

Consultation Response submitted by
Association for Real Change, Northern Ireland (ARC NI)
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MENTAL HEALTH STRATEGY 2021 – 2031

ARC NI supports 45 cross-sector learning disability providers across Northern Ireland who lend support to people with a learning disability in all aspects of their lives. ARC's Vision is to achieve real change that puts people with a learning disability at the centre of decision-making, and in the heart of their communities.

This response was developed in partnership with, and on the behalf of, the membership.

Vision and Founding Principles

ARC NI welcomes the proposed vision within the strategy, which promotes the need for a shared approach to meeting the mental health needs of all people living in Northern Ireland.

Furthermore, the founding principles are in line with the values that learning disability service providers promote and practice.

That said, **ARC NI sees a real risk in the lack of reference to adults with a learning disability throughout the three overarching themes**, namely

- Promoting wellbeing and resilience through prevention and early intervention
- Providing the right support at the right time
- New ways of working

The learning disability population

Learning disability is a life-long condition that affects cognitive and social functioning resulting in the need for ongoing support and supervision for many persons throughout their life. In Northern Ireland, many people live with family carers often into their old age. They too require support.

Whilst there is no accurate data set confirming the learning disability population in Northern Ireland, the 2011 NI Census recorded a total of 40,177 (2.2%) usual residents as having a "learning difficulty, an intellectual difficulty, or a social or behavioural difficulty"¹.

People with a learning disability suffer from health inequalities. The NHS Clinical guidance issued to support the management of patients with a learning disability during the coronavirus pandemic underscored their vulnerability: "People with a learning disability have higher rates of morbidity and mortality than the general population and die prematurely. At least 41% of them die from respiratory conditions. They have a higher prevalence of asthma and diabetes, and of being obese or underweight in people;" (p.2)².

¹ http://www.niassembly.gov.uk/globalassets/documents/raise/publications/2014/employment_learning/5014.pdf

² <https://www.nice.org.uk/Media/Default/About/COVID-19/Specialty-guides/learning-disability-autism-during-pandemic.pdf>

Evidence suggests that 40% of this population experience additional mental health issues³.

They also experience poor educational attainment, loneliness and social isolation and can live in poverty⁴.

The Bamford Review recognised that learning disability and mental health problems are very distinct and separate conditions and in turn a separate but parallel review occurred focused on learning disability.

The Equal Lives Review (2005) identified 74 recommendations required to improve the lives of people with a learning disability across six themes, namely Transitions; Health & Wellbeing; Family & Carers; Citizenship; Home; and Assessment & Treatment. Equal Lives was directed toward attaining change over 15 years.

More recently there has been efforts to develop a new model for learning disability, “We Matter”, which continues to focus on the six themes identified by Equal Lives. This is yet to go out for public consultation but a Task Group has already been established and is scoping Community Based Assessment & Treatment. Nowhere in the strategy is this referenced, an example whereby silo working will risk the health of people with a learning disability.

In 2005, concern had been expressed about the fact that other committees within the Bamford Review were addressing some of the specialised areas of policy and service development that will affect people with a learning disability. This included child and adolescent mental health, adult mental health services, services for offenders and the mental health needs of older people (P5)⁵.

This concern, in our sectors experience proved correct and has detrimentally impacted on the support to people with a learning disability with their mental health.

The strategy currently makes little reference to people with a learning disability, yet it is a strategy to support the mental health needs of all NI population.

Theme 1: Promoting wellbeing and resilience through prevention and early intervention

ARC NI welcomes and agrees with the content within the focused section on children, young people and their families. We assume that whilst not specifically referenced, paragraph 51-55 equally applies to children and young people with a learning disability. If this is not the case, **ARC NI would strongly advocate that paragraph 51-55 includes children and young people with a learning disability.**

This emphasizes the point that a human being with a learning disability has this condition for life but due to their cognitive disability, will require and benefit from ongoing opportunities to build their understanding and resilience in trying to manage their emotions throughout life. This requires reasonable adjustments and a range of additional communication aids to be applied. For ARC NI this ongoing capacity building throughout life, continues to fall within the remit of early intervention and prevention.

³ <https://www.assemblyresearchmatters.org/2017/08/22/learning-disability-northern-ireland-now/>

⁴ https://arcuk.org.uk/northernireland/files/2018/06/2018-050-APGLD-report_Final-May-2018.pdf

⁵ <https://www.challengingbehaviour.org.uk/learning-disability-files/equallivesreport-NorthernIreland.pdf>

People with a learning disability should be considered first and foremost a person, with the same needs, hopes and wishes as the rest of the population. However, there are many barriers which they must overcome to receive equal access to be able to achieve these.

Many learning disability providers, family members and carers in Northern Ireland encourage and empower people with a learning disability to live a fulfilled life, including living independently in a community, developing relationships with friends and partners; and ensuring days involve meaningful activities, including work, college etc.

In turn, people with a learning disability are at risk of facing ups and downs, similar to the rest of the population but they may struggle to understand it. Furthermore, their behaviour may escalate as a result of difficult emotions such as fear, anxiety, confusion and sadness and some display behaviours of self-harm.

Those that provide support have found themselves on many occasions having to attempt to prevent the escalation of poor mental well-being for people with a learning disability as a result issues such as loss and bereavement; a move in home; sexuality confusion; drugs and alcohol and relationship breakdowns. They do so willingly but with little resource, recognition and in the case of some, expertise.

Accessible community based mainstream support that can build the capacity of people with a learning disability to understand emotions better, develop resilience in managing these to the best of their ability and with the correct support, is urgently required. Furthermore, annual health checks undertaken with a person's GP, could be extended to include consideration of a person's mental well-being.

ARC NI would also propose the year-on-year Mental Health action plan needs to ensure its, consideration and targeted inclusion, of people with a learning disability but would recommend that this be closely aligned to the 'We Matter' key ambition Health & Well Being and any associated key actions within its Delivery Plan.

ARC NI welcomes the proposal of expanding talking therapy hubs but would advocate the need to ensure the necessary reasonable adjustment are in place to make this type of support accessible to people with a learning disability. Furthermore, we would propose these hubs should include other therapeutic interventions including arts and music.

Theme 2: Providing the right support at the right time

ARC NI welcomes paragraph 62 in particular, and within the information above has evidenced the context for this to be further strengthened.

ARC NI welcomes the proposal to resource and grow GP Federation areas which will be the point of contact, coordinating person-centred models of care across primary, secondary and community services for the population living in their area, including the organisations and family that support them.

Furthermore, we welcome the recognition within the Strategy of the need to view Community and Voluntary (C&V) providers as critical stakeholders with valuable expertise. This in our view, needs to be broader than C&V Mental Health focused services. As described above, there are many C&V services which support people with a learning disability, that also find themselves supporting that person with their mental health.

As a result of COVID, the learning disability sector has been able to support more people with a learning disability and/or their family members in utilising digital technology but this depends on capacity and consent. We agree therefore of the need to continue to grow and establish a portfolio of communication and support, however not all people with a learning disability would be able to access a digital mental health model.

In-patient support for people with a learning disability has a long and most recently, jaded history, scared by an inability to fully complete resettlement and more recently an abuse scandal resulting in a Public Inquiry. The most recent statistics gathered in February 2020 and published by the Department of Health show that 45% of inpatients with a learning disability (children and adults) leave hospital within a two-year timeframe – the remaining 55% are inpatients with a recorded 3-30+ year stay. Of the total number of inpatients recorded with a learning disability, 53% are recorded as bed type 'Assessment & Treatment'.

A regional Task and Finish Group has been established and is facilitated by the Health & Social Care Board to scope a model of service for Community Based Assessment and Treatment across the Region, for individuals with a Learning Disability and Complex needs, who require significant support to prevent crisis, at times of crisis, and during periods of transition to manage and avoid crisis. **ARC NI would strongly advocate the need for joined up collaboration. This would need to consider capital spend, future units and integrated wards; and any rehabilitation service.**

Theme 3: New Ways of Working

ARC NI welcomes the approach of achieving a regional service which demonstrates outcome-based accountability.

We also recognise the value that a review of workforce will lend to achieving the change as proposed by this strategy, however **ARC NI feels this needs to link with workforce reviews as outlined by other policy areas namely the Department of Health's Workforce Strategy and the reform of Adult Social Care.**

This would ensure the recognition that many different social care roles, such as Support Workers, contribute to supporting people with their mental well-being as part of early intervention, prevention and during a crisis. **ARC NI would advocate that this would offer not least the recognition of the professional capability of Social Care Workers, but also enable equitable access to statutory training to further support them in their daily tasks.**

ARC NI has seen the value of peer support in action, as it facilitates peer support networks for particular roles namely, Safeguarding Champions and Registered Managers. Individuals feel better connections to their peers and in turn greater support. ARC NI strongly welcomes the proposed establishment of a Peer Support and Advocacy model across mental health services.

ARC NI welcomes the proposal to establish a Centre for excellence and this is clearly a growing area of interest by Government Departments, as identified by the same proposal within the learning disability model 'We Matter'. With that in mind, there is a risk that if multiple Centres are established there will continue to be dis-jointed silo working which may impact on areas such as dual diagnosis. Without a full understanding of how this Centre will operate, there is also a risk in the requirement for significant funding which may be duplicated if multiple Centres are established. Furthermore, for the community and voluntary sector and people with lived experience to be able to contribute, learn and innovate, it would

be helpful to fully understand the Centre of Excellence's remit in full and how the participation of all partners will be encouraged and enabled.

ARC NI would advocate the Department of Health develop a clear and costed model for the development of any such 'Centre for Excellence', including a brief stating clearly its purpose and method of engagement with stakeholders.