

Consultation Response submitted by  
Association for Real Change, Northern Ireland (ARC NI)

DECEMBER 2025

## **CONSULTATION RESPONSE – PUBLIC HEALTH AGENCY PARTNERSHIP & ENGAGEMENT STRATEGY**

The Association for Real Change Northern Ireland (ARC NI) is an umbrella organisation supporting 60 providers of services for people with a learning disability, autism and other support needs across Northern Ireland. We also directly support over 50 Experts By Experience. These are our Telling It Like It Is members, all of whom have a learning disability. ARC NI provides leadership, enabling a collective voice for the sector, through the fostering of collaboration between statutory, independent and voluntary providers. Everything we do is to improve the quality of life for people with a learning disability and autism.

### **Section 1**

We strongly support the PHA's commitment to Partnership and Engagement to protect and improve the health and wellbeing of people and to reduce health inequalities. As would be expected our strong support to this commitment is due to the significant and well documented health inequalities people with a learning disability experience. In line with our continuing advocacy for people with a learning disability, we wish to highlight several important issues and questions. Many of these build on previous engagement with the PHA.

We believe that without specific attention and targeted action, people with a learning disability in NI risk being overlooked, even in well-intentioned engagement frameworks. To engage requires information in a variety of accessible formats to enable the opportunity for participation and a voice to be heard. As a charity that advocates for the rights of people with a learning disability, autism and other support needs we were disappointed that the draft 'Partnership and Engagement Strategy' was not available in an Easy Read format. We do note there was a short film created but Easy Read information is a requirement for many people with a learning disability. ARC NI therefore advocates that all future publications are available in accessible formats, specifically Easy Read.

## 1.1. Is the information contained in the below sections easy to understand?

1.1a. *Easy to Understand - Section 1.0 Context of the Strategy:*

**Strongly disagree**

b. *Easy to Understand - Section 2.0 Stakeholders:*

**Strongly disagree**

c. *Easy to Understand - Section 3.0 The Plan:*

**Strongly disagree**

d. *Easy to Understand - Section 4.0 Conclusion:*

**Strongly disagree**

## Section 2

Vision/Aim Comments:

Both the vision and aim of the strategy highlight the importance of collaboration and inclusivity. However, the strategy will only strengthen partnership working if supported by clear accountability structures and if it actively embeds co-production with groups experiencing the greatest inequalities. At present, the strategy lacks clarity on how engagement will shape decision-making, not merely inform it. This includes people with a learning disability and their respective organisations.

There is a clear policy direction in HSC of early intervention and prevention and ARC NI welcomes this. However, we have raised concerns with how the ICS can equitably support the learning disability population and we continue to reiterate this within the new neighbourhood model. To that affect, ARC NI would encourage the PHA Partnership and Engagement Strategy acknowledging the disproportionate inequalities faced by our community and include 'We Matter' as a key strategic driver.

ARC NI welcomes the inclusion of Appendix 2 which demonstrates the variety of stakeholders identified as critical to the success of this strategy. ARC NI would urge caution at citing one umbrella organisation which represents a particular service type e.g. Care Home and Programme of Care area e.g. older people. ARC NI as a charitable umbrella, representing cross-sector organisations offering multiple social care service types for a different Programme of Care area has not been identified.

ARC NI would seek expansion on the thinking of 2 areas, namely the Community & Voluntary representation; and the third largest Programme of Care area, people with a learning disability. As clearly referenced within the Chief Executive's Forward, the aim is to reduce health inequalities through listening to people's experiences and involving

them in effective commissioning, design, delivery and evaluation of services. These are powerful and central elements to move up the ladder of participation to success in true co-production. ARC NI would therefore recommend the aim be strengthened to reflect this.

Furthermore, we see no reference to data sets relating to health inequalities. This therefore leads to a lack of clarity as to how measurement will be sought to report the impact of this strategy. ARC NI would recommend the strategy when complete, teases out and transparently elaborates on outcome measures linked to the priorities.

## 2.1. Vision and Aim of the Strategy

*2.1a. The Partnership and Engagement Strategy clearly states the strategies that drive forward the work of Experience and Involvement.*

**Agree**

*b. The Partnership and Engagement Strategy clearly demonstrates the range of internal and external stakeholders impacted by the strategy.*

**Disagree**

*c. The Partnership and Engagement Strategy clearly demonstrates the Vision for Experience and Involvement in the PHA.*

**Agree**

*d. The Partnership and Engagement Strategy clearly demonstrates the Aim for Experience and Involvement in the PHA.*

**Disagree**

## Section 3

Priority comments:

ARC NI welcomes PHA's commitment within priority 1 to provide strategic leadership. ARC NI would welcome clarification on roles within the PHA that are learning disability specialists. With PHA's recent restructuring, can you provide more clarity on the staffing structure for the experience and involvement team and particularly which senior lead(s) will be responsible for learning-disability-specific engagement?

The strategy speaks of embedding lived experience and involvement in PHA's culture. What formal co-production mechanisms will PHA establish or strengthen to ensure that people with a learning disability are meaningfully involved not just consulted across all

stages of PHA's public health work? We note the mention of 'Reach outs' in the Equality and Human Rights Screening Template for people with disabilities to have their input in the Partnership and Engagement Strategy. We welcome this intention, however the lack of detail and concrete mechanisms that are specifically designed for people with a learning disability must be noted. Without such mechanisms, the lived experience of people with a learning disability, risks being aspirational rather than embedded practice. This is of particular importance considering the stark health inequalities the learning disability population face in Northern Ireland. Moreover, this is something the PHA are aware of and highlighted in the 'Dying for Change Conference' in March of this year. ARC NI would advocate that more detailed consideration is required and articulated to concrete co-production mechanisms that ensure the lived experience of the learning disability population, whose lives are already cut short by such disparities, is prioritised.

ARC NI welcomes the ambitions listed in Priority 2. Regarding the partnership with universities and healthcare education providers, we would like to highlight ARC NI's experience of over two decades in delivering high quality health and social care training. In fact, we often provide learning disability induction training to help staff develop the appropriate skills and knowledge to ensure a basic understanding of learning disability and the impact it has on people's lives. We also supported the PHA raising awareness of the various cancer screening programmes amongst social care staff that support people with a learning disability. Our website hosts a range of information and resources that the learning disability community, including family carers, benefit from. Thus, we would like to extend the support of ARC NI to the PHA should it be of mutual benefit.

ARC NI welcomes priority 3 of connecting and engaging. Establishing accessible ways for people to play a key role in informing and influencing services is an important ambition. The draft strategy itself does not go into much detail regarding this, however, in the Equality and Human Rights Screening Template, there are various examples mentioned of ways to accessibly connect and engage. Firstly, the template states that the Partnership and Engagement strategy has been screened for accessibility and translated into Plain English. Moreover, it is 'intended' that the strategy will also be translated into Easy Read format. Whilst the intention is to be inclusive, genuine inclusion requires accessible communication methods from the outset. Thus, the strategy being translated into easy read format should be a general standard adopted by the PHA to ensure that people with a learning disability are involved in the consultation process from the very beginning.

Additionally, it is stated in this same document that the PHA 'actively promotes the inclusion of disabled people in service planning, monitoring and evaluation through Personal and Public Involvement Initiatives and advisory groups.' Again, this is a worthy

ambition, however we would argue that ‘promotion of’ and ‘inclusion of’ are not the same thing. Thus, genuine inclusion must meet the needs of the learning disability population to ensure genuine engagement. ARC NI seeks clarification as to how the PHA will ensure accessibility in its engagement processes for people with a learning disability? How will people with a learning disability be meaningfully involved, not just consulted, across all stages of PHA’s public health work?

ARC NI welcomes priority 4 as in our opinion, this is the vehicle for measuring the success of this strategy. To measure success, data is required. ARC NI hold concerns however that there is inadequate robust data systems currently established that can report our population. Firstly, we are unable to account for each person (regardless of age) living in Northern Ireland with a learning disability. Whilst figures reported by the most recent Census would suggest total population is exceptionally small, the limitations in and barriers to reporting within Census data are well documented for our population. The Department of Health's figures whilst also low recognise they only count those that meet the entry criteria, this does not negate the right for those that fall below this to have their health protected. Furthermore, DoH data also acknowledges there are many people who would meet entry point criteria but who live at home and are not yet supported by statutory services.

In prior correspondence and consultations, including with the Department of Health, PHA and the Programme for Government, ARC NI has raised the need for robust health data for people with a learning disability. ARC NI would therefore welcome clarity on which data sets and indicators PHA will use under this engagement strategy to monitor inequalities specifically for the learning disability community? Moreover, how will you ensure that lived-experience feedback, from people with a learning disability, is translated into measurable performance metrics in your strategy?

### **3.1. Strategic Priorities**

*3.1a. The priorities listed in section 3.4 are clearly stated and support the implementation of the Vision and Aim of the Partnership and Engagement Strategy.*

**Unsure**

*b. This question refers to Priority Area 1 – ‘Provide Strategic Leadership’. The indicators set out in this priority area are clear and will support meeting the goal of this priority area.*

**Unsure**

c. *This question refers to Priority Area 2 - 'Building Knowledge, Skills and Understanding'. The indicators set out in this priority area are clear and will support meeting the goal of this priority area.*

**Unsure**

d. *This question refers to Priority Area 3 - 'Connect and Engage'. The indicators set out in this priority area are clear and will support meeting the goal of this priority area.*

**Unsure**

e. *This question refers to Priority Area 4 - 'Identify Learning and Demonstrate Impact'. The indicators set out in this priority area are clear and will support meeting the goal of this priority area.*

**Unsure**

## **Section 4**

### **Overall, do you have any final comments to make on the Partnership and Engagement Strategy?**

ARC NI very much welcomes the ambition and direction of the PHA's draft Partnership & Engagement Strategy 2025-2030. We believe, that with stronger emphasis and commitment to the learning disability population, the PHA can make significant strides in reducing health inequalities and embedding meaningful involvement in everything it does. We have one query regarding pages 36-37 of the Equality and Human Rights Screening Template. Under 'What else could you do to encourage disabled people to participate in public life' there are various intentions stated. So, are these just examples of what 'could' be done or are these intentions going to come to fruition within a time period? We would appreciate clarification on this as most of these statements seem essential to the basic workings of the PHA, for example, encouraging 'positive attitudes to disabled people' and challenging 'negative stereotyping'.

Based on the above concerns and questions, ARC NI recommends that the final published Partnership and Engagement Strategy:

1. Explicitly identifies people with a learning disability as a priority engagement group, rather than being subsumed under generic 'Section 75 groups.'
2. Includes an explicit commitment to collecting, monitoring, and reporting health inequality data disaggregated for people with a learning disability. This should include specific indicators and targets.

3. Establishes dedicated structures at both regional and local levels to ensure consistent and meaningful involvement of the learning disability population. For example, specific LD advisory panels or advisory panels chaired by alternating 'service users' that represent all Section 75 groups. Moreover, we stress the importance of tailoring these engagement tools for people with a learning disability. Importantly, any co-production structures employed must ensure that the voices of people with a learning disability shape public health work.

4. Includes robust and genuine accessibility commitments from the outset.

ARC NI looks forward to opportunities of collaboration and partnership with the PHA to ensure that people with a learning disability are central to public health improvement in NI and the more active inclusion of people with a learning disability participating and engaged in the work of the PHA.