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NORTH WALES SOCIAL CARE AND WELL-BEING
SERVICES IMPROVEMENT COLLABORATIVE

North Wales Learning Disability Strategy: Local authority and health staff event

18 July 2018 at The Oriel, St Asaph

About the event

The event was part of the consultation on the learning disability strategy which has so far included:

- [North Wales Provider Forum Event 9 April 2018](#)
- Working with the North Wales Learning Disability Participation Group
- Online survey open from April to July 2018
- Group and individual interviews with people with learning disabilities and parents/carers and easy read questionnaire.
- Reviewing consultation findings from the North Wales Population Assessment

The invitation was circulated to local authority and health staff in both children's and adults' services in all six North Wales counties as well as to the Learning Disability Participation Group.

In total, 104 people attended the event from a variety of different services across North Wales. Four members of the Learning Disability Participation Group attended with support to give a presentation about their lived experience of health and social care services and two members stayed for the whole day. Simultaneous translation was provided by Catrin Gilkes.

Agenda for the day

- 9.30 Registration and refreshments
- 10.00 Welcome and introduction
- 10.15 Update on the consultation
- 10.45 Tea and coffee
- 11.00 Workshop 1
- 12.30 Lunch
- 13.30 Workshop 2
- 15.00 Tea and coffee
- 15.15 Presentation by members of the Learning Disability Participation Group
- 15.30 Feedback from workshops
- 16.00 Close

Introduction and presentations

Neil Ayling, Chief Officer for Flintshire County Council Social Services introduced the event and the vision, values and background to the strategy. Then Sarah Bartlett gave an update on the findings of the online survey and Emma Pugh gave an update from the North Wales Citizen's Panel (see appendix 1 for the slides).

In the first workshop, each group discussed one of the seven themes for the strategy, what needed to be done next and who needed to be involved. On each table was a poster including information already collected about the theme. After around 30 minutes the facilitators moved to the next group, gave a brief summary of the discussion so far and then continued the conversation about the theme. After another 30 minutes they moved again so each table discussed three themes.

In the second workshop, people chose a theme that they wanted to discuss and hadn't had chance to so far, then the groups were asked to come up with three priorities which were shared in feedback to the whole group.

Members of the Learning Disability Participation Group then gave a presentation about their lived experience of health and social care services. The first presentation was from Bryn and James from Denbighshire supported by Helga (see appendix 1 for the slides) who spoke about the importance of communication, respect, fairness and the need for more jobs, support and choices. Then Michelle from Conwy spoke about her experience with A&E. This included a long wait, doctors not having information about her specific needs, receiving a leaflet about head injury that was difficult to understand and feeling rushed. She said the traffic lights system would have helped along with staff training and having health liaison nurses available at A&E. Shayna gave examples of how self-advocacy had given her opportunities and a chance to change things and make a difference. Celia from Conwy Connect then gave an example from a manager of a person with learning disabilities who had been diagnosed with diabetes but not had the right support and advice to manage the condition leading to rapid weight loss.

Event feedback

Event feedback forms were filled in by 74 of the 104 people who attended. Of these, 92% said they found the event useful and 93% said they felt able to give their views. The comments included:

“A well organised event, good facilitators with the right approach. A very informative event. Good discussion groups with a willingness to share their experiences, knowledge and share information.”

“Good to meet different people, different counties.”

“Enjoyed the group work, listening to the views across all services. Discussions were open, honest and informed.”

“I enjoyed hearing from the participation groups and their thoughts on what is important.”

A few people commented that it would be good to include a wider range of people at the event including third and independent sector providers and that there weren't enough people with learning disabilities, staff from children's services, education or youth services, or representation from Welsh speakers. Unfortunately, not everyone invited was able to attend and due to the number of stakeholders involved it is difficult to bring everyone together at the same time in a meaningful way. Also a couple of people felt they were not comfortable sharing their views at an event like this. We'll continue to experiment with different approaches and consultation methods to address these points.

Feedback on the morning workshops was very positive with some mixed views about the afternoon, partly because of difficulties hearing and summarising the range of views into three key points. There was one comment that the day was too long and others that wanted more time for discussion to go more in-depth into the themes, discuss more of the themes and make links between them.

Practically, we need to make sure we make better use of the microphone in future so everyone can hear the feedback and ensure the venue provides more food for all-day events.

Some people raised concerns about how the findings from the event would be summarised and whether they would reflect the discussions. This report includes a summary of the findings from the day along with additional comments from the evaluation forms. This report along with a copy of the flipchart notes were circulated to facilitators and attendees for checking.

A few people highlighted that we need to make sure the discussions become actions and that things change as a result.

Event findings

Overall

- 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.

A good place to live

Priorities

- Developing assistive technology, knowledge and training around what is available. Use at a younger age. Involve families and education in making it part of daily life. Include readily available technology such as Alexa.
- Right accommodation and support must go together along with the right *joint* investment.
- Access to approved assessment facilities for adults and children which will inform future planning and development of right types of accommodation and services. There is currently no assessment and treatment unit for children which means they have to travel far out of the area. This would help avoid out of county placements as well as preventing over-provision.



Other ideas

- Learning disability mental health crisis placements closer to home particularly for younger people.
- Understand the expectations of young people and their families for the future. Include them in 'planning for the future' services and identify outcomes at a younger age. Provide support for families, education and transfer of skills.
- Understand the number of adults living with older carers and their future housing needs.
- Community living – share information, preparation, careful transition planning. Develop understanding around benefits, budgeting. 'Accommodation Guide' – works well, idea what to expect. Tenancy agreement – rules. Not just about appropriate housing but also about housing appropriately with other people. A poor match leads to placement breakdown which then leads to a loss of house. Need a designated matching services?
- Co-services – more information to others around individuals with learning disabilities. Look at residential care for individuals with learning disabilities. No discrimination.
- Invest for the future – understand future needs, work with housing. Need more respite care for people with profound and multiple learning disabilities due to demographic changes and increase in the number of individuals who need specialist care. Also need more respite care for children, especially Welsh language provision in Gwynedd. There are no residential colleges in county – do we need something like this in each county or would it risk a returning to a Bryn y Neuadd type model? Need for specialist nursing homes for young people with a learning disability and residential placements for older people with learning disabilities.
- Offer more choice. Not enough options of building/properties or where there is a range of options there's not the right capacity.
- There needs to be a way to not lose adapted houses after someone moves from it – a net loss when there has been an investment.
- Look at why we have to place people out of county, what's being provided and why can't we provide at home. Repatriation can become so difficult the person stays out of county.
- Community relationships – neighbours often don't know each other and aren't briefed about or introduced to the people with learning disabilities living close by. Would it help if the whole community was more aware?
- A regional framework for supported living is being developed.

Something to do

Suggest we also look at 'something to be', which is more about being ambitious for people and making sure they have a meaningful role. Add sport to this theme.



What can we do / priorities

- Share knowledge about what's already available within communities and support people to access them.
- Collect information about the number of people with learning disabilities in work across North Wales, good practice examples and lists of positive employers.

Other ideas

- Connect individuals with others sharing the same interests/experience. Individuals need support to do this. Professionals should focus on facilitating not doing. Recognise an individual's own strengths and skills that they can share. Produce one page profiles. Could use technology, set up website such as friendship co-operative, local area coordinators, community connects. For example, Flintshire Do IT / Recovery Champion. Look at buddy systems, inclusive club nights. Use our own skills, ideas, connections, resources and time to raise awareness.
- Build community, be creative and make connections for individuals so that when staff are not around those connections are still in places. Set up sessions for parents to keep in touch.
- Link person from local authority to take initial lead with making employment links. Share positive stories about how benefits and identify barriers to employing people with learning disabilities (perhaps with a questionnaire). Provide support for employers to take people on and/or apprenticeship schemes. Recognise that not everyone can do paid work (perhaps only 10% of the client group can), so need options of other meaningful activities based around what the person wants.
- Increase expectations and re-design what 'good' looks like – it shouldn't depend on one person.
- Support professionals to share information and knowledge across North Wales – suggestions include bulletins, information about summer holiday activities/grants to support children to attend
- Work with existing services such as Job Centres, leisure centres, VA services, sport. Make sure facilities are inclusive and address barriers to access, for example changing facilities in sports centres and cafes, transport, issues around impact on benefits of moving into paid work, direct payments, integrate activities and timetables. Good examples include fit steps, Active8 and +moves.

- Support people to make choices for themselves even if their families don't agree.
- Subtle aspects of life are important such as dressing well and make up.
- Specialist support for breaks, for example, 'care farms'.
- Sport: working with big sporting events to make a disability enabled group – try adapted programmes in athletic clubs; use learning disability sessions to raise funds for sports clubs, provide social opportunities and ways to integrate with the wider community.
- Make use of adapted facilities out of hours, including schools, hydrotherapy pools.
- Trio-day services – three in a house with support, different houses and different themes. Increasing accessibility and reducing cost.
- Provide employment opportunities for people with learning disabilities in mainstream hospitals to help all people find where they need to go.

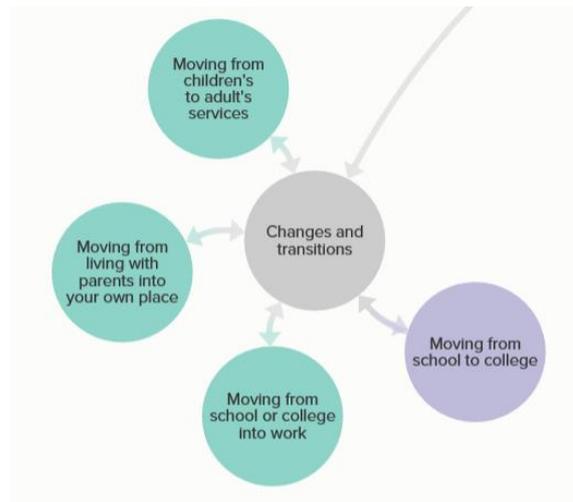
Also identified there's a gap for people who don't have severe learning disabilities but might have mental health problem and that we need to make sure people with profound and multiple learning disabilities are included.

Who needs to be involved?

- Need to identify key people/connectors in communities
- Looked after children coordinators
- Transition team
- Specialist providers
- All of us to use our own ideas/connections and resources.

The right support

1. Have consistent approach, consistent team and professionals involved throughout person's journey from child to retirement. Strong focus on advocacy for individual and parents/carers to provide support. Need accountability and governance to achieve goals. To achieve: pooled budgets, care coordination, co-production and resource for designated transition



- worker (nurse). Leads to improved communication / information sharing of what's available. Positive risk taking by knowing individual very well.
2. Skilled workforce – trained staff team. Importance of investing resource/funding to develop bespoke, mandatory learning disabilities training for all health care/local authority staff. Communication – Positive Behaviour Support. Value base – ASM.
3. Very important to be person focused/person centred. Idea to develop a portfolio 'this is me!' from child to adult. Photo based, focus on person's skills, aspirations and strengths to support future, jobs/college/independent living, real assets for transition and careers advice. Possible to invest in software package/technology.

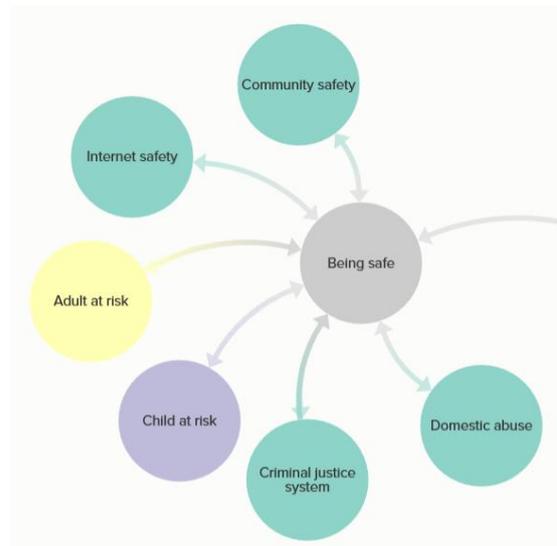
Other ideas

- Support parents to accept positive risk taking. Enable focus, time and resources for this (skill building), for example, around managing a tenancy. Help the individual realise that it's OK to want to move.
- Joined up working between agencies, such as Career's Wales's structure around school to college especially around funding agreements. Information in a timely manner around future planning – proactive!
- Role models and champions who have gone through the process who can share learning.
- Flexibility in support provided – issues such as working time directives. Need a choice of provider and staff, financial support and advice around direct payments.
- Equipment, aids and adaptations that promote independence, such as, telecare.
- Involve, individuals, parents / guardians, education agencies, multi-disciplinary working, adult services, children's services.

Being safe

Priorities: positive risk taking, culture change and information sharing

- Raise awareness of what can be expected from people with learning disabilities and take positive approach to life/risk. Skills assessment can maximise independence and minimise risk. Agencies, families and individuals should have outcome focussed actions in plans about positive risk taking. Develop systems for empowering carers (paid or unpaid) to take risks without fearing repercussions.
- Important to address the real risks rather than perceived in different environments. Acknowledge that the biggest risks are – road traffic (crossing the road) and abuse on social media *not* strangers. Build safety from basic awareness. OT involvement to educate all around basic areas of risk as well as more publicised vulnerabilities. For example, falls, choking and wandering often overlooked risks. Also how to identify risks when people live alone such as overmedicating – links with GPs. Review use of 2 to 1 to manage risk by working with providers.
- How do we get to a stage where people with learning disabilities can do normal things like going for a pint? Accept consequences of getting drunk when normal for peer group so shouldn't trigger safeguarding investigations if, for example, they fall and hit their head.
- Use telecare to minimise risks. Information sharing campaign about what telecare is, what it can do and how we keep up with it.
- Financial, sexual, physical and emotional abuse awareness. Education around safeguarding, acceptable relationships, rights and risks. Could identify specific groups to target.
- Provide support with knowing what relationships are and what they should be like – what wrong and right look like. Enable teenagers to have relationships and help them manage risks. A realistic assessment of risks can reduce intrusion, for example, with sexual relationships
- Our citizens can also cause risk (and therefore be vulnerable). Need better processes for assessing this risk and work with the criminal justice system.
- Support for families: carers will often fear changing arrangements or going against previous advice. Give parents reassurance that moving out is going to end well. Let them talk to other parents who have been through it and are. Sharing experiences of how the individual got from A to B.



- Give individuals with learning disabilities the confidence to join mainstream groups. Overcome requirement for 1:1 support, for example, for girl to join Brownies. Not always necessary – challenge assumptions.
- Give all children and young people the experience of playing, learning and networking with children with learning disabilities. Encourage familiarity and don't single out. Start young as differences don't matter to children and integrate wherever possible. More work on friendships and citizenships in school. Work with schools and youth groups to promote group safety.
- Let people develop natural networks for natural protection – not always about paid support. Link to 'local area co-ordinators'. Relational security is important for people to feel safe.
- Information sharing: need a way to record and encourage third party reporting – making it convenient / accessible to report concerns. Directory of people to contact and resources to access - need to know who to contact in order to feel safe. Library of resources on relevant topics.
- Communication and resources need to be in the right format for the person. Involve the people who support them (providers and families) so they can remind them. Start early and build on training across life span.
- Internet safety and social media – joint working with police – early intervention / prevention at schools – latest information shared with professionals so we know what to look out for.
- Encourage communities to accept that people with learning disabilities need to experience normal activities and take risks. Work with voluntary organisations. Promote 'safe places', 'dementia friendly' communities, 'learning disabilities friendly' communities. Training for all providers to have an understanding of learning disabilities.
- Safe places: currently up and running in Wrexham. Venues are trained to deal with issues and pay to be involved. Information around this needs to be shared with other areas/accessible information.

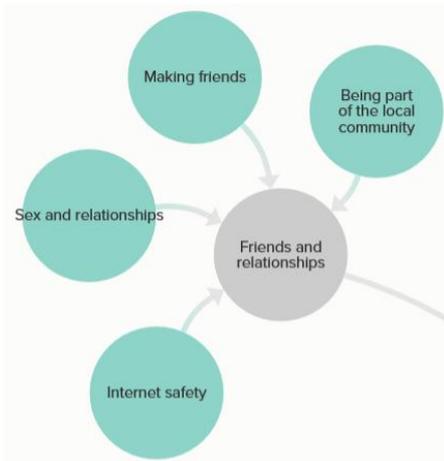
Who needs to be involved?

- Individual concerned - needs to be person centred
- PCSO's and Police (link with community safety)
- Education – across mainstream, special needs
- Dangerpoint
- Charities / funding resources
- Providers
- Multi-agency involvement
- Family input
- Service user groups
- Community involvement
- School nurses
- Make links with public transport and taxis.

Friends and relationships

Local community

- Local communities include neighbours, locality, sports clubs, learning disability groups and so on. Each individual's community will be different depending on their views – be mindful of this when signposting people with learning disabilities to activities of groups. Look creatively at current support networks. Develop bespoke services for the individual which reflects their view. Some people want to be involved in learning disability focussed events and others would prefer involvement wider community events.
- Engage with communities to identify and nurture them to help people to link together, for example, develop safe places, linking with and learn from existing initiatives. Community social / coordinator, helping people link together, invest in local community, collate what is going on (invest to save).
- Raise awareness with the local community about the needs of people with learning disabilities and involvement. Work with mainstream services, service-users, staff, communities, carers, parents to change culture.
- Local organisations/communities should forward plan when a facility is taken away to identify what gaps it will leave in terms of relationships as well as practical facilities. Consider how these relationships will be affected and how they can be replaced, for example, Denbigh College left a big gap in terms of established relationships for the people attending. There should be joint working and planning when facilities are removed or services terminated.
- Promote access to generic courses and resources in the community that aren't just for people with learning disabilities.
- Positive approaches to risk assessment and management – reduce 'red tape restrictions'.
- Promote safeguarding awareness.



Support people to begin, maintain and end relationships.

- Development of friendships for people with learning disabilities is often restricted by the support they receive. For example if support is available to go to places with people with learning disability, friendships will be developed, but when the service is not on offer or the staff available, the opportunities are limited.
- Need to address issues around transport and support especially in the evenings – suggest discussion with dial a ride.
- Befriending services and 'buddies' system - a voluntary activity. Link people with those with similar interests, skills, goals. Promote better peer friendships and less reliance on carers and services.

- Building of friendships is much easier for those who are verbal. Need to consider people who are non-verbal or who have difficulties in forming social relationships.
- Staff/communities/teachers should be more aware of the impact of lack of friendships for people who don't manage to build them very effectively.
- Grief and loss with relationships: Needs to be understood better and given more attention / focus. Effect on others around / close to the individuals.
- Use of computers to build relationships & friendships is common but not always well supported for people with learning disabilities. Staff may feel unsure about their skills/roles/boundaries. There should be a balance between the abstract online relationship and tangible face-face relationships. Need training and clarity.
- Support families to learn to let go and allow risks, and enable people with learning disabilities to make and build relationships.
- Provide training in shared positive risk taking and values.
- Promote cross border friendships and relationships. Support individuals in supported accommodation to visit friends elsewhere. See what services are provided in other counties.

Sex and relationships

- Help people to access relationships and date people. Dating agency.
- Sex and relationships no longer core business in health (not challenging behaviour, PMLD, Mental health or Forensic) so reduced opportunities to run groups. Could relook at this as groups very successful and can have a massive impact on the people who fall into the core business 'groupings'. Often down to the individual practitioner's interest/motivation to run sex/relationships groups. These groups can reduce challenging behaviour and poor mental health – a recurring theme in inpatient services.
- Quality of the relationship is key – more important than the nature of the relationship.
- Care staff need to be aware of the nature and impact of their relationship with the service user.
- Definition of 'what's ok' may be useful as otherwise it's down to common sense (which varies). Staff need training in what their own psychology brings to a relationship in a positive and in a negative way.
- Train other providers to support relationships/pregnancies. Accessible resources for everyone to work together to support people. Peer support. Provide people with enough information about sex and what it can lead to.

Internet safety

- Can be difficult to understand the abstract nature of an online relationship – how to explain and make real to people with learning disabilities so it doesn't create more vulnerability.
- Staff need clarity about their role and training.

- Do 'dodgy' websites get barred or should we raise awareness for people with learning disabilities on the risks/uses?
- Social media opportunities – sometimes online relationships can be rewarding and feel safer but need responsible use.
- Limit to availability of IT hardware – may need to adapt to support the use of equipment. Staff/parents/carers may need support in how to use or teach how to use these.
- Improve skills – IT courses, literacy courses, use symbols/pictures. Making computers easier.

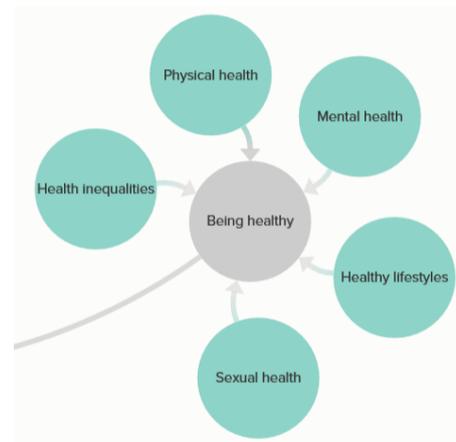
Who needs to be involved?

- CD/learning disabilities joint team – link in with self-advocacy groups
- Self-advocacy groups / forum
- Community navigators (have role in collating what is happening)
- Dial a ride (help to sort out issues with transport and support, especially in the evenings)
- Talking points and progression project in Denbighshire
- Regional partnership
- Learning disability champion – to be identified from within the community.
- Share best practice across the region.
- Education
- Parents/providers
- Health and safety – risk assessors.
- Individual
- Contracts / commissioning

Being healthy

Health inequalities

- Improve GPs understanding/awareness of learning disabilities and 'capacity' around health issues. Understand the individual's communication needs. Have GP learning disabilities champions. Accessing health service can be tricky, for example, requirement to phone at 8am. GPs should make adjustments and structure services to be more accessible.
- Train health professionals in communication and learning disability issues. Mandatory training around learning disabilities from individuals with learning disabilities. Student health professionals to access learning disabilities services as part of training. Talk to individuals, parents and carers.
- Provide user friendly documentation.
- Screening - document whether individuals engage or dis-engage. Check why a person doesn't access. Parents may say no – is this in the person's best interest? How much effort is made by staff/family to encourage. Action plan to flag up when people have refused/not gone (consistent psych writing to GPs). Could contact those on register who have not had a screen and identify those in supported circumstances or with failing health and remind of need for screen.
- Links at hospital for someone to talk to when preparing for appointments. Virtual reality technology to prepare for hospital appointments like breast screening.
- Have support at appointments if needed.
- Look at reasons why appointments are missed, such as not being able to read a letter instead of taking people off the list, for example CAMHS.
- Too many people accepting that 'John doesn't go to the dentist' and so on. There are consequences long term for example where treatment is required in an emergency. Could undertake 'de-sensitising' work such acclimatisation with ambulances and dentists. Need to overcome the dilemma of individual refusing check-ups and preventative treatments.
- Offer and carry out annual health checks. Many people still missing.
- Care pathways to access A&E and special adjustments to facilities so people feel safe, quiet and have access to food/drink.
- Passport, such as a lanyard to help health professionals identify a child that may find it difficult to wait in a waiting room. Electronic version of 'passport' could work well, for example, when someone with learning disabilities presents at A&E. People will probably have their 'passports' for planned admissions but may not for unplanned admissions (IT info sharing protocols). App on phone instead?
- Improve waiting times and make it easier for individuals to access appointments / assessments. Families currently have countless appointments with different



specialists at different clinics. No coordination - one clinic to cover all/most issues could resolve this.

- Generic issues affect all families such as poverty, mental health.
- Ageing learning disability population with dementia – learning disabilities not the issue, focus should be on dementia – training of residential staff.
- Realising that the mental health issue is not always as a result of the learning disability. Share information if dual diagnosis. Provide access to specialist services such as drug and alcohol, eating disorders. Primary need
- Lack of access to learning disabilities mental health facilities close to home.
- Recent improvements in 'health liaison service' working well, especially with children (in Ynys Môn and Wrexham). Expand this service.
- More acceptance around relationships and sexual health. Better education, opportunities, change attitudes. Wider understanding. Health giving talks in school on sexual health topics, such as LGBT.
- People with learning disabilities should be employed or volunteer in health settings – to support others.
- Look at what is already available - 'Paul Ridd Foundation' – traffic light system. 'Care bundle' – in hospitals.
- Advocacy groups to share concerns and feedback to everyone around main issues. Health to share information with advocacy groups.

Healthy lifestyles, prevention and early intervention

- Teach individuals, staff and support workers about being active and nutrition. Information needs to be accessible and easy read with alternatives for people who don't read - not a 'one size fits all'. Push more for info on social media.
- Consistent messages from childhood through transition into adulthood.
- Need to steer away from 'you are overweight' to 'let's go outside'. Encourage more well-being activities (with a knock on effect of losing weight).
- Engage in local sporting events. Information sharing on Disability Sports Wales
- Train outside providers such as gyms
- Having fun! Singing!

Transition

- No clear agreement re who does what and when. Could be experienced as 'dropping off a cliff' in relation to changes in teams such as CALDS/CAMHS. Need to develop better partnerships to give seamless support to individuals.
- Health promotion. In this population (mild and moderate) this can make a difference. Train carers (paid or not) around this. Ready meals/frozen food easier than cooking from scratch. Does this impact on diets of those in supported living?

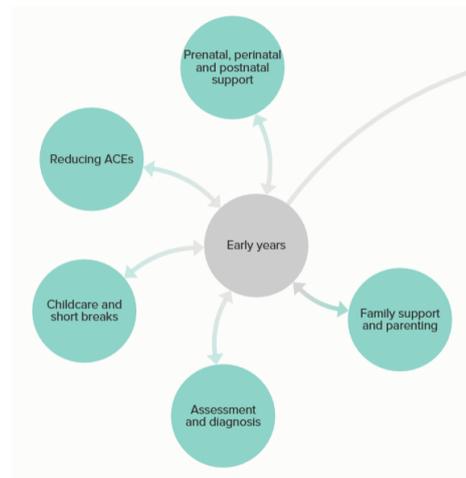
Other ideas

- Re-charge hospitals when provider services support patients.
- Health and social services working in same buildings

Early years

Actions

- Links with broader services such as CAMHS - mapping and joining up work.
- See Ireland example Mencap – training for parents (possibly GPs)
- Provide information on criteria for services (easy read) and make people aware of this so less frustration.



What needs to happen?

- Correct/timely support in early years – early intervention. Positive Behaviour Support training for parents of children of a young age – support to understand and manage behaviours to minimise escalation in the future. Access to evidence-based interventions early.
- Parents and families knowing what support is available. Information needs to be joined up and available to people early on. Better information sharing during transition so that families are better prepared for what they can expect.
- Access to parenting courses that are specifically geared towards parents of young children with learning disabilities.
- Information and practical support for parents with learning disabilities.
- Parent network events – multi-agency approach.
- Joined up working between health and social care – front line health staff having the knowledge such as GPs, midwives and health visitors. Training in schools for teachers and teaching assistants.
- Communication needs to be improved.
- Consistent workers as much as possible. Allow time for workers to get to know children and families to build relationships. Understand what each family needs and ensure adequate information. Families should not have to re-tell their story to every new worker. Could use iPad for information sharing.
- Developing positive communities.
- More activities and respite opportunities for children and families of under 5s. Easy mechanism into respite (including for young carers).
- Promotion of Dewis – Family Information Services. More child related content and focus. Easy access, such as at libraries – more information and advice to people in relationships with learning disabilities.
- More opportunities for people with learning disabilities to develop relationships.
- Better balance between the here and now and future planning – avoid information overload.
- At 13/14 years of age work together and have conversations about possibilities post transition – too late at 17.

- Mental capacity needs to be used more at the age of 16.
- CHC frameworks need to be reviewed – currently not fit for purpose. Confusion and inconsistencies including ridiculous funding percentages such as 17.5% health funding.
- Health liaison role – more investment in GP.
- Earlier diagnosis
- Person centred planning guidance.
- Prenatal counselling.
- Help parents grieve – service support.
- Professionals to be based at family centres/community hubs such as health liaison, social worker, as primary interface between families and services.
- Increased integration between disability and non-disability services (inclusive rather than specialist approach).

Who needs to be involved?

- Parents, families and children. Individuals. Network around the individual.
- Health, GPs, midwives, health visitors. Health liaison role – more investment in GP.
- Schools.
- Voluntary/third sector organisations.
- Communities.
- Social Services. Joint working between children's and adult services. Front line workers i.e. social workers / SCA etc. Children's social workers need to take responsibility for ensuring families are informed post-18. E.g. direct payments, PIP, respite.
- Advocates.
- IT, information, data gatherers – families' information should be complete, correct and up to date so families have confidence straightaway.
- Careers Wales – improve their offer – residential college not suitable for all – should not be default recommendation.
- Education.
- Teaching Assistants.
- People with more skills.
- Youth service.
- ALNCOs/SENCOs – needs to have training.
- SPOA – voluntary groups e.g. createasmile.
- DEWIS
- Team Around the Family (TAF) and Together Achieving Change (TAC) in Wrexham.