



Department of
Health

An Roinn Sláinte

Máinnstríe O Poustie

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Learning Disability Service Model

Consultation Response Document

Personal details				
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Are you responding on behalf of an organisation?				Yes
Organisation (if applicable)	Association for Real Change, Northern Ireland (ARC NI)			
Learning Disability Services provide care and support to individuals with unique and often complex support needs. The Learning Disability Service Model aims to enhance service delivery by ensuring that each person receives tailored, person-centred support, designed to enhance independence and maximise quality of life.				
1. Principles underpinning the Learning Disability Service Model - Do you agree with the ambitions underpinning the Learning Disability Service Model?				
Fully agree	Mostly agree	Neither agree or disagree	Mostly disagree	Fully disagree
X				
Please add any comments:				
ARC NI was a member of the DoH Task & Finish group and fully agrees that the evidence garnered validated these ambitions, confirming they are as relevant today as they were, when stated within 'Equal Lives' policy in 2005. ARC NI supports the learning disability community. In our role we hear personal stories on a daily basis that confirm these ambitions continue to be just that as, dreams for the future. Dreams because they reflect the reality of required progress still to be achieved to ensure that people with a learning disability are supported to overcome barriers of inequalities to lead full and meaningful lives.				

One of the opportunities of setting clear ambitions for policy direction is that of changing culture by establishing a shared value base across hsc, the workforce delivering services and wider society attitude. To do this consistent and ethical language is very important. It comes across to the reader, that the model and delivery plan have had multiple authors. For example, using people with learning disabilities and people with a learning disability. Furthermore, whilst internally within social care 'placements' may be discussed, counted and considered; however we would advocate that none of the population call their home a placement. The aspiration of having a home and receiving support to enable independence is in line with the wider policy initiative of 'shift left', and the current Neighbourhood model of care.

ARC NI recommends both the model and delivery plan need to be reviewed to ensure consistency of language and to reflect the centrality of a human being through a human rights approach.

2. Current Services: What aspects of our current Services are working well?

- The collaborative relationship between DoH Policy and the learning disability community
- The mixed economy of service delivery partners is felt to be a positive thing, with reference to the value the CVS adds within social and community care.
- Providers driving person-centred support with a focus on building skills for greater independence
- Many services being co-designed by people supported and their families
- Staff with high skill mix doing great work and delivering with passion and commitment

3. Current Services: What aspects of our current Services are not working well or could be improved?

- Data is poor, lacking transparency and results in a lack of accountability
- Lack of early intervention and prevention approach as we tend to be highly responsive to crisis points – rather than a planned, coordinated and inclusive way of working.
- Lack of a shared approach to risk taking, resulting in risk-adverse systems and at times services
- Inconsistency on a multitude of levels, from variance in approach by individual Trusts, postcode lottery of provision etc.
- Approaches to commissioning and procurement with great funding uncertainty presenting risks to providers

4. The Learning Disability Service Model outlines 6 Key Ambitions to improve services. Please rank order these Ambitions in order of priority (1 = most important; 6 = least important) and provide any comment(s) in relation to the Ambition

Key Ambition	Priority ranking (1 - 6)	Comments
Life Changes		Strategically this area if correctly implemented and meaningfully delivering good outcomes,

		<p>covers critical processes that impact and benefit people through all life changes.</p> <p>With core assessment of need identified at the earliest possible point, care planning which is reviewed to take into account a person's circumstances changing, partnership working across a range of Government departments programmes and providers of services and support with the person at the centre.</p> <p>ARC NI feels this is clearly articulated within the model but less so in the delivery plan as the focus is on transition from children to adult services.</p>
<p>Health and Wellbeing</p>		<p>The health inequalities of people with a learning disability are unacceptable. Whilst annual health checks and hospital passports are not new, we look forward to the learning and scale up of successfully proven new initiatives.</p> <p>This may be an ambition area that would benefit from being delegated down to the Neighbourhood Model as key areas of inequalities experienced by our population, relate to primary care – see below. We also feel PHA has a critical role and would welcome clarity of KPIs linked to their work to support the learning disability population.</p>
<p>Carers and Families</p>		<p>We firmly believe that the daily uphill battle experienced by family carers is unacceptable. Family carers should be treated as recognised partners with their loved one at the centre of all communication, decision making and support. Family carers should also receive individual support. We therefore welcome this ambition's intention to equally empower and support family carers in their role in ensuring their child's voice remains central.</p>
<p>Meaningful Lives and Citizenship</p>		<p>This ambition is heavily reliant on a cross-departmental strategy, including Economy, Education operationally and should fundamentally be grounded in human rights. However Community is key and therefore cross-referencing the Disability Social Inclusion Strategy is key when published.</p> <p>We believe this is also an ambition that could, if adequately resourced, urgently address some of the current challenges around meaningful day activity.</p>

<p>Home</p>		<p>First and foremost resettlement must be complete and this should be included with a clear statement that ‘to go back will <u>never</u> occur’. The below ambition relating to mental ill health is also a key deliverable here to the success of resettlement.</p> <p>The modernisation of different living options as a real and tangible offer must not waiver and reform of modern regulations and standards are required to include recognition of many individuals having tenant rights and therefore the home not being considered a placement.</p>
<p>Mental Ill Health and Behaviours of concern or distress</p>		<p>This is the ambition we hold most immediate concern about due to a lack of services within the tiered approach referenced within the model. This is at a time when bed availability for assessment and treatment is low to non-existent. We are aware of more cases where with no criminal conviction, prison is being inappropriately used with some referring to ‘the structure proving very helpful to the young person’.</p> <p>We cannot allow prisons to become a replacement of a long-stay hospital institution.</p>
<p>Additional Outcomes – Are there additional outcomes which you feel should be included as a Key Ambition? Please outline details</p> <p>ARC NI does not agree with ranking these ambitions in any particular order, as each one is equally important. In our experience of listening to the community, when any and each ambition is not addressed, this results in significant trauma to the lives of people with a learning disability and their family carers. Some are fundamental basic human rights – the right to a home that I choose and to live with the people I want.</p> <p>We query whether review of access/entry criteria for adult learning disability services should occur given the co-morbidity issues many of our population experience.</p> <p>We fundamentally believe this Programme of Care area requires cross-departmental working and we are delighted to see this referenced within the delivery plan for Ambition 1, 4 and 5. We do however believe a cross-departmental representation within the Governance structures should be agreed, committed to as these ambitions above cannot be tackled by Department of Health alone – see below for detail.</p> <p>There is heightened anxiety currently which is felt by the learning disability community at this time, due to a clear DoH policy shift from reform to neighbourhood models, particularly as social care seems to be less of a focus in comparison to primary, secondary and community care. In our view this is a slight pivot, but a reinvention of Integrated Care System.</p> <p>In May 2022 ARC NI sought reassurance that when engaging in locality planning, that the needs of the learning disability population would be equitably considered and addressed. In a response from the Co-Chair of the Future Planning Model Project they responded: “We recognise AIPBs will take time to develop and therefore their initial scope and areas of interest will grow during their initial years. Informed by the forthcoming Strategic</p>		

Outcomes Framework and supporting population needs assessments, the system will need to establish effective ways of ensuring regional consistency whilst allowing for local needs. One of the ways we will achieve this is through the *Regional Group*.

We would advocate that a representative for the learning disability community is part of any regional group structure linked to Neighbourhood Model. Furthermore, they are a representative on any governance structure linked to 'We Matter' – with the role of improving accountability of interlinked DoH policy.

- 5. Service Delivery Plan** – The Service Delivery Plan outlines a number of strategic actions designed to improve the delivery of services for adults with learning disabilities. What actions or innovative approaches do you believe should be made to make services better?

We are aware of the pressure on the NI budget, and in particular health and we hold concern that the actions as outlined currently in this plan, will not be considered a funding priority – see below.

Equal Lives is twenty years old and the time it has taken to complete this review of learning disability policy is unacceptable. We are the third largest programme of care area, supporting a small number of individuals but in a population of growing need. We have been faced with endless crisis points that have cost the Department additional investment. This investment, in our opinion is simply firefighting further crisis without urgent targeted action to address all ambitions.

ARC NI feels the Delivery Plan requires further work. There is a high volume of statutory roles being re-initiated or created. An example of this is Transition Coordinators, previously housed within Trusts which failed to deliver and the CVS creating similar roles and creating greater outcomes for the people they support. To place these roles within Trusts comes at a high cost.

ARC NI would seek clarity of any new role and perceived or proven effectiveness in achieving change.

There is also a number of reviews proposed within the Delivery Plan. Whilst we accept that an evidence base following a review can translate into clear directive action, there is a real risk without an urgent commitment to 'reform and transform' further delay will become a reality.

ARC NI would advocate the urgent need for clear and robust key performance indicators and a clear and transparent costed implementation plan.

- 6.** Do you have any additional suggestions or recommendations to help strengthen the Learning Disability Service Model and Delivery Plan? We welcome your ideas on how we can improve services and better meet the needs of adults with learning disabilities.

ARC NI welcomes the statement within the model as follows:

*“We also recognise the scale of change required. Implementation will be phased and prioritised in partnership with service users and families. It will depend on **sustained investment, workforce development, and — where appropriate — legislative reform to unlock new models of support and rebalance existing provision.**”* (Page 10)

We do not feel however that action to address these three areas have been transparently communicated. We recognise elements link to a costed implementation plan, yet to be completed however would argue that more is required.

Funding

As noted on several occasion above, the learning disability community is concerned that at a time where budgetary pressures are well documented, that we are not a priority. Targeted adult services for people with a learning disability are largely delivered through social care and in our experience, insufficient targeted approaches are achieved through primary and secondary care.

ARC NI would welcome within the delivery plan, the inclusion of a specific ambition and action to address sustained investment for the learning disability community and to achieve the ‘We Matter’ Model.

Workforce

Within the Delivery Plan the only reference to workforce is in light of new posts within HSC; and Ambition 6. As articulated regularly by ARC NI to DoH the crisis faced by learning disability providers to recruit and retain staff is at an all time high, not helped by the recent decision and inaccurate communication delivered by Minister regarding the sector and Real Living Wage. The evidence garnered through a Learning Disability Multi-disciplinary Team Workforce Review presented clear evidence of need and required action. We have called for a Social Care Workforce Strategy for decades and with this now in place, there is a vehicle to further raise the profile of our workforce.

ARC NI would welcome within the delivery plan, the inclusion of a specific ambition and action to address workforce development specifically for the learning disability community.

Legislative reform

ARC NI is mindful that legislative reform is required as much of it is outdated, discretionary and not designed for lifelong planning. We are also in support for the need to reform regulation standards for all service types, and specifically the need to create these for Supported Living.

We are however mindful that this can take time and therefore the risk is unnecessary delay, resulting in further crisis.

Choice and control is a central theme throughout the model and the implementation of a full Self-Directed Support offering is key here. That is a mix of contracted services, managed budgets to spot purchase and Direct Payments for the use of Personal Assistants. We believe only when this is a real offer to people and family carers, will more choice and control occur and furthermore, a solution for young people with complex health

needs in addition to their learning disability can be met. ARC NI is delighted to have been instrumental in encouraging progress on NI delivering 'Managed Budgets'. We welcome the support the DoH has lent to this to date from a policy perspective, however are concerned that progress could be stalled as a result of legislative limitations. Creative suggestions have included DoH developing guidance for Trusts to enable them to feel able to continue. We are in support of this measured approach taken by decision makers in the interim of legislative reform.

ARC NI would welcome within the delivery plan, the inclusion of a specific ambition and action to address legislative reform required specifically for the learning disability community.

Accountability & Governance

We would propose that a cross-departmental group be established with sub-groups of reasonable wider representation in line with each ambition. We understand there are elements of this in the pipeline as a result of various reviews e.g. SEN Review in Education; Post-19 Leavers review in Economy. In our experience without this being set within a learning disability model accountability framework, implementation by one department will risk a consequence to another department.

We accept and understand this plan is however targeting action that is predominantly health responsibility so we welcome the proposal to also develop a Learning Disability Collaborative Leadership Board. ARC NI believes local Trust action plans should report into this.

ARC NI believes the governance and accountability structures need to be strengthened.

Please send your completed questionnaires to us by post or email.

Post them to us at Learning Disability and Autism Unit, Department of Health, Room D2, Castle Buildings, Stormont, Belfast BT4 3SQ or email to: ldsm@health-ni.gov.uk

You must send us your answers by 5pm, 25 November 2025.