

Consultation Response submitted by
Association for Real Change, Northern Ireland (ARC NI)
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PROGRAMME FOR GOVERNMENT – DRAFT OUTCOMES FRAMEWORK

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 NI'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.

ARC NI is heavily committed to ensuring that people with a learning disability are considered first and foremost a person, with the same needs, hopes and wishes as the rest of the population in Northern Ireland. Furthermore, the rights of people with a learning disability in our view, should be upheld and their choices should be at the forefront of all support provided.

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

Outcomes

ARC NI and its members welcome the nine outcomes listed within the draft Programme for Government. We feel these are simple, easy to understand and outline the ambition to reflect an inclusive society that responds to the needs of our citizens to live prosperous and fulfilling lives.

We agree that all outcomes require cross-cutting Government Departmental action and would encourage the establishment of an accountable group for each outcome area, to recognise that a single Department is unable to account for all aspects. In addition, we look forward to the publishing of draft action plans each individual outcome.

However, ARC NI members are experienced in outcome-based accountability and therefore understand the critical importance of measuring the fundamental question of 'Is anyone better off?' It is with this in mind that we would strongly advocate the risk that people with a learning disability will be under-represented or worst, continue to be the forgotten, due to the significant absence of adequate population data.

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.

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

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.

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.

In ARC NI members’ experience, various strategies that address particular areas, for example Children and Young People; Mental Health; Disability; DfC Employability, continue to fail people with a learning disability, as they represent such a small proportion of the population the strategy’s theme attempts to tackle.

In October 2002 the Department of Health initiated a major, wide-ranging and independent review (Bamford) of the law, policy and provision affecting people with mental health needs or a learning disability in Northern Ireland.

In 2005, the Bamford Review expressed concern that other areas addressing some of the specialised policy and service development that will affect people with a learning disability would fail to recognise the nuance required by this particular citizenship group.

This concern, in our sectors experience proved correct and has detrimentally impacted on the support to people with a learning disability in fulfilling equal access to a meaningful life.

The Equal Lives Review (2005), the learning disability strand of Bamford, 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.

In 2015/16 a substantial evaluation of learning disability was completed. This documented progress achieved against the six themes of Equal Lives and highlighted areas that required further attention. Unfortunately, this was not published because of the breakdown of the NI Executive.

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. In this absence of strategically coordinating policy and subsequent practice that will continue to improve the lives of all individuals with a learning disability, we must revert your attention to what we currently have.

ARC NI would advocate the need to refer to Equal Lives.

ARC NI would advocate the need to access the Bamford Evaluation completed by the Department of Health in 2015/16 to inform thoughts of indicators.

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

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