

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

February 2025

## **PHA Draft Corporate Plan 2025-2030**

Since 1999, the Association for Real Change in Northern Ireland have been bringing people together. We change thinking, change practice, and change the lives of people with a learning disability, autism, and other support needs. 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

### **Q1: Do you agree with our purpose? If not, what alternative do you suggest?**

ARC NI's vision is for communities to celebrate the difference, respect, listen to and include people with a learning disability, autism and other support needs. We therefore agree with, and welcome your purpose, to reducing health inequalities.

According to a research article by a University of Ulster student, there are a range of health inequalities amongst people with a learning disability:

“Figures show that 17% of people with learning disabilities in England are [underweight](#) in contrast to just 2% of the general population (in part due to hyperactivity). In contrast, people with learning disabilities can also be prone to higher levels of [obesity](#) (which can lead to type 2 diabetes) for various reasons, such as anti-psychotic medication and sedentary behaviour. Other health issues include around half having vision problems, a quarter with hearing loss, a third with limited verbal communication and a fifth with no verbal communication. Furthermore, 40% experience additional [mental health issues](#)” (McVeigh, 2017).

Based on statistics from 2021 , other than COVID-19, the most commonly recorded causes of death for all ages from 2018-2021 : diseases of circulatory system, diseases of respiratory system, cancers, diseases of nervous system, congenital malformations, and diseases of digestive system.<sup>1</sup> People with learning disabilities may also have

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<sup>1</sup> LeDeR. *Learning from Lives and Deaths- People with a Learning Disability and Autistic People*, 2021. P. 28. (Table 2.4: The 10 most commonly recorded ICD-10 chapter causes of death for 2018 to 2021)

poorer health resulting from lifestyle issues such as diet and exercise for which they have not received enough advice and support.<sup>2</sup> Also many face issues accessing other healthcare such as dental checks. Another issue within the learning-disabled community that must be addressed is the perceived over medication of people with a learning disability. Psychotropic medicines can benefit some people with mental health conditions however they are also given to people because their behaviour is seen as challenging. People with a learning disability, autism or both are more likely to be given these medicines than other people. A 2018 NHS England leaflet, STOMP, project in England to stop the overuse of psychotropic medicines noted that everyday approximately 30,000 to 35,000 adults with a learning disability are taking psychotropic medicines, when they do not have the health conditions the medicines are for. The issue with these medications being overused is that they can cause problems when people take them over a long period of time. Undesirable side effects include weight gain, feeling tired or ‘drugged up,’ and serious problems with physical health.<sup>3</sup>

These statistics highlight the clear health disparities in comparison to the general population. The health system should meet everyone's needs, yet people with a learning disability face worse physical and mental health outcomes. They have higher rates of premature death and a shorter life expectancy—men with a learning disability die 23 years earlier, and women 27 years earlier than the general population. Additionally, 60% die before age 65, compared to 10% of the general population. While some of this is due to health conditions, people with a learning disability are four times more likely to die from preventable causes.

Whilst we agree with the PHA’s overall purpose and the focus on reducing health inequalities, we have concerns as to how this will be achieved if specific effort is not made to interrogate the data sources that we do have, to inform these priorities. Dr Lesley-Ann Black (2013) discusses this in her research paper, stating that because there is no central register maintained by the Department of Health, it is “difficult to target services at this group and to monitor the state of their health in terms of health inequalities”.

A study<sup>4</sup> led by Ulster University in 2018 aimed to access and analyse existing administrative data relating to learning disability in NI, from 2007 and 2011, in order to highlight the availability, utility and importance of learning disability data in NI. The study revealed (i) the value and potential of Census data, alone, in identifying and locating individuals with learning disability in NI, and describing much about the socio-economic, health, education and demographic characteristics of the learning disability population, (ii) the limitations of poorly defined/designed Census survey questions and the importance of survey item specificity for accurately recording learning disability

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<sup>2</sup> National Institute for Health and Care Excellence. Care and Support of People Growing Older with Learning Disabilities. (April 2018), P. 42

<sup>3</sup> STOMP: Stopping the Over Medication of People with a Learning Disability, Autism or Both. (NHS England 2018 leaflet), [STOMP Everyone working together to stop the over use of psychotropic medicines and to improve people's quality of life \(england.nhs.uk\)](#) p.3.

<sup>4</sup> [https://arcni.org.uk/wp-content/uploads/2024/04/LD-Final-Report\\_DataResearch.pdf](https://arcni.org.uk/wp-content/uploads/2024/04/LD-Final-Report_DataResearch.pdf)

prevalence, (iii) the immense value of disability-focussed household survey data obtained using probability-based sampling methods and its potential to contextualise and amplify the findings from Census data, (iv) the presence of, but, inaccessibility to, a variety of important Northern Ireland administrative data resources that have the potential to transform our understanding of important learning disability issues relating to e.g. health, service use, medication use, education and employment, and finally (v) the importance of administrative data awareness and timely use of data by all.

ARC NI's response to the PfG (Programme for Government) consultation, recognised the benefit of a 'Wellbeing dashboard' as a summarising tool for metrics on the general population, which in turn helps to inform the Executive on the specific data relating to their priorities. We therefore urge thorough interrogation of the data sources that we do have, to inform the PHA priorities and target specific action to reduce the health inequalities experienced and barriers faced by people with a learning disability and autism.

ARC NI also welcomes the reference of reform within the PHA's Corporate Plan. ARC NI is an active member of the Social Care Collaborative Forum. There is a tendency when thinking of social care to purely think through the lens of how this supports older people. People with a learning disability, autism and other support needs, seek support through social care from birth. If the recognition of this is not adopted more widely, the required cultural shift to meaningfully address barriers and inequalities will not occur.

We are aware the PHA are facilitating a conference on 6<sup>th</sup> March and will be in attendance. Our hope is that this event will reiterate the need for more targeted action led by PHA in addressing the health inequalities of people with a learning disability.

**Q2: Do you agree with our vision and values? If not, what alternative do you suggest?**

ARC NI agrees with your vision and values. In terms of vision, a healthier Northern Ireland for everyone is of utmost importance. As an organisation we advocate for and work towards a healthcare system that is for everyone and thus, meets individualised needs.

In regard to your values, we appreciate your focus on individuals and communities. Moreover, ensuring that everyone is treated with dignity, respect and compassion are core values that we too pride ourselves on. We hope that these values will continue to be evidenced in practice, and that positive outcomes will result.

We welcome the use of an Easy Read document for this draft consultation. This ensures greater accessibility and the right to access knowledge and information for everyone. We think the Easy Read document could be strengthened with the use of key terms and subsequent definitions. For example, the inclusion of 'health inequalities' followed by a simple explanation of the term. This term is of great relevance to people with a learning disability, autism and other support needs and thus, should be included in this version.

Finally, we note that collaborative working is referenced in the values and reiterated through your focus on whole system cross departmental/government approach. At ARC NI we have been championing cross-departmental collaboration for decades. As our event during Learning Disability Week<sup>5</sup> highlighted, a barrier to accessible transport can result in an inability to maintain employment which can impact on a person's health. Furthermore, insufficient support to live independently within the community can result in an individual who is unable to read, missing appointments with GP's which implicates their medicine management plan. We would therefore urge more detail outlining how the PHA plans to achieve cross-departmental/government working to reduce health inequalities.

**Q3: Referring to the draft plan, do you agree with Outcome 1: Protecting Health and the priorities listed?**

We do agree with Outcome 1: Protecting Health and the accompanied priorities. However, we do want to address some gaps.

Firstly, under this outcome you state that one of your priorities is to “lead the development and commissioning of vaccine programmes to ensure they are accessible to all, addressing the associated barriers and inequalities and ensure there is a key focus on seldom heard groups.” This is a commendable aim, and we welcome the focus on marginalised groups. Additionally, addressing barriers and inequalities is integral to ensuring accessibility, particularly for people with a learning disability, autism and other support needs. Due to this document's draft nature, we assume that these various and specific barriers and inequalities will be further examined in a final document, as well as explaining how they will be addressed. We will take the opportunity in 4.5 to share some intrinsic knowledge on the barriers and inequalities faced by people with a learning disability, autism and other support needs and suggest what can be done to overcome these barriers.

In addition, whilst ensuring greater uptake in vaccination programmes is of huge importance, we would also stress the need to increase participation in screening programmes as a priority. Aiming for high-quality screening programmes is a laudable priority, however perhaps an explicit focus on uptake would be more fruitful. Furthermore, screening programmes are a particular area of concern for people with a learning disability. DHSSPS (2012) highlight this, stating that:

“Even with such a dramatic health profile, the learning disabled population is less likely to get some of the evidence-based screening, checks and treatments they need, and continue to face real barriers in accessing services. Information on, and activities in, health promotion can be difficult to access. These factors

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<sup>5</sup> <https://arcni.org.uk/meaningful-citizens-our-stories-of-barriers-to-inclusion/>

contribute to preventable ill health, poor quality of life and potentially, premature death.”

Thus, for individuals with a learning disability, autism, or other support needs, participating in health screenings can be difficult. Services are required to make reasonable adjustments to remove barriers and ensure equal access. This includes providing easy-to-read information, allowing extra time for appointments, and offering wheelchair access. Additionally, individuals with a learning disability are at higher risk for certain cancers, such as bowel cancer, due to underlying health conditions, longer life expectancy, delayed diagnoses, and lifestyle factors like poor diet and obesity. Improved healthcare access, better data collection, and training for healthcare providers are essential for addressing these health inequalities. Better awareness, increased screening participation, and providing accessible healthcare can help reduce cancer risks and improve early detection for individuals with a learning disability. However, NHS data shows lower screening participation for people with a learning disability: 75% for bowel cancer, 51% for breast cancer, and 30% for cervical cancer, compared to 83%, 67%, and 76% in the general population, respectively.

Barriers to screening include inaccessible invitations, complex booking systems, time pressures, mobility issues, communication difficulties, and lack of knowledge among healthcare workers and carers. Additionally, concerns about consent and stigma around certain screenings, like sexual health, create further challenges.

To improve participation, it's essential to provide training for healthcare workers and carers, use accessible resources like easy-read materials, focus on understanding rather than judgment, and raise awareness about available resources. At ARC NI, people with a learning disability have been delivering training to Trust staff working in learning disability teams for over 15 years. This links to another priority under Outcome 1 - “Build public confidence and trust in public health advice, information and messaging through health literacy via education and engagement with the public.” We welcome this priority but stress the importance of a specialised/individualised approach to this education and engagement, in order to meet the needs of people with a learning disability, autism and other support needs. Hence, we would stress the importance of prioritising the development of screening programmes, as well as vaccine programmes, to ensure they are accessible to all. Early detection saves lives, thus addressing these barriers and inequalities is of intrinsic value.

Additionally, we note the commitments to “strengthening co-ordinated approaches.” We urge the PHA to ensure statutory, voluntary, and private sectors collaborate as equal partners in developing and implementing joined-up response plans.

**Q4: 4 Referring to the draft plan, do you agree with Outcome 2: Starting Well and the priorities listed? If not, what alternative do you suggest?**

We agree with Outcome 2: Starting Well and the priorities listed.

ARC NI is firmly committed to early intervention and prevention. We note prioritising the support for families with a particular focus on the first 1,000 days. However, children with a learning disability and their families, need ongoing support beyond these first 1,000 days given this is a life-long condition.

We welcome the explicit references under this outcome to those with additional needs and Special Educational Needs (SEN). “Health inequalities can have a profound impact on a child’s start in life. All children and young people, including those who have additional needs, should have the opportunity for better health and wellbeing.” The profound impact of health inequalities on a child’s early life is especially prevalent within the learning disability community. Black (2013), highlights this, writing that, “Health inequalities start early in life and result from barriers to accessing timely and appropriate care.”

Supporting children and young people with SEN, along with families and carers in “addressing the unique health challenges and disparities they face, by enhancing access to services, resources and support systems that contribute to their physical, mental, emotional and social wellbeing.” We welcome this whole-system approach. At ARC NI, we believe that collective advocacy is the way to create positive change. Furthermore, whilst prioritising the “support of adolescents to establish patterns of behaviour that can protect their mental and physical health” is again an important priority, the translation of this for children and young people with a learning disability needs to be explicit. The risk is that a reader could mis-interpret this to relate to managing behaviour rather than supporting a person to learn the importance of a balanced diet. Furthermore, the support for children, young people and their family carers as they transition into adulthood are more complex when you have a learning disability, autism and other support needs. This has been acknowledged through the recent reform led by DoH of children with disabilities and the reform of the Learning Disability Model. We encourage and therefore urge the PHA to consider a cradle to grave model of support for people with a learning disability, autism and other support needs.

**Q5: Referring to the plan, do you agree with Outcome 3: Living Well and the priorities listed?**

Things have improved from the 1990’s as outlined in Equal Lives (2005), including:

- an increasing number of people with a learning disability are living longer and have healthier lives
- a greater number of children with complex health needs and multiple disabilities are surviving into adulthood; and

- people with a learning disability who experience mental health problems are living in local communities rather than specialist hospitals.

However as evidenced at the outset of our response, people with a learning disability experience substantial health inequalities and there is more to do.

We therefore welcome Outcome 3's focus on health inequalities and the targeted approach that will be adopted for those most vulnerable in our society. We assume these 'targeted approaches' will be further developed and explained in the final draft. We stress the importance of understanding the different and specific health inequalities experienced by individuals with a learning disability, autism and other support needs. Thus, we would encourage the following examples be encompassed under your 'targeted approaches'. For example, more learning disability training for healthcare professionals, reasonable adjustments in health care settings, increased number of annual health checks, more health facilitators to help with patient understanding and better collaboration between Learning Disability Teams and primary care staff. These examples are just a start in overcoming the barriers faced by people with a learning disability, autism and other support needs.

Additionally, under outcome 3, there is also a focus on improved mental health and emotional well-being. We agree with this priority as it is certainly a major issue of concern for people with a learning disability, autism and other support needs. We would encourage cross-collaboration with the Department of Health's work on the Learning Disability Model. It is important to note the disparities in mental health in NI, for example, the prevalence amongst young men and members of LGBTQ+. People with a learning disability can fall into each of these categories and statistically, are more likely to experience poor mental health, have it overlooked or misattributed.

**Q6: Referring to the plan, do you agree with Outcome 4: Ageing Well and the priorities listed? If not, what alternative do you suggest?**

ARC NI agrees with Outcome 4 and the priorities listed and were delighted to be asked by the Department of Health to create accessible films on Advanced Care Planning through our Experts By Experience, TILII TV. We stress the importance of advance care planning tools and end-of-life care for people with a learning disability, autism and other support needs and their families. Ensuring that everyone has a say in end-of-life decision-making is of integral importance. Thus, making sure reasonable adjustments are made for those with a learning disability to help support their decision-making is a priority. For example, Trinity College Dublin created an '[Accessible Planning Tool](#)' to allow individuals, families and carers to plan and support thinking ahead, end of life care, wishes to be respected and death.

Additionally, support for the older population is an agreeable priority. But again, an intersectional approach to this support needs to be taken. Many people with a learning disability, autism and other support needs, whilst having a lower life expectancy, now

live into old age. Thus, what measures are being put into place to ensure that they are getting the best support in their old age? Additionally, there is no reference to supporting older carers. For carers, this role lasts a lifetime as many continue to care for relatives well into adulthood. Moreover, unfortunately the significance of their role is often overlooked by society, as well as the challenges they face as an ageing person providing care. Therefore, explicit reference to the role of older carers and how best to support them should be included in the final draft.

**Q7: Referring to the plan, do you agree with our organisation ambition and priorities listed? If not, what alternative do you suggest?**

This section of the Plan focuses too much on PHA's internal structure, lacking clarity on its strategic and external role in public health partnerships. The 'Our Organisation' section and diagram need simplification, for example, the distinction between 'Chief Executive' and 'Chief Executive Office' is unclear. We support the ambition to be an exceptional organisation and its commitments but suggest clearer articulation of its partnership role.

Lastly, we commend the focus on evidence-based research and data use, especially the clear infographics. For the final version, an accessible summary with key infographics would enhance communication of the Corporate Plan.

**Q8: Is there an outcome you feel is missing or is not sufficiently reflected?**

We welcome the focus on health inequalities but suggest improving it by emphasising that they are not only avoidable but also unfair, unjust, and a human rights issue. Additionally, we would suggest that the definition of 'health inequalities' be explained in simpler terms and used consistently across HSC services. This should enable a better understanding for the public, free of jargon, and for those directly impacted by said health inequalities.

Finally, whilst the term 'disability' is mentioned in the document, it is only explicitly stated three times and in the Easy Read version, there is no explicit mention. As aforementioned, in 4.1, there are issues with grouping individuals with a learning disability under the pan-disability umbrella. Considering how impacted people with a learning disability, autism and other support needs are by health inequalities, we would strongly encourage explicit reference to this community in the final draft.

**Q9: Have you any other comments or suggestions to improve the document as a whole? If so, please outline these.**

We have already offered some thoughts on more information that should be included and the importance of this information in full being accessible. ARC NI is happy to consider any requests for support.