the same team – less transition issues
- Same criteria, joint working, all agencies

- Services to promote continuity e.g. 0-25 services such as C2A FCC
- Meeting staff before the age of 18
- They should be gradual, gentle, when the person is ready – as happens when a YP does not have a LD
- Predictable
- Know if will be there from pre/early adolescence
- Social gatherings/open sessions to meet young people in adult services & staff
- Better communication with Education
- Start early and involve appropriate professionals, family & young person all the way

Specific feedback on transition from the volunteer/children's group;

- Learn to go to college
- Learn to cook
- What do we do when we leave school?
- Going into the community on my own
- Learning to live on my own
- Going shopping
- Paying bills
- How to get a job
- I want to learn about;
  - Going to college
  - Going to work
  - About haircuts and working in the hairdressers and learning how to cut peoples hair and working in the café that is there

How can we help make Short Breaks better for everyone?

- First – provide them!
- Provide the money so my son can decide what short break he wants
- A wider variety of options for short breaks
- Have them in local people's homes
- A better variety of placement
- Having crisis/emergency placements available
- They need to be considered before things escalate to crisis
- Flexibility
- Varying lengths and intensities of activities
- Easily available, timely, simplified system
- Services working together to fund
- Listening to families and what they want rather than what is there
- They need to be timely – when needed
- Enjoyable, fun, a holiday
- Preferable in county or ideally same country! (NOT England)
- More respite options and more frequent & flexible
- Regular, flexible and local

- More flexible, longer, more frequent
- Care packages need to be flexible to meet family needs as and when, not restricted by contracts
- At home respite that enables children to stay in familiar surroundings and the parent to have break away
- More accessible
- More choice based on individual choice & need rather than fitting them into existing provision, often resulting in limited break or delay in receiving it
- Parents often feel they still need to be at the end of the phone during the break – this is not a break!
- More facilities available and shortening waiting lists from 18 months!!
- Respite accessible for all
- Take children to fun places and do exciting activities
- Short break carers trained in disability
- More funding for carers
- Bespoke

### Appendix 3: Feedback from ALN Workshops

Strengths	Weakness
<ul style="list-style-type: none"> <li>• Consistency and integrated working across sectors</li> <li>• Continuity</li> <li>• Communication</li> <li>• Shared Knowledge</li> <li>• One plan – understanding the child better</li> <li>• Provide information on where to get support from</li> <li>• Child and parent listened to more</li> <li>• Having technology</li> <li>• Fairer</li> <li>• Less meetings to attend (parents)</li> <li>• Child is more involved</li> <li>• Up to 25 years old</li> <li>• Like One Page Profile</li> <li>• Strong links, ownership between MHS, LD, LA Services</li> <li>• Focuses on person’s needs / function rather than diagnosis</li> <li>• Person centred focus – focus on citizen</li> <li>• Early identification (current system flawed)</li> <li>• Fix some of the gaps e.g eligibility criteria for LD</li> <li>• More visual document rather than the Statement alone – prefer that it is person centred, gives the young person a voice.</li> <li>• Young adults can take this with them to college</li> <li>• Makes sense / easy to understand</li> <li>• Parent’s views are listened to and offer solutions</li> <li>• Outcomes section is good</li> <li>• Children involved with the One Page Profile</li> </ul>	<ul style="list-style-type: none"> <li>• Capacity to attend meetings</li> <li>• Where meetings are held</li> <li>• Some children might not receive the support they currently receive</li> <li>• Nothing on this about work, independent living.</li> <li>• Link with MH plan? CTP (Care and Treatment Plan) works well.</li> <li>• Form is very bureaucratic / not easy to read / too formal / not very interactive</li> <li>• Who is the form for? Wording very clinical.</li> <li>• Those on first level (universal??) who will monitor their needs, variations across schools in terms of provision / inclusion.</li> <li>• Worry about universal provision and this level. How will this be addressed as part of the Act?</li> <li>• Will children with Learning Disabilities miss out?</li> <li>• How will it work Post-18 / Universities – how does it link?</li> <li>• Time constraint – unable to be truly person centred.</li> <li>• Can become process driven with new forms</li> <li>• Current IT systems not accessible to all</li> <li>• Could be construed as a ‘wish list’</li> <li>• Increase in tribunal cases is potential</li> <li>• Will the Act bring resources – services can struggle at the moment e.g. education – resources and time.</li> <li>• Will it address battleground for services / resources e.g. ASD?</li> <li>• The IDP ends when the child leaves ‘education’, which is typically 22, IDP doesn’t necessarily end at 25. What constitutes ‘education’?</li> <li>• Technical access (Gwynedd) – Parents find the process really difficult – passcodes / contacting school etc.</li> </ul>

Strengths	Weakness
	<ul style="list-style-type: none"> <li>• Format of the form is open to interpretation</li> <li>• One page profiles need to be more detailed</li> <li>• People are confused about what part of the process they should do.</li> </ul>
Opportunities	Challenges
<ul style="list-style-type: none"> <li>• Meet the child's outcomes quicker</li> <li>• Meet up with all involved – more input</li> <li>• Look at links with MH CTP as working well</li> <li>• Focus on long term aspirations e.g. work / independent living</li> <li>• Co-design IDP with families</li> <li>• To develop consistency between school / LAs</li> <li>• Proactively involve children, young people and families</li> <li>• Multi-agency working</li> <li>• Continuity between provisions</li> <li>• To educate and support parents / carers</li> <li>• A training cascade to multi-agencies – Health and social care approach.</li> <li>• Move away from silos – more integrated.</li> <li>• Focus on Early Years increased.</li> <li>• Taking the IDP across education up to 25 allows the opportunity to standardise other agencies – social services / health to increase to 25.</li> <li>• Develop a more wide spread offer of education – day centres etc so young person can gain qualifications in a work place – thus allowing the IDP to cover up to 25.</li> </ul>	<ul style="list-style-type: none"> <li>• Who is responsible for completing the form?</li> <li>• Hand written/typed – no access to a computer?</li> <li>• 0-25 does not fit in with ever service – how managed?</li> <li>• Fitting in with the Welsh Language Act</li> <li>• Advocacy – thin on the ground, detective work, funded by LA / conflict of interest, quality of existing services</li> <li>• No focus on diagnosis which is required to access some support / services within health</li> <li>• Inequality between service specialist mainstream school</li> <li>• To get all relevant persons at the review / paperwork in on time</li> <li>• Time to undertake reviews</li> <li>• Small provisions may struggle</li> <li>• Supposed to be cost neutral!!</li> <li>• May challenge relationships between parents / placements re. expectations</li> <li>• Access to resources</li> <li>• Health / Paediatrics – definition of which stops at 18 – CHC funding</li> <li>• HB in special measures</li> <li>• Current system is broken – how will this 'fix' it?</li> </ul>

## Appendix 4: Outputs from 'Support Workshop'

What does good support look like?

- Understand ME when it goes wrong
- Having a voice & control
- Continuity
- Positive risk management – support me to do what I want
- Flexible – changes with me
- Made to feel safe and valued
- Has to work for ME
- Consistency
- Learn new skills & opportunities
- Accountability is Key
- Reliability
- Realistic outcomes

What's working?

- Carer advisor – helps co-ordinate appointments etc.
- Under Derwen Specialist Children's services
- 1 DP system, condenses information as it goes along, all in one place
- Flexibility in the evenings, when not in school, buddies system in place
- *Refunds* for being on duty, L&D, ICF Funded
- Dedication of staff
- ICF Short term
- Direct payments
- Pooling of DPs to enable trips away
- 0-25 team in 3 of the areas, no 18 cliff edge (good journey feedback)
- Integrated children's teams in Health
- People with LD helping skill up GPs etc
- Derwen – grants – working with families that don't meet the criteria
- Linking up with other families post diagnosis

What's not working?

- IQ Thresholds – loss of specialist help when IQ assessed over 69
- Thresholds; if had physical disability alongside LD, would be able to access but if no physical disability, could not access
- Little consistency between W/SS/Education
- Workforce pressures
- Transition
- ICF long term, not permanent, services finish when money stops. Post code lottery
- Resources are limited
- Promises to parents that are not kept
- Consultation fatigue
- Direct payment recruitment – PAs can't be recruited
- Charging policy – reduces money available (only for adults – no charge)
- 1 to 1 support in the community, isolating & expensive, not good value



- Becoming an employer is not working
- Arguments between health, SC & Education
- 'Bounce' culture between services – the impact on the service user
- Poor communication between services
- Revolving door
- Health – health promotion etc
- Setting up a service that might fall away – limited grant funding
- Post diagnosis support – a booklet or internet is not enough
- No follow up appointments
- Too fixated on diagnosis
- Seamless services eq betwenn H & SS but also between teams Calds/etc
- Good networks
- DP
- Transition
- Flexibility
- Battles between families & decision makers
- IQ cut off is an issue
- LGBT
- Vacancies eg for psychology, constantly compromised, families get the brunt
- Co-ordinator posts – valuable co-ordinator posts, SS led (Rachel)
- Overwhelming to have too many people piling in
- Strain on staff when individuals go into crisis
- Involve people – accessible format to help people
- Support to take risks
- Do what we say we are going to do – its about trust

#### **What would make the support offer even better?**

- If all LA's were lifespan, dependency could be addressed as children get older
- Prevention & early intervention
- Integrated services
- Health & SS Boards
- Improve the profile of carer – we need to value carers
- Educating/engage young people in carers roles
- Better communication – integrated centralised system
- Not having to repeat
- Need continuity in the follow up – with signposting
- Better follow up process
- LGBT element of service needs to be developed
- Can we change age threshold across the area, lifespan, 0-25 across area
- Change IQ – make it needs based
- We had more resources
- If expectations of parents were more honestly managed
- We were able to capture views better

#### **Post-it notes**

- Take risks
- Be who I am
- Hands on support
- Child/YP being listened to
- Being allowed to grow up – become more independent
- YP being involved in finding solution
- Support to be team around the individual rather than other way round
- Supported to achieve what I want (child)
- Enabling YP to feel empowered
- Joined up working
- Know me
- Support friendships and relationships
- Involved less meetings
- Non judgemental
- Professional
- In common
- Someone who I can trust & engage with
- Consistent
- Who I want
- Reliable
- My age
- Patience
- Quality
- Continuity
- Timely
- Credibility
- Respectful
- Realistic
- Transparent
- Accessible
- Track record
- Relevant
- Choice
- Accessible
- Non judgemental
- Clear direction
- Inclusive – with modifications if required
- Evolving
- Realistic outcomes
- Respect
- Respectful of position & boundaries
- Flexibility
- No false promises
- Evolving & moving forward
- No question/comment is silly
- Professional
- Being listened to

- Honest both ways
- Holistic
- Realistic
- Consistency
- Like the things I like
- Being helped to make my own decision
- Being included
- Suited to my interests
- Adaptability
- They make me feel safe
- Confident in my being a person in my own right
- Being listened to
- Happy smiling faces, jokes, good sense of humour
- Accountability
- My needs, wants, likes, dislikes & preferences are understood
- Support being suited to my personality
- Family members
- They communicate in a way that I understand – language, Makaton, assistive communication
- Joined up, multi-agency, not in 'bits'
- Empowering & promotes independence
- Person centred
- Feels natural
- Approachable
- Friendly ☺
- Flexible & creative – thinking outside the box
- Someone who listens to me
- Thinking outside the box
- Reliable & dependable
- Having a choice
- Consistent
- Reliable
- ☺
- Fun
- Focuses on the individual and not on resources
- Confident approach
- Quality & efficiency
- Helps me, not do things for me
- Non judgemental