



Association for Real Change, Northern Ireland

'We Matter' Event Feedback Report

Department of Health NI

20 October 2025

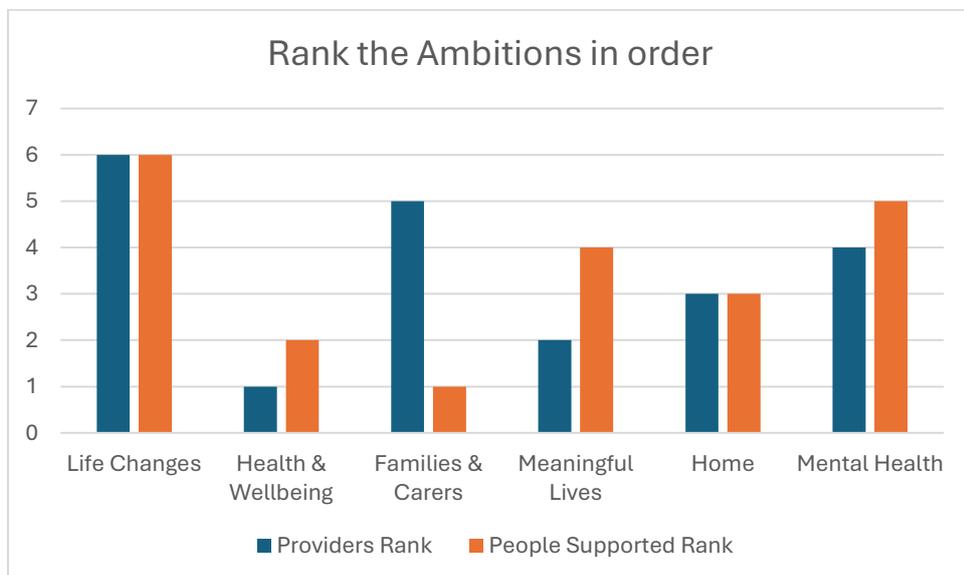
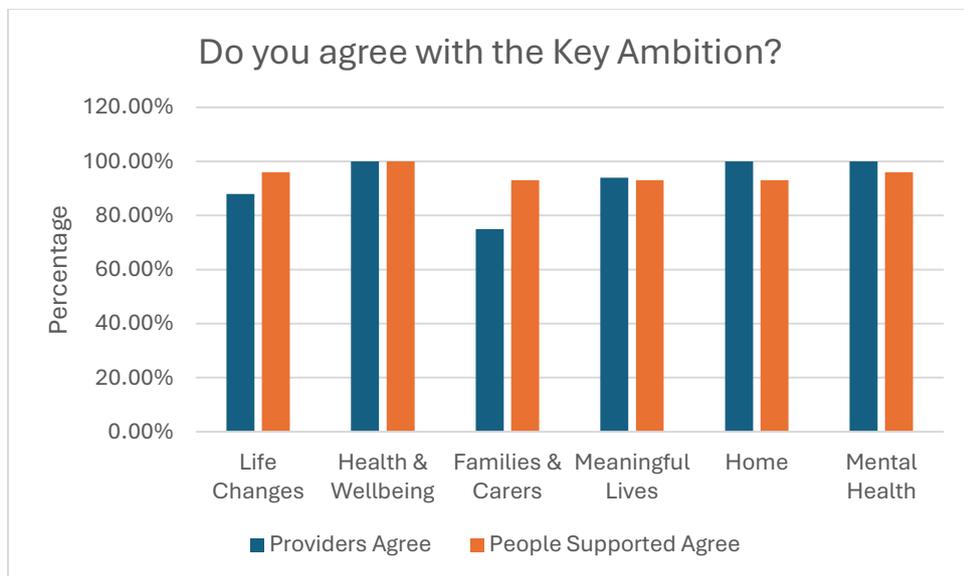
Executive Summary

The Department of Health asked Association for Real Change (ARC NI) to run an engagement event to collect feedback on the new Learning Disability Service Model – “We Matter”. The event took place on 1 October 2025 at the Dunadry Hotel and included two workshops:

- **Service Provider Workshop** – 21 senior staff from 19 organisations
- **Experts by Experience Workshop** – 27 people with a learning disability and 16 support staff

In total 64 people took part from 19 organisations across Northern Ireland.

Key Messages



Providers

Senior staff from provider organisations welcomed the ambitions (dreams) of the new model but raised concerns about how it will be delivered. They said:

What works well now:

- Strong commitment and flexibility in the community and voluntary sector
- Person-centred support and services co-designed with people
- Positive progress in transitions for some individuals
- Focus on building skills for independence

What is not working:

- Poor transitions between children and adult services
- Lack of mental health support for people with a learning disability
- Inconsistent access to services across Trust areas
- Funding uncertainty and short-term contracts
- Transport barriers and lack of choice
- Risk-averse systems that limit independence

Most agreed with all six ambitions however, providers want clearer roles, accountability, and consistent delivery across Trusts. They also called for early intervention, fair funding for community organisations, and less bureaucracy.

Experts by Experience

People with a learning disability also supported the six ambitions (dreams) in the model but raised concerns.

What works well now:

- Support from good staff
- Opportunities to build friendships and learn life skills
- Some good day centres and supported living services

What is not working:

- Long waits for services
- Lack of joined-up support between health, education and social care
- Not enough paid job opportunities
- Transport difficulties making people feel isolated
- Confusing systems and too much paperwork

Most agreed with the planned delivery but felt there needed to be simpler information and easier access to services consistently offered across all Trusts to make real choice happen.

Conclusion

People welcomed the vision behind the “We Matter” model, but they want action, not just words. Both providers and people supported said the same key things:

- Services must be person-led and flexible
- Funding must be fair and long-term, especially for community services
- The system must be joined-up, easier to access, and consistent across NI

This feedback highlights strong support for the new model but also clear worries about delivery, staffing, and accountability. Future plans must focus on practical steps that make a real difference to people’s lives.

Introduction

Association for Real Change (ARC NI) was commissioned by the Department of Health (DoH) to facilitate an engagement event. The purpose of the event was to seek feedback on the proposed Learning Disability Service Model, 'We Matter'.

ARC NI facilitated 2 parallel sessions at the Dunadry Hotel on the 1st October 2025. The Providers' workshop was attended by senior staff members from 19 organisations. One representative left early and three representatives arrived late. The Experts By Experience workshop was attended by 27 people supported, and 16 support workers. These Experts By Experience represented 11 organisations of the 19 participating (identified in italics).

People Supported	27
Support Staff	16
Senior Staff	21
TOTAL	64

The organisations that participated in the event are as follows:

1. *Ashton Community Trust*
2. *Bolster Community*
3. *Caring Breaks*
4. *Cedar Foundation (The)*
5. *Compass Advocacy Network (CAN)*
6. *Inspire Wellbeing*
7. *Kilcreggan Homes*
8. *L'Arche Belfast*
9. *Mainstay DRP*
10. *Orchardville*
11. *Triangle Housing*
12. *Autism Initiatives*
13. *Stepping Stones*
14. *Camphill Community Glenraig*
15. *Healthcare Ireland Ltd*
16. *IncredABLE*
17. *Informing Choices NI*
18. *Live Life Well-Being Centre*
19. *Presbyterian Council for Social Witness*

Evaluation forms were requested from people supported and Senior staff. Support staff were not asked to complete evaluation. Of the applicable 48 participants, 45 returns were received. Key points were as follows:

- 100% had a good experience *"Great session, thank you. I have hope!"*
- 98% felt able to say what is and isn't working now in services *"This was an informative event and a good opportunity to talk about any concerns about the delivery plan"*
- 84% thought their feedback will help make things better *"Hopefully feedback will be seen as constructive and taken onboard"*

See Appendix 1 for the full evaluation results.

Service Provider Workshop

Feedback from Senior Staff on the Learning Disability Service Model

Introduction

The session looked at the 6 Key Ambitions and the Delivery Plan.

We asked providers to consider:

- What part of the current Learning Disability Service Model is working well and what is not?
- If they agreed with the proposed 6 Strategic/Key Ambitions and why?
- The proposed Delivery Plan, and tell us their thoughts on what is good and what is not?

We also asked the same question(s) before break and at the end of the workshop to see if there was any change in their views following the collective discussion. These questions were to:

- Reflect on their feedback from a previous workshop in 2019 and consider if it has been taken on board within this consultation?
- Rank the Key Ambitions in priority order

Feedback

- **What part of the current Learning Disability Service Model is working well and what is not?**

Working well:

- voluntary sector - being able to be more reactive to need, flexible and adaptable, being able to tap into a diverse range of funding
- Community and voluntary sector
- Passion among the staff teams at each provider
- Services that have been designed and shaped by the people who use them.
- links into other services and in the voluntary sector
- Community and voluntary sector
- Person centred support
- Community and voluntary sector innovation and creativity and being responsive to need
- C&V services are designed and driven by the people we support
- Inclusion of voluntary sector. We can innovate and be inspired by Learning Disability and Autism community on the ground
- Working within the community allows us to genuinely get to know are individuals and being able to provide a service for what they want and need
- C/V sector and our ability to be more person focused.

- Voluntary sector and their innovative initiatives as they address genuine need
- Planned transitions
- Services that ensure independence, and aspirations for an independent life
- Community voluntary sector is providing services that are designed by and for people who use our services.
- Planned transitions
- Engagement with daily skills- learning to live with support not doing everything for the individual
- Services where people are actively involved and represented.
- Transitions from long term hospital stays to community intervention and prevention
- C & V are building lives, not empires!
- Recognising early intervention
- Vol sector being able to do a lot more with a lot less cash
- Person centred support
- Positive behaviour support, increase in services
- An ethos of care and a willingness to work towards more collaboration and early wrap around information, signposting and supports at 14.
- Everything else

Not working well?

- Continuity of care over different services.
- Support and services for individuals who have both an LD and a mental health.
- The hospital/ medical experience for people with LD.
- Everything else
- Transition service not working
- Direct payments have the potential to be excellent, but it's not allowed to be promoted
- Expectations have moved on, community has moved on but the services have not
- Statutory provision
- Central directory of services.
- Trust services are expensive, unionised and they carry the rhetoric in relation to how good they are with zero evidence of impact on people.
- Lack of investment in the community care
- Being moved out of residential care without the correct support in place
- individual being squeezed into where there is a space
- Resource allocation for comm vol sector - people and finance
- Early support & information does not happen in a consistent & joint up way between public/private sectors, & service users. Largely, services commissioned are reactionary & bureaucracy led.
- Transition from children to adults
- Lack of quality of life measuring
- Statutory services
- Recruitment and retention
- Resources
- One size does not fit all - people should not be shoe-horned into services because there is a space which is often the case.
- Rigid and inflexible services with focus on risk to the trust rather than the outcomes for people
- Rigid and inflexible services with focus on risk to the trust rather than the outcomes for people
- Transport

- No standardisation of quality
- Services can be treated differently from trusts. Invest in the community services and spend wisely. Lack of communication between trusts and services
- Transition from children's services to adults' services
- Services not knowing if they will be funded the following year.
- Contracts completed are in no way reflective of the services we actually provide
- Limited or no support for the world of work/employment, travel training to that increase independence and a real inclusive life
- Outcomes of work less focused on than outputs
- Transport
- Inequalities of services between the trusts
- no whole life planning - LD is there for life, plan
- Rigid and inflexible services with focus on risk to the trust rather than the outcomes for people
- The money is spent in the wrong places. We are building lives they are building empires especially now the money is being scrutinized.
- Provision of services allocated on the basis of spaces available, and not on behalf individual choice.
- There is enough money in the system it is spent badly.
- Outcomes are measured in a quantitative rather than qualitative way
- Choice and Control? Contracts department and daycare panels assessed need barriers.
- No requirement from Trust to deliver evidence-based outcomes - just metrics measuring attendees

- **Do providers agree with the proposed 6 Strategic/Key Ambitions and why?**
- **What are your thoughts on the proposed Delivery Plan, specifically what is good and what is not?**

1. Life Changes

a) 88% agreed with the key ambition prepared and supported throughout life changes, with the remaining 12% unsure.

- Individuals are on a journey. They need to be able to dip in and out of support.
- People with a learning disability experience the same life stages and should be offered the same support and access to services as the general population
- We are on a journey with our people. Services need to flex and change as their needs do.
- It is important the transition process starts early, to look at all available options, prepare the child for adult services, look at their needs and development. Look at appropriate locations.
- Important that people with a learning disability have the same opportunities as everyone else.
- Promotes independence, greater choice for young person to make informed decisions, empowering
- Families need to be aware early as it allows for the child to prepare for the process of transition. It also gives services an idea of what will be happening in the future.
- Because people with a learning disability should have the same live choices as you and I, and should have the support to have a fulfilled live and bright future

- It's what young people and their families deserve.
- Active planning for life changes means people can have support and services responsive to need at times when they need it in their life. Life changes happen at different times for different people
- Choice needs to be person centred and focused. Support throughout life will help make choices and the earlier support around person centred choice is implemented the better prepared for adult life.
- Consistency for person & their family, prevention of crisis management if no placements available when child turns 18, reduced anxiety for child & their family, plan for service capacity
- Because there is a significant gap in care and support between children and adult services. Emphasis on continuity of care is important for quality of life and transitioning
- Streamline services. Better gauge of what is needed for individuals rather than a one fits all. Long term better use of money. Investment in individuals' future.
- It's what young people and their families deserve
- We need to aspire to giving the best opportunities possible
- Everyone deserves to live their life supported and included regardless of ability or needs
- It is imperative that these important transitions are well planned and implemented rather than a reactionary response to breakdown or crisis. Lessen trauma, promote real informed choice and meaning.

b) In the Delivery Plan, what is good and what's not?

What's Good?

- Information available to families and carers. As long as it is user friendly/accessible.
- Consistency through transitions.
- Avoid postcode lottery.
- Evidence of gaps in geographical areas.
- Can providers access the transition plans?
- Link workers between children and adult services.
- Possibility of database access for everyone involved in a individual's care.
- Transitions Link Worker – one person to act as link is so important.
- Database of current provision is a good idea but needs to be maintained.
- Aims on the list are aspirational.

What's Not?

- Transitions Link
 - Statutory or Independent
 - Who governs this?
 - No clear accountability ie Health and Education
 - Seems focused on YP – what about their life changes
 - Is it managed by children's or adult services?
- Currently direct payments seems to be the focus and seen as the solution: community audit carried out, Newry Area.
- Nothing about quality or monitoring of the quality service.
- Consistency across the trusts.
- Link workers need to be a very defined role.

- Maintenance and keeping info up to date.
- Has to carer all providers and not just statutory services.
- Fragmented information.
- Postcode lottery
- Responsibility of link officer in comparison to those in schools etc at the moment, so many already involved.
- Transitions currently disjointed so massive unpicking required.

2. Health & Wellbeing

a) 100% agreed with the key ambition improved health outcomes and reduced health inequalities.

- Current systems are not supportive of the health needs individuals with a learning disability and autism have.
- Children and young people with learning disabilities should have the correct access and support with their physical health as anyone else. Physical health needs are important in child development into adulthood
- Supportive of an overarching theme of Learning Disability and Autism in every aspect of Health & Social Care
- People are often missed when they cannot communicate or advocate well. This is an equality and human rights issue. GP's and MDT's should have more training and awareness.
- At higher risk of health issues including mental health declines, can display through behaviours if unwell. Improved health outcomes/support will improve quality of life & reduce barriers to services/
- To help promote good health and wellbeing for people with a learning disability and their families.
- It's important that these young people's health needs are assessed and addressed as many do not have an advocate who can act on their behalf
- People with a learning disability need specialist supports and adjustments to access high levels of healthcare to ensure an equal and healthy life as equal citizens of our society
- Everyone should have access to appropriate healthcare regardless of ability. Hospital passport worked well in our organisation recently for all involved in hospital admission
- Everyone deserves to be treated equally, have fulfilling lives and the support to do so.
- Current system is not always listening to the individual with a learning disability and being flexible in their approach to respond to their wishes. More of an approach to slotting them in where there is an opening.
- It's a human right that should be accessible to all but current systems make it inaccessible
- Because it's a human right.
- Need for health interventions is a given, so we need to improve access to health services and how services are implemented and delivered.
- Every individual should be entitled to health checks and choices around their health. Informed choices and inclusion in health choices... decisions should not be made for an individual

- Medical systems for learning disability are so focused on medication that a large portion of the LD community are massively over medicated and do not have the same opportunities to participate and make choices
- To enable early intervention and flag up physical issues
- Because they deserve the same access to healthcare as everyone else, diagnostic overshadowing is unfortunately far too common in the current health care set up, where people supported are overlooked

b) In the Delivery Plan, what is good and what's not?

What's Good?

- More formality with medical professional.
- Continuity of care/access to relevant info.
- Crisis prevention
- If implemented well will provide us more positive experiences and health outcomes.
- Hospital Learning Disability Liaison Nurse
- Think it is good to be aspirational about offering better access to healthcare.

What's Not?

- Concerns about 'specialist' Drs and Nurses – What expertise constitutes specialist? Why is this needed. Surely all clinical professionals should be learning disability training.
- Aims are too clinical and not showing any flexibility.
- Lots missing – holistic, softer approaches to health.
- Think this could have the potential to actually create more segregation.
- RSE hasn't been mentioned.
- A&E/GP Practices.
- Hospitals not suited to support individuals with learning disability.
- Expectations on support staff in hospital environment.
- Consistency -what's allowed/what's not.
- Awareness of learning disability throughout nursing/healthcare services.
- General pressure on GP Practices – lack of access.
- Lack of engagement in MDT process.
- Diagnostic overshadowing.

3. Families & Carers

a) 75% agreed with the key ambition family carers needs are understood and support is available, with the remaining 25% disagreeing.

- If the needs of an individual with LD & Autism are met the family should feel supported
- Most often families and carers know the individual best and have their best interests. They can advocate for the young person
- Families are currently carrying the pressure for individuals particularly those with more complex needs and only getting support when a crisis hits.
- Emphasis should be placed on the individual, absolutely the family should be supported but not overshadowed by their family

- Whilst the focus should be on the individual, we need to acknowledge the impact of family life.
- Families should be included in decisions, but only if the individual (age appropriate) agrees. Better understanding means better support. The person should be the main decision maker.
- Reduce demands on services if crisis intervention is needed through family breakdown/burnout, links to improved health outcomes if carers are supported (lower levels of anxiety/depression)
- Families' voices should not be more dominant than individuals
- The needs of family carers must be recognised as they are pivotal to supporting their son daughter with a learning disability.
- To support people to live at home if that is what suits them, to prevent crisis of placement breakdown and carer stress
- Family/carers support is often a critical component of the adults' lives - if they are informed, they can support their adults appropriately
- Our systems cannot support the needs of all our young people without the support of families and carers.
- Families are often left alone in the wilderness and may not have the information to advocate, communicate with loved ones and plan effectively. This is required for truly informed choices.
- Focus should be on the individual but balancing the input of supportive families in the background
- It is important to avoid carers fatigue as they are often the voice for their loved ones with learning disabilities, families and carers need to feel like they are being heard
- Because they support the person in the family unit. However, the aspirations and the choice of the LD person should take priority over family
- The individual needs to be empowered and to be independent.
- So people can live at home if that suits them and have their needs met preventing the crisis of placement breakdown and carer stress

b) In the Delivery Plan, what is good and what's not?

What's good?

- Reduce family/carers stress / crisis response.
- Increase choice and control/autonomy.
- Longterm benefit for family/carers maintains people in their own homes.
- Better use of funding rather than high-cost crisis response.
- Stronger rules for SOS would be superb, especially if they were consistent across all Trust.
- Short breaks aim is aspirational.
- Named person/link worker – good idea but is it realistic?
- The ideas are good again – how realistic and how do you recognise which families need extra support?

What's is Not?

- Holding beds for emergencies.
- Wark point – training for families not happening in a functional way.
- Managing family expectations.
- Family training – need information, support and signposting rather than training/feels patronising/about control. Health and future planning.

- Sh*tshow at present – short breaks due to red tape. Bureaucracy eligibility
- Focus seems to be on engagement at start with families rather than at different stages.
- Difficulty with regulators when setting up short breaks/rigid framework.
- What is a short break – hours/days/Youth groups/clubs?/ funding etc.
- Short breaks criteria?

4. Meaningful Lives

a) 94% agreed with the key ambition greater opportunities to pursue meaningful activity, with the remaining 6% unsure.

- People with learning disabilities should have the same opportunities as other people their age
- Maybe- this is ambiguous. It doesn't support the current good work being done in the communities. What funding is there for this?
- People should have choice about how they spend their time and have options and opportunities available to them.
- Access to meaningful activity creates a better quality of life, which is proven to reduce behaviour and improve mental health
- These are all important aspects of quality of life. Relationships and activities are vitally important for an individual to live a fulfilled life. They should have the same access to these as others
- Because individuals have the right to choose their activities and support that meets their needs. They shouldn't be restricted to what a trust says they have available.
- Person centred - offering choice, control & autonomy over own life. Happy if involved in meaningful activities, fulfilled life, improved health & quality of life
- Individuals should not be treated any differently than the rest of the population. The right to a social and meaningful life should be front and centre. Our fears should not dictate a person's life.
- To assist people with LD to pursue their own interests and hobbies. To help them feel included and part of the community.
- In the last six months I have witnessed the difference offering new, more meaningful opportunities to our clients - the impact has been unreal
- Meaningful activities support and promote good mental wellbeing and socializing with other members of the community.
- We see how young people thrive when given purposeful opportunities, so many are missing out on opportunities to thrive
- People with LD have the right to be stimulated, have lifelong learning, enjoy interests and encourage their skills. We all have one life to live to experience.
- People with a learning disability should have the same opportunities as other people their age
- People should be supported to reach their individual goals and aspirations, express themselves and feel like they contribute to society in a meaningful way and feel a sense of belonging
- People should be supported to reach their individual goals and aspirations, express themselves and feel like they contribute to society in a meaningful way and feel a sense of belonging
- opportunity must include the opportunity to experience the world of work for people with LD as part of a meaningful life.
- Meaningful lives are imperative to mental health. Many 'opportunities' are currently tokenistic.

- People should be supported to reach their individual goals and aspirations, express themselves and feel like they contribute to society in a meaningful way and feel a sense of belonging
- I would push for a government approach to work with employers to push for more paid job opportunities for people with LD. Larger firms e.g. H&M open at shop floor but then it's a no at a HR level

b) In the Delivery Plan, what is good and what's not?

What' Good?

- Yes, with cross departmental buy-in.
- Smaller services that meet need rather than broad daycare.
- Staff openness to engage in positive risk-taking to try new things with service users, especially if they feel adequately trained.
- A regional approach to Day Opportunities is rally positive and might enforce standardisation.

What's Not?

- There will always be a need for buildings-based-services.
- SDS – still no framework or clear directive regarding direct payments/managed budgets/combi packages.
- Serious transport issues and lack of consistency or fairness when transport is being allocated.
- Transport
- Appropriateness of Day Care Centres.
- What is a meaningful activity? Day Centres sometimes aren't engaging in this and completing activities to pacify.
- Availability of capable environments.
- Over reliance on transport and a lack of skills in accessing/using transport – equally a lifeline to others.

5. Home

a) 100% agreed with the key ambition supported to live with the highest level of independence possible.

- Less draw on the funds, more responsibility equals more happiness
- Encourage choice, increase skills, live the way they want to live and increase independence
- Over supporting is restrictive, disempowering and life limiting in many cases.
- Having choice on how and where we live is fundamental to everyone.
- Independence creates confidence, positive self-esteem, resilience and empowerment.
- Being independent reduces the vulnerability of an individual and gives them more control
- People with a learning disability have the right to be treated as equal citizens and that means living where they want and with the right level of support.

- With the correct support in place there is no reason an individual cannot live independently. The support should be what's needed, not what we think is best support and should not be risk focused.
- To increase feelings of self-worth and empowerment, to allow for choice, capacity building and equality
- Quality of life - environment needs to meet the needs of the person or it will have a negative outcome & increase risk. Preferences should be accommodated where possible
- Independence is so important to a sense of self; however, it must not become abandonment and can only work with the correct support
- People with learning disabilities should feel as though they are part of the community and involved in their transition decisions (where possible) promoting independence
- As Adults independence is what we all strive for. People with LD are no different. With supported programmes this can be achieved.
- Where possible this is very important, for others it can be overwhelming and a more calming, nurturing environment is more important.
- It promotes independence and allows opportunity to integrate
- People should be actively supported to be as independent as possible and not feel restricted or controlled within their home
- Promotes independence in many aspects of life - socially and economically. Transport is one of our greatest barriers - if this is mitigated, creates more opportunities
- This isn't about living independently from family etc it's about choice and having those systems in place
- Too often people are further disabled by too many services being placed on them as opposed to trusts taking a pro-active holistic support approach. Too many individuals are risk averse and not taking

b) In the Delivery Plan, what is good and what's not?

What's Good?

- Better future planning/determination of need.
- Availability of housing options.
- Better coordination with Housing Executive/SP.
- Maintain relationships/friendships.
- Crisis support workers – appropriately trained.
- Consistency throughout environments.
- So many organisations doing amazing work. It's just lacking consistency across the board.
- Choice / multiple providers / quality standards.

What's Not?

- Requirement in housing are dependent on your postcode.
- Lack of clarity between tenancy, support pack and care.
- No clear definition of Supported Living.
- Buildings – who is building the homes/ affordability / funding model.
- NIHE - Role & Responsibility.

- Constant Review Process – but where are the actions? Are we just going to review the letter every year?
- Independent living skills/capacity not mentioned.
- Jobs – it's going to require a huge workforce which is already struggling to cope.
- An understanding of what Supported Living actually is.
- Do families have access to the information they need to make informed decisions on housing/supported living/residential.
- Too much emphasis on shared accommodation instead of bespoke placement; compatibility.
- Don't want clusters of housing - true community integration.
- Continuity across supported living and day opps – where care is provided.

6. Mental Health

a) 100% agreed with the key ambition better mental health outcomes through integrated community and specialist hospital services.

- To help people to maintain their own health and wellbeing and to reduce the need for emergency interventions.
- Unsure if this is how mental health can be improved... there should be more of an emphasis on why mental health is bad rather than just supporting it when it happens
- Early intervention is critical with upstream support in communities essential to ensuring people have opportunities for friendship and engagement.
- It's important not to forget about mental health as it can get overshadowed by the disability
- Better outcomes for individual. Would help them integrate back into their original home when they are discharged from hospital. Help staff support them in the correct way after discharge.
- Informed and congruent working is essential to agree upon, implement and review strategies.
- Proactive planned mental health support should reduce numbers of crisis incidents so providing people benefits as well as making financial sense
- So no one falls through the gap of LD and mental health.
- Lack of appropriate services/ at the right time leads to escalation of issues, escalation of risk to person as well as others, leads to hospital admissions which could have been prevented & stigma
- Current services do not meet the need or demand, people with learning disability deserve the same range of services available to the general population, crisis prevention and maintaining placements
- When everyone is working more closely together, issues are resolved faster. More streamlined services
- Skill specific professionals who know how to communicate and manage behaviours decrease likelihood of distress and mental health related issues
- Health in general needs to be a joint up approach. More often than not its reactive and not person focused. Training for staff is need across all health sectors.
- To thrive we need to have good mental health. Whatever the model support and the right level of support is the key.
- This promotes consistency, reduce stress on services and on the individual. Mental health cannot be forgotten it is vital. Early intervention is important

- Because people with LD are not immune from bereavement, illness and poor mental health
- The focus should not be on discovering issues of MH but an array of holistic services to support
- Prevent crisis and placement breakdown, current service does not meet the need or demand, they deserve the same range of services available to the general population

b) In the Delivery Plan, what is good and what's not?

What's Good?

- Need for therapeutic services for Mental Health Support.
- Crisis appropriately trained.
- Accessibility of services.
- Community access – maintain placements.
- Smarter environments.
- All suggestions are good – its dependant on the application.
- It is good that there is an aim for better forensic and inpatient services but think we should be skilling up mainstream Mental Health Services.

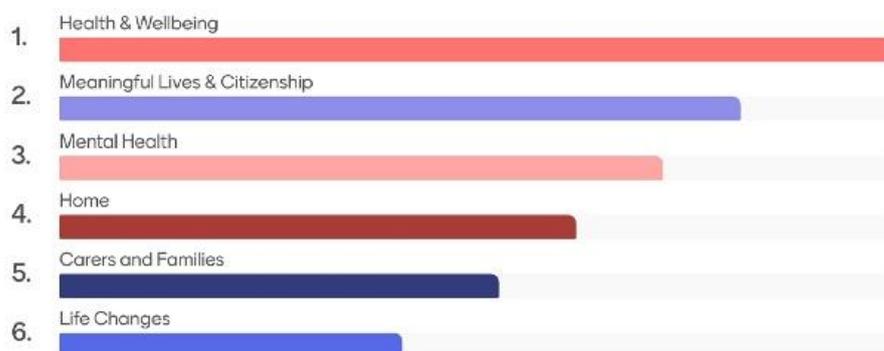
What's Not?

- Better forensic and impatient → what does better mean?:
 - More of
 - Different type of model
 - Different definition
- Think that Mental Health and behaviour, needs to be separated.
- Absolutely no collaborative between Learning Disability and Mental Health.
- If you are deemed to have a learning disability, Mental Health won't help and vice versa.
- No availability of community mental health support.
- Aby support that's there isn't person centred.
- Learning Disability always get referred for behaviour support even if it's clearly mental health.
- DBT/CBT does not solve everything.

➤ **Rank the Key Ambitions in priority order**

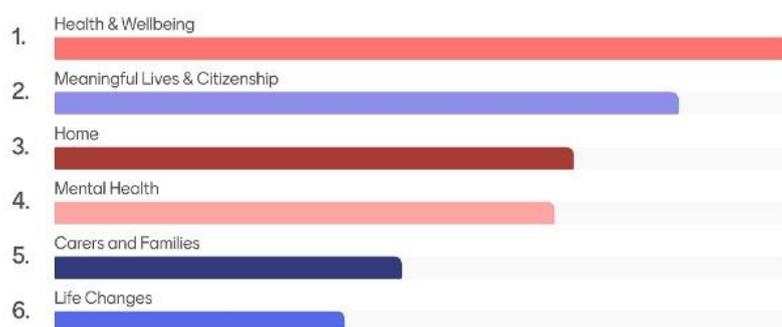
We asked the providers to rank the ambitions in order of priority before considering the delivery plan, and after considering the delivery plan. There was little change in the order of mental health and home ranking as follows:

Please rank the six **ambitions** in order of priority:



When asked after considering the detail in the delivery plan, ranking changed to:

Please rank the six **ambitions** in order of priority:



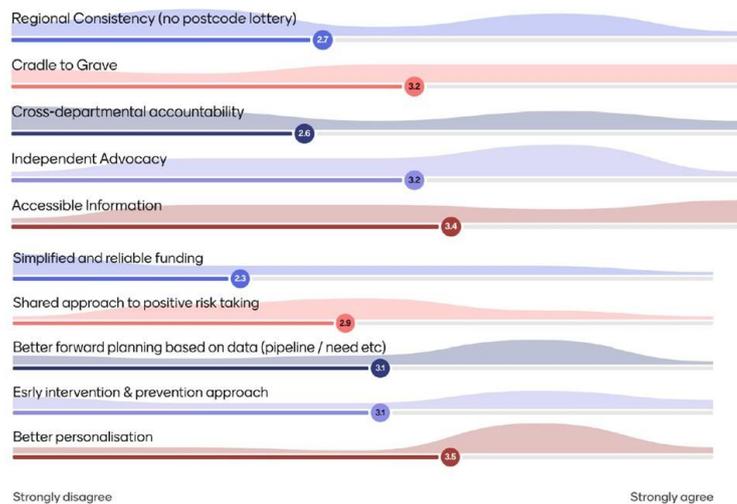
- **Reflect on their feedback from a previous workshop in 2019 and consider if it has been taken on board within this consultation?**

In 2019, the Health & Social Care Board had asked ARC NI to facilitate a preparatory workshop with providers to get ready for public consultation on the revised Learning Disability Service Model. Providers identified the following critical elements:

- Regional Consistency (no postcode lottery)
- Cradle to Grave model
- Cross-departmental Accountability
- Independent Advocacy
- Accessible Information
- Simplified and reliable funding
- Shared approach to Positive Risk Taking
- Better Forward Planning based on Data
- Early Intervention & Prevention Approach
- Better Personalisation

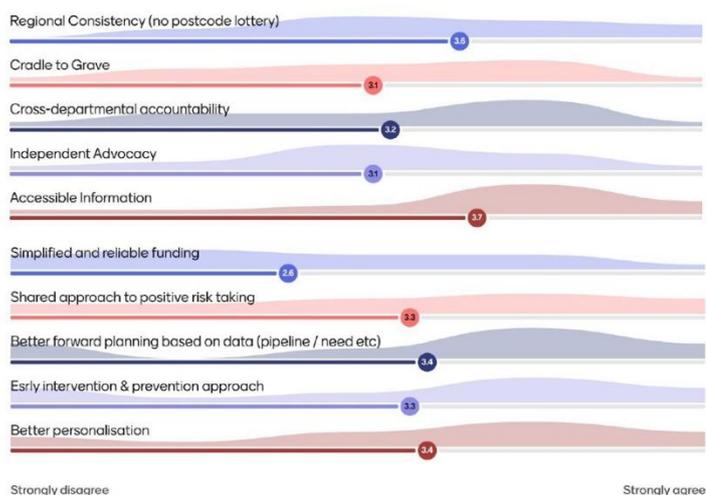
We asked the providers to rate whether they strongly agree or disagree if these elements have been addressed in the public consultation. We asked them to do this before considering the delivery plan, and after considering the delivery plan. There was a noticeable increase upon reflection in both regional consistency and cross-departmental accountability.

In 2019 you told us you wanted the following. Does this draft model address that vision?



When asked after considering the detail in the delivery plan, ranking changed to:

In 2019 you told us you wanted the following. Does this draft model address that vision?



Concluding Comments from Providers

In summary, the providers felt some hope and referenced this was a good start but worried about the operational delivery and reality for people supported, citing a number of barriers to implementation.

“I think if this is all carried out it will make a huge difference. Some of it seems unachievable though and may be better to be realistic.”

“More consistent communication between Trusts, Schools and families early on is key.”

“Good start but need to see the costed plans and statutory services being held to the same standards.”

“I think the plan is great. I hope it gets the opportunity to be implemented.”

“I hope it works. It would make a massive change to service users and their carers lives.”

Experts By Experience Workshop

Feedback from People Supported on the Learning Disability Service Model

Introduction

The session looked at:

Part 1 – The 6 Dreams (Ambitions) What life should look like.

- What is working well in services right now?
- What is not working in services right now?
- What could be better?

Part 2 – The Delivery Plan How services will make these dreams happen.

The Big Question What should happen first?

Part 1 – The Six Dreams (Ambitions): What Life Should Look Like

Participants looked at each of the six dreams in the new Learning Disability Model and said whether they agreed.

Almost everyone supported the dreams, saying they reflect what a good life should look like for people with learning disabilities.

However, there were many concerns about how the plan will be delivered — especially around staffing, consistency, and funding.

After this, people discussed what is working well in services, what is not working, and what could be improved.

1. Life Changes

Do you agree with the dream = 26 smiley faces and 1 not sure

- i) What people liked:
 - Everyone agreed that planning early for life changes is very important.
 - People liked having a named worker and a plan that follows them from school to adult services.
 - Families being part of planning was seen as positive.

- ii) What might not work:
 - Transitions should start earlier than 14 – ideally when starting senior school.
 - There is no proper transition support between CAMHS and adult services.
 - Some worried the Information Hub could be “a massive list that’s overwhelming” unless it’s well designed and accessible.
 - Consistency across Trusts was a big issue, everyone should get the same level of support.
- iii) Ideas and improvements:
 - Have one easy-to-use place for all information about services, with links and referral forms.
 - A Communication Hub or toolkit could help people and families find the right support.
 - Allow people to self-refer into services.
 - Transition link workers should introduce themselves early and stay consistent.
 - Plans should be reviewed regularly and shared across services.

2. Health and Wellbeing

Do you agree with the dream = 27 smiley faces

- i) What people liked:
 - People were positive about yearly health checks, Health Passports, and Hospital Liaison Nurses.
 - They liked the idea of better training for health staff and linking health checks into care plans.
- ii) What might not work:
 - Many said they only get good annual checks if they have another condition like diabetes.
 - Hospital Passports can feel too short and impersonal, “only three lines per box.”
 - A single Learning Disability Doctor sounds unrealistic, better to train all doctors to understand learning disability.
 - Hospital liaisons are helpful but someone who knows me (e.g. supported living staff) is better support.
 - Current NHS delays mean some health ideas might look good on paper but not work in real life.
- iii) Ideas and improvements:
 - Make annual health checks a legal requirement so nobody is missed.
 - Give all health staff disability and communication training
 - Involve people with learning disabilities in health roles as co-trainers or support workers.
 - Services must meet the needs of older people and those with dementia.
 - Add appointment reminders and make it easier to book appointments.
 - GP surgeries could send out renewal medicines (like EpiPens) automatically.
 - Create priority triage for people with profound and multiple learning disabilities.
 - Health professionals should use clearer, more inclusive language.

3. Families and Carers

Do you agree with the dream = 25 smiley faces and 2 not sure

- i) What people liked:
 - Families having a named contact person was seen as extremely important.
 - People liked the focus on short breaks and more support for carers.
 - They agreed carers should be involved, but not instead of the person themselves.
- ii) What might not work:
 - Some Trusts (like the Southern) do not offer Direct Payments (DPS).
 - Families can “slip through the cracks” if there is no consistent worker.
 - Some carers may resist supported living because they fear losing respite.
 - Data and registers must benefit carers, not just record their details.
- iii) Ideas and improvements:
 - The carers register should be used to help families directly.
 - Services must talk to people with learning disabilities first, not only to carers.
 - Short breaks should happen more often — not just once a year.
 - Future planning must be part of all care plans.
 - Self-Directed Support needs to be explained better — many don’t understand it.
 - Each family should have a named advocacy contact.
 - Ensure funding and resources are in place so these supports actually happen.

4. Meaningful Lives and Citizenship

Do you agree with the dream = 25 smiley faces and 2 not sure

- i) What people liked:
 - Everyone wants more opportunities for work, volunteering, and social activities.
 - People supported staff training for complex needs and more community-based options.
- ii) What might not work
 - Transport is one of the biggest barriers:
 - Too expensive (especially taxis).
 - Rules and funding are inconsistent.
 - Access is a “postcode lottery.”
 - Day centres are still important for many, they shouldn’t be lost.
 - Community services often can’t support people with complex needs.
- iii) Ideas and improvements:
 - Translink should support not-for-profit services and ensure fair transport rules.
 - Bring back funding for local classes and activities like technology or art.
 - Create paid work placements, not just voluntary roles.
 - Build peer advocacy groups and networks.
 - A Regional Day Opportunities Forum should include people supported.
 - Staff training should be regular, accessible, and focused on complex needs.

- Improve rural transport and access for wheelchair users.
- Social life, relationships, and friendships should be part of everyone's care plan.

5. Home

Do you agree with the dream = 25 smiley faces and 2 sad faces

- i) What people liked:
 - People liked the idea of more supported living and adapted housing.
 - They agreed housing needs should be reviewed regularly.
- ii) What might not work:
 - People doubt where new homes will come from given the housing crisis.
 - Adaptations take too long (up to six months).
 - Incompatible housemates can cause distress and affect mental health.
 - Delays and differences between housing associations are unfair.
- iii) Ideas and improvements:
 - Make accessible design standard (e.g. bungalows, walk-in showers).
 - Build small supported flats or shared homes with on-site staff.
 - Allow people to move if they're unhappy with housemates.
 - More homes for people with dementia and complex needs.
 - Use smart technology and alarms for independence.
 - Create a regional crisis support service to keep people at home.
 - Make repairs and maintenance quicker.
 - Improve joint working between Health and Housing.
 - Ensure people can keep pets, which help their wellbeing.

6. Mental Health and Behaviours of Distress or Concern

Do you agree with the dream = 26 smiley faces and 1 sad face

- i) What people liked:
 - Strong support for a 24/7 crisis service.
 - Agreed that staff training and more specialist teams are vital.
 - People want better links between learning disability and mental health services.
- ii) What might not work:
 - People worry 24/7 crisis cover won't happen everywhere, "too costly" and "needs more staff."
 - Waiting lists are already too long.
 - Services for mental health are already not working well for the general population.
 - Unclear how consistency will be achieved across all Trusts.
- iii) Ideas and improvements:
 - Make behaviour training mandatory through RQIA inspection standards.
 - Have a mental health specialist available 24/7 for crisis response.

- Provide counselling and talking therapies.
- Everyone should have a Wellbeing Recovery Action Plan (WRAP).
- Build more specialist inpatient beds and assessment units.
- Create Mental Health Champions for learning disability in every Trust.
- Ensure equal access to crisis support across all Trusts.

Part 2 – The Delivery Plan: How Services Will Make It Happen

After exploring the dreams, people supported looked at the Delivery Plan — the “how” of making change happen.

- Most people said it covers the right areas but were unsure how it will work in real life:
- “It sounds good but needs more substance.”
- “We’ll still be saying the same in twenty years unless things change.”
- “We need more staff, money, and proper planning.”

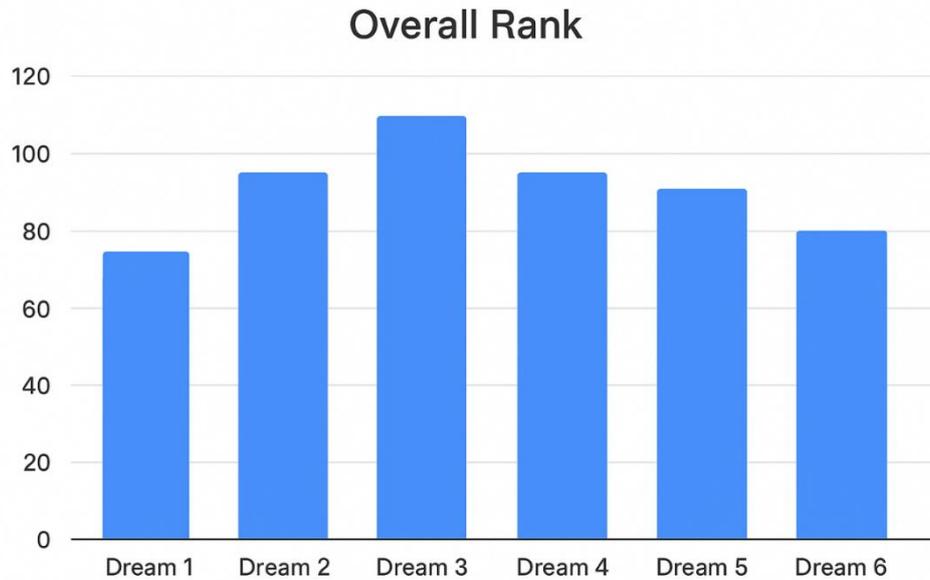
They agreed:

- The plan is ambitious but needs real action, not just words.
- Legal requirements would help things actually happen (e.g. health checks and behaviour training mandatory).
- A national database linking all services and supports would make life easier.
- More supported living is essential.
- Progress must be consistent across all five Trusts.

Part 3 – The Big Question: What Should Happen First?

At the end of the session, each person ranked the six dreams in order of importance. Some gave all six equal value, but the overall scores showed clear priorities.

Dream	1s	2s	3s	4s	5s	6s	Total Score	Overall Rank
Dream 1 – Life Change	7	3	4	2	0	7	86	6
Dream 2 – Health & Wellbeing	9	5	3	1	4	1	103	2
Dream 3 – Family Carers	9	6	2	1	4	1	104	1
Dream 4 – Meaningful Lives	7	2	5	4	4	6	98	4
Dream 5 - Home	8	2	6	5	2	0	101	3
Dream 6 – Mental Health	6	5	4	2	2	4	91	5



Concluding Comments from People Supported

People supported across ARC member organisations liked the six dreams. They think the ideas are good and would make life better.

Although some people gave certain dreams higher scores than others, they would prefer all six dreams to happen together, rather than waiting years for the whole plan to be delivered.

They are worried it might not really happen. They said the Delivery Plan needs:

- Enough staff and proper funding.
- Legal rules so health checks and behaviour training actually happen.
- Services that work together and are consistent across all Trusts.
- Early planning for life changes so nobody gets left behind.

People want the Department of Health to make the dreams real, not just write them on paper.

“The ideas are great, now make them happen!”