

Consultation Response submitted by

**Association for Real Change, Northern Ireland (ARC NI)**

October 2024

**Draft Programme for Government (PfG) 2024-2027**

In Association for Real Change, we change thinking, change practice, and change the lives of people with a learning disability, autism, and other support needs.

Since 1999, the Association for Real Change in Northern Ireland (ARC NI) have been bringing people together. We work with Experts by Experience and the people, organisations and communities that share our vision in order to put real change into action. We do this through, research, networking, collective advocacy, policy, and training.

**Doing What Matters Most Today: 'Grow a Globally Competitive and Sustainable Economy'**

ARC NI **strongly agrees** that the priority 'Grow a Globally Competitive and Sustainable Economy' should be included in the Programme for Government and **agrees** with the actions outlined.

Social Care is a low paid, undervalued career and there has been a lot of work attempted to address this and seek the wider system's acknowledgement of this role as a valued profession. The Department of Health is leading the way in Northern Ireland through its facilitation of the Social Care Fair Work Forum, in partnership with providers, regulators and unions. We are therefore concerned there is no reference to the Social Care Fair Work Forum within the draft Programme for Government.

We welcome the proposed new 'Skills Fund' and will be keen to see the detail of this to ascertain if it is a good use of public spend. Over 15 years ago, ARC NI developed a project to support economically inactive people joining the social care workforce. This was a highly cost-efficient and successful collaborative project where upon completion of training and an accredited certificate, individuals were able to access real vacancies in the learning disability community. No public funds were provided to us as a charity to deliver this. Our model was then attempted to be replicated by Council's creating Health & Social Care Academy's. These have not been effective, cost a lot more money and failed to adequately skill up people to be employed by the sector. We would expect Social Care to be included within the 'Skills Fund' and we would expect this funding to be available to organisations that can prove their ability to deliver.

We also welcome the planned action to introduce new Employment Rights Legislation and a Good Work Charter. However when considering the detail, as outlined in the previous Department for the Economy's consultation, there are significant financial consequences for businesses and in particular non-profit making businesses, charities. Hence we would emphasise the importance of ensuring that the outworking's of this and, in particular the

additional funding required to realise the principles of good work, are made available to the social care sector through public fund contracting arrangements.

We also welcome the focus to increase European and UK-based funding and the proposal to introduce a new 'Apprenticeship Inclusion Challenge Fund. The learning disability community has significant experience of delivering programmes to support the progression to employment of individuals with a learning disability, autism and other support needs. Funding has included both European Social Fund, and more recently the UK Shared Prosperity Funded programmes. We would expect however that detailed and group specific research be carried out to evidence the impact of funding programmes on those furthest from the labour market. We believe this should better enable NI government departments to understand reasonable adjustments required to make employability a meaningful aspiration for everyone, identify gaps in European & UK funding and allocate NI funds to better target need.

These actions must be further developed and implemented to support people with a disability to have greater access to appropriate training, vocational and employment opportunities.

### **Doing What Matters Most Today: 'Deliver More Affordable Childcare'**

ARC NI **agrees** that the priority 'Deliver More Affordable Childcare' should be included in the Programme for Government and with the actions outlined.

We welcome the prioritisation of affordable childcare and the emphasis on early intervention, which is crucial for long-term positive outcomes, especially for disadvantaged children. We also support the commitment to early support for children with additional needs. In planning for this priority, we urge that strategies include support for:

- Improving the quality of childcare for all; affordability alone is not enough.
- Providing targeted assistance to children with complex needs and their families, who often face significant barriers in accessing suitable childcare and support.
- Addressing the unique needs of children and families facing multiple challenges, such as complex medical or mental health issues, behavioural concerns, geographic isolation (e.g., in rural Northern Ireland), limited support, and impacts from the cost-of-living crisis.

To bring meaningful change for children with a learning disability, autism and additional needs, including those with the most complex challenges, enhanced childcare must be paired with improved support for families carers. This includes opportunities for increased community-based support and regular short breaks/respite options to help family carers manage the often significant demands of caring for a child with additional or complex needs.

### Doing What Matters Most Today: 'Cut Health Waiting Times'

ARC NI **agrees** that the priority 'Cut Health Waiting Times' should be included in the Programme for Government but **disagrees** with the actions outlined.

While we agree that waiting times must be cut, our view is that the priority is too narrow and that 'cut health waiting lists' should be included in the Programme for Government as a success measure of an improved health and social care system for all. We suggest that the priority should be broader to focus on improved access to and quality of health and social care support for all. This would acknowledge the vital early intervention and preventative role that social care, along with primary and community care play in tackling health inequalities. And would challenge the regularly defined 'social care' offering as being solely the vehicle to unblock hospital beds. We believe that until such times as social care is truly seen and valued for what it lends to each citizen in Northern Ireland, it is at risk of continuing to be underfunded in comparison to acute services.

We were pleased to see the work of the Social Care Collaborative Forum referenced which is encouraging a partnership approach to progressing the required reform of adult social care. ARC NI as a small charity is part of this collaborative and is heavily investing its resource and leadership in support of this work. And we will continue to do so. However the task of 'increasing productivity and efficiency' as expected of the Forum's work, also requires investment to enable the curve to be turned. We would expect a stronger acknowledgment of this within the final Programme for Government to support this significant cultural change of 'spending more money on community based care and support for people before they go to hospital'.

### Doing What Matters Most Today: 'Ending Violence Against Women and Girls'

ARC NI **agrees** that the priority 'Ending Violence Against Women and Girls' should be included in the Programme for Government and with the associated actions.

We are in broad agreement with the priority and associated action but would remind of the need to consider the additional barriers faced by women and girls who have a learning disability, autism and other support needs.

A report by PSNI and NISRA showed that Disability motivated incidents<sup>1</sup> and crimes has been rising since 2017/18 and 2021/22 recorded the highest level since data was recorded in 2004. And outcomes rate particularly poorly as the PSNI find it challenging in gathering witnesses and evidence to achieve criminal justice outcomes. Most incidents occur at home and victims are often left feeling isolated. This is especially the case for people with communication or cognitive issues.

Furthermore, children and adults with a learning disability, autism and other support needs, receive little if any support, in understanding relationships and access to information on good sexual health. In the absence of this education and capacity building opportunities to promote rights, responsibilities and healthy relationships, they are at an increased risk of potential abuse, including violence, exploitation and crime. We would advocate that within this priority there is an acknowledgement that further work and in particular, reasonable adjustments are made, to ensure ending violence for all women and girls can become a reality.

### Doing What Matters Most Today: 'Better Support for Children and Young People with Special Educational Needs'

ARC NI **agrees** that the priority 'Better Support for Children and Young People with Special Educational Needs' should be included in the Programme for Government but **disagrees** with the associated action.

Too many of our children with a learning disability, autism and additional support needs face significant challenges and barriers that exclude them from reaching their full potential and participating fully in society. This continues unfortunately throughout into adulthood. The August 2023 report on the UK's implementation of the Convention on the Rights of Persons with Disabilities (CRPD) found several issues in Northern Ireland:

- **Slow Progress:** There has been little movement on recommendations made in 2016 to improve the rights of disabled people.
- **Limited Engagement:** Governments are not meaningfully involving disabled people in decision-making.
- **Data Gaps:** There's a lack of data to understand the diverse experiences of disabled people.
- **Social Reforms Not Assessed:** Governments haven't properly assessed the combined impact of social security and tax changes on disabled people.
- **Financial Struggles:** Many disabled people live in poverty or low-income situations, and rising living costs hit them hard.
- **Pandemic Impact:** COVID-19 severely affected disabled people's rights.
- **Social Care Shortage:** There is insufficient social care, harming disabled people's rights.

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<sup>1</sup> <https://www.bbc.co.uk/news/uk-northern-ireland-63861232#:~:text=In%202021%2F22%2C%20police%20said%20there%20were%20123%20incidents%2C,ill%20health%>

For children with disabilities, the risk of experiencing poverty is higher, and this gap has widened since 2010.

Northern Ireland still lacks a comprehensive Disability Strategy to tackle social inclusion, and this policy gap has stalled progress on disability rights. The report urges the Northern Ireland government to prioritize human rights for people with disabilities across all ages—not only educational outcomes for children—to prevent NI from falling further behind other UK regions.

We strongly welcome the inclusion of a specific and dedicated priority within Programme for Government to better meet the needs of our children with a learning disability, autism and additional support needs. We see a risk however as through a focus on SEN, the priority fails to give sufficient attention to the period of birth to preschool. These are often extremely challenging years for families who have children with additional needs that are identified at birth or early years of life.

We would therefore argue that intervention, services and supports lent to the learning disability population, and their family carers should be a cradle to grave cross-departmental priority. This would enable better planning and provision for early years support, respite and short breaks for carers, educational placements with individual attainments leading to employability offers, homes in the community and social connections and relationships.

### Doing What Matters Most Today: 'Provide More Social, Affordable and Sustainable Housing'

ARC NI **agrees** that the priority 'Provide More Social, Affordable and Sustainable Housing' should be included in the Programme for Government but **disagrees** with the associated action.

We are in broad agreement with this priority, however the CRPD Report, August 2023 reported the current failings to meet the basic human rights of people with a disability. Within the CRPD Report, August 2023 it is noted in relation to housing for people with a disability in NI:

"The Disability Strategy Expert Advisory Panel has reported that there continues to be a lack of accessible and affordable housing for people with a range of disabilities. Long delays in accessing housing restricts the realisation by disabled people in Northern Ireland of the right to live independently.

There is no statutory right to independent living recognised in UK or Northern Ireland law. A survey carried out by Disability Action (2021) found that 76%... of deaf and

disabled respondents indicated that they do not have enough access to support to live independently.

The absence of an integrated strategy for independent living combined with little or no co-ordination between services relating to education, childcare, transport, housing, employment and social security programmes undermines policies which, if all working together, would support disabled people to live independently."

The actions as stated within the draft Programme for Government are not ambitious enough to address these fundamental inequalities and failures to meet people's human rights. If more social, affordable and sustainable housing is to be achieved for all, including those with a learning disability, autism and additional support needs, it is our view that the plans to deliver a NI Housing Supply Strategy must be developed as an integrated strategy. This strategy will link economic growth, childcare, education, housing, healthcare and employment.

### Doing What Matters Most Today: 'Safer Communities'

ARC NI **agrees** that the priority 'Safer Communities' should be included in the Programme for Government and with the associated action.

ARC Scotland produced a report in 2016<sup>2</sup> which sought to inform and guide local and national planning and practice related to improving support for people with learning disabilities whose behaviour brings them into contact with the criminal justice system and to reduce offending by them. The report identifies 6 key challenges and the opportunities to address them.

The six key challenges identified are that-

1. People with a learning disability who are at risk of coming into contact with the criminal justice system should receive the individual support they need to address their (potential) offending behaviour.
2. People with a learning disability coming into contact with the criminal justice system should have access to a full range of sentencing options.
3. There should be Information sharing protocols between different organisations in the criminal justice pathway.
4. People with learning disabilities have the information and support they need to ensure that they are not dis-advantaged as a result of their disability.
5. The right to a fair trial of people with a learning disability is protected.
6. Suitable support is available to people with learning disabilities to help end the cycle of reoffending.

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<sup>2</sup> <https://soldnetwork.org.uk/wp-content/uploads/criminal-justice-pathway-challenges-opportunities-for-change.pdf>

We would encourage the NI executive to work with ARC NI to consider and review this Programme for Government priority to better support people with a learning disability, autism and other support needs.

### Doing What Matters Most Today: 'Reform and Transformation of Public Services'

ARC NI **strongly agrees** that the priority 'Reform and Transformation of Public Services' should be included in the Programme for Government and **agrees** with the associated action.

We agree that a fundamentally new approach is needed for our public services, especially within the health and social care system. To bring about meaningful change, the voices of those who access these services, including the most vulnerable, must be central to any reform process. Specifically, within the health and social care sector, we urge that the 2016 recommendations from 'Power to People' are revisited to drive the bold actions necessary for real transformation. As highlighted in that report:

"... the system is collapsing in slow motion. Maintaining the status quo is not an option. Nor is a piecemeal approach to reform. The agenda we have set is ambitious, and we do not underestimate the challenge of delivering it, but it is a challenge which must be tackled if a total collapse of the system is to be avoided."

These conclusions, made in 2016 by the expert committee led by Des Kelly and John Kennedy, underscore that the time to act on these recommendations is long overdue. The Programme for Government must now illustrate how its commitments will translate into real, substantial change within health and social care and across all public services.

### Building New Foundations

ARC NI **agrees** that these are the right commitments in relation to the plans for investment in infrastructure. We welcome the planned investment programme however would urge integrated cross-departmental strategies and associated funding.

### Shaping a Better Tomorrow

We welcome the focus on key missions however we note the consultation asks for feedback about the 9 priorities, then 8 commitments to 'Building new foundations' and then 3 Missions and 1 cross cutting commitment re Peace. The draft Programme for Government is generally clear but it starts to get somewhat confusing by the end as to how the mission statements, the priorities and the commitments to 'building new foundations' (plus the planned outcome domains) are all linked and interrelated. A one page overview as part of the final Programme for Government would be useful to illustrate the overall programme.

## People Mission

Whilst we accept the action proposed, we feel strongly that the learning disability population, and their family carers are unlikely to benefit unless there is a clear reference made to this population. In our opinion, this is currently a significant gap throughout the Programme for Government proposals and our experience would conclude yet again, this population will be forgotten, becoming further disadvantaged.

In 2005 the 'Equal Lives' Report (2005) stated that progress needed to be accelerated on establishing a new service model, tackling areas where inequality hits people with a learning disability the hardest. The report stated a model should draw a line under outdated notions of grouping people with a learning disability together and their segregation in services where they are required to lead separate lives from their neighbours. Whilst some progress has been achieved, it is fair to say the model of the future continues to need to be based on integration, where people participate fully in the lives of their communities and are supported to individually access the full range of opportunities that are open to everyone else. The Department of Health is reviewing the model but cross-departmental action is critical in achieving this mission of 'wanting everyone to benefit from a fair and inclusive society where everyone flourishes, no one is left behind, and everyone is made to feel welcome'.

The learning disability community would therefore have expected to see reference to the Disability Strategy as this is the cross-departmental approach to tackle inequalities and promote inclusion of the people we support.

Furthermore there is no reference to the reform of adult social care within the people mission. Our adults with a learning disability, autism and other support needs are arguably the most frequent users of adult social care in comparison to, for example, older people. We would expect to see the reform of adult social care included within the list of action, particularly as reform of children's services is listed.

It is well documented that transition from children to adult services is challenging for people with a learning disability, autism or other support needs. The reform teams are working closely together for the benefit of the learning disability population. This model of good practice should be acknowledged and included within Programme for Government.

## Understanding Missions by Tracking Wellbeing

ARC NI **agrees** with the proposed approach outlining how progress will be measured through a Wellbeing Framework.

The Wellbeing dashboard is an excellent tool and provides a summary of metrics based on the general population, which offers the Executive data to analyse in line with the Programme for Government priorities. However data relating to children and adults with

a learning disability, autism or other support needs has, and continues to be lacking. At best this is captured within 'pan-disability' statistics. This is at risk of masking the reality of the nuanced barriers faced, and specific inequality experienced, by children and adults with a learning disability and or autism.

We have been calling for this to improve and change for a significant number of years and whilst the recent change to the Census data helps, it will not fully meet the needs of this well being framework.

We therefore will assume that the imminent cross-departmental Disability Strategy which will soon be issued for consultation, will attempt to address this and counterbalance the risk of inaccurate reporting.

### Concluding Comments

In conclusion we do not feel the Programme for Government fully acknowledges and demonstrates its value to partnership working, and the Independent and Charitable sectors that lend their support to public services in achieving progress under a Programme for Government. We would have expected to see this clearly articulated throughout Programme for Government.

Furthermore, we feel the NI Executive needs to better acknowledge those that face the greatest inequalities and in response, reference within Programme for Government their four Social Inclusion Strategies, namely disability; gender; poverty; and sexuality. We would also advocate the opportunity to acknowledge within Programme for Government their commitment to strengthening its rights-based approach by adopting the UNCRPD.

Overall, there felt a real disconnect between the four missions and the nine priorities. And the lack of specific, measurable, achievable, realistic and timely (SMART) objectives makes it challenging to identify outcomes, which in turn reduces accountability and risks real change and progress from being achieved.

We propose that the final Programme for Government illustrates how the missions link with the priorities and a set of key actions (one page per priority).

Action plans can then articulate SMART objectives that aim to fulfil the priorities and contribute to the missions, both in the immediate and longer-term.

Whilst we appreciate an Easy Read version of the consultation was available, it failed to include information, for example how progress will be monitored e.g. through a Well Being Framework. We would expect to see a final publication of the Programme for Government which is accessible for all and ensures everyone has the right to the same information.

Finally, we acknowledge the restraints that the NI Executive face when setting the NI budget, including having to currently work within single year funding envelopes. Furthermore, we understand everyone is affected by rising costs which fall outside of

budgets, including inflation and legal requirements such as National Living Wage. However, until such times as government departments consider ways to work more efficiently together, setting clear 'shared priorities' there will continue to be significant waste of public funds. Partners find this infuriating, particularly as they experience inequitable treatment through public fund contracts which often are driven to the lowest cost, and which fail to acknowledge a business need to fulfil full cost recovery.

We would therefore expect to see a costed implementation plan published on an annual basis in line with the final Programme for Government, detailing how each department is going to contribute financially to the proposed action.