

Consultation response submitted by
Association for Real Change, Northern Ireland (ARC NI)
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REFORM OF ADULT SOCIAL CARE

Association for Real Change (ARC NI) is the representative organisation for the learning disability community. We have been operating in Northern Ireland since 1999 and our goal is to achieve real change that puts people with a learning disability, autism, or other additional support needs at the centre of decision-making, and in the heart of their communities.

We support 49¹ learning disability providers, 29 of whom are charitable organisations, 16 private and 4 Trusts. Excluding the Trusts, members employ approximately 17,000 staff and support approximately 70,000 people.

ARC NI welcomes the opportunity to respond to this consultation.

The importance of social care for an adult with a learning disability

ARC NI welcomes the explanation within the public consultation documents outlining the purpose of adult social care, recognising the diversity of supports, the individualised approach required and the value of maintaining well-being. This is of particular importance to people with a learning disability, as learning disability is a lifelong condition.

Research by Carers UK and the University of Sheffield in 2015 cites that there are approximately 22,000 family carers in Northern Ireland, providing care and support to a loved one with a learning disability, many of whom are in ill health.

The Health budget is currently supporting approximately 9,000 adults with a learning disability that meet an IQ threshold. This spend is increasing year on year and yet we are not collaboratively achieving the outcomes we want to best support people with a learning disability.

Whilst the population percentage may be lower than other programme of care groups, individuals with a learning disability will seek social care support for most of their adult life. Hence any reform of social care needs to recognise and reflect this in recommendations.

ARC NI does not feel the proposed consultation document acknowledges the bespoke needs of people with a learning disability.

We recognise however this proposal is about high level reform and further scoping will be required. Below we have detailed key issues of concern expressed by our members.

¹ See Appendix 1 for full list of ARC NI members

Vision for the Future

ARC NI strongly welcomes the vision outlined for an adult social care system and naturally we would lean on a strategy/vision for learning disability to base our feedback on. Recent work to develop a transformational regional position is unfortunately incomplete and so the current policy framework for learning disability is 'Equal Lives' (2005), many elements of which are echoed in this 2022 consultation, as required to reform and shape the future of adult social care.

Specific 'Equal Lives' objectives pertinent to the current reform include the following:

- OBJECTIVE 3 - To ensure that the move into adulthood for young people with a learning disability supports their access to equal opportunities for continuing education, employment and training and that they and their families receive continuity of support during the transition period.
- OBJECTIVE 4 - To enable people with a learning disability to lead full and meaningful lives in their neighbourhoods, have access to a wide range of social, work and leisure opportunities and form and maintain friendships and relationships.
- OBJECTIVE 5 - To ensure that all men and women with a learning disability have their home, in the community, the choice of whom they live with and that, where they live with their family, their carers receive the support they need.
- OBJECTIVE 6 - To ensure that an extended range of housing options is developed for men and women with a learning disability.
- OBJECTIVE 7 - To secure improvements in the mental and physical health of people with a learning disability through developing access to high quality health services that are as locally based as possible and responsive to the particular needs of people with a learning disability.
- OBJECTIVE 8 - To ensure that men and women with a learning disability are supported to age well in their neighbourhoods.
- OBJECTIVE 9 - To enable people with a learning disability to have as much control as possible through developing person-centred approaches in services and ensuring wider access to advocacy and Direct Payments.
- OBJECTIVE 10 - To ensure that health and social services staff are confident and competent in working with people with a learning disability.
- OBJECTIVE 11 - To ensure that staff in other settings develop their understanding and awareness of learning disability issues and the implications for their services.

It is sad that over 15 years later, in spite of DoH endorsement, very few of the recommendations for Equal Lives, are being articulated. Until such times as honest and transparent, collaborative conversations occur with clear accountabilities built into the system to reflect on why these areas continue to require significant change, we fear true reform being operationalised is at risk.

ARC NI is in agreement with the urgent need to reform adult social care to better meet the needs of people with a learning disability.

Sustainable Systems

The experience of members with the commissioning arrangements is often very frustrating. Contracts are often short term, some reliant on cross-departmental funding and regularly considered a cheaper option. This has significantly de-stabilised the future of services and supports to people with a learning disability over the years.

At a recent meeting with the Permanent Secretary of Health, 50% of the members were presenting deficit budgets. These are not for profit organisations which are currently not even in a position to develop break even budgets.

Furthermore, the lack of forward planning for lifelong transitions for individuals with a learning disability has more often concluded in crisis support at a significantly higher cost than if properly planned with an individual, their family and in a timely manner.

Members are regularly held to account but there has been a lack of accountability by our statutory colleagues and this needs to change.

ARC NI welcomes the commitment referenced to a culture of getting it right for the people supported focused on outcomes however would strongly advocate that accountability needs to be strengthened.

Legislation

ARC NI welcomes the proposal to introduce legislation to support reform of adult social care and specifically the opportunity this presents to not only assess the needs of carers but mandating the responsibility to meet the needs of carers.

But legislation requires adequate resource and this has not been the case in the recent introduction of the Mental Capacity Act in Northern Ireland. This lesson must be learnt to enable true reform of Adult Social Care.

ARC NI advocates the need to adequately resource legislation for reform.

We also feel strongly that further legislative reform is required to support the change in culture outlined throughout the consultation. Specifically, the brief description of “supported living” reflects a very limited understanding of this approach.

Rather than supported living being a “model” of support, it is an approach which provides individuals with an opportunity to live the life they want where, how and with whom. This lack of understanding and the fact that a supported living approach is regulated within Domiciliary Care Standards, has for years created problems for members providing support in this way.

ARC NI would advocate the need to review the Health and Social Care Act with a view to developing specific standards to govern Supported Living.

True Cost of Care, Safe Staffing & Tariffs

ARC NI understand that tariffs can be identified for some social care services. The consultation refers to the breadth and diversity of social care. It also promotes the need to place the person at the centre to plan around their needs. Hence many aspects of social care are bespoke to the individual. A tariff, or standardised rate therefore is not always possible.

This is linked to safe staffing levels. Using a person-centred approach to service delivery requires that staffing levels, including skills necessary, are determined by the needs of the individual supported.

There is no reassurance provided within the consultation, that the true cost of these nuances will be recognised and met. This is at risk of contradicting other aspects of the consultation e.g., balancing the mixed economy.

ARC NI strongly advocates the need to acknowledge the inappropriateness of creating a regional standardised rate/tariff for all services within social care.

Where a rate can be identified and applied it is critical that appropriate annual uplifts are applied to maintain the true cost of a service. In ARC NI's experience many day services within social care have not had uplifts over several years. Not only are providers expected to deliver more but for less which has a knock-on effect on staffs' terms and conditions. Recognising and reflecting these issues in the reform of adult social care is critical in the maintenance of these very specialised services.

ARC NI would advocate that 'learning disability' be held at a regional level within the new proposed 'Integrated Care System' structure.

Valuing Workforce

Workforce

ARC NI welcomes the multi-disciplinary workforce review that has begun in learning disability. ARC NI is keen to ensure this includes all social care services. This will hopefully offer baseline data which can be further built on, to scope numbers and demography of our workforce; breadth of skill mix; and salaries of both statutory and non-statutory workers.

ARC NI fundamentally believes this will support the future planning required to meet growing demands placed on social care. However, the review in learning disability will take at least a year.

In the meantime, we are in the middle of an urgent and critical workforce crisis with our members managing risk on a daily basis. Across a sample of members, in the month of May 2022 alone they had an average of 22% vacant staffing hours which equates to an average of 70 full time equivalent staff. This has resulted in 42 referrals paused or turned down.

The Social Care Fair Work Forum has met twice since its establishment October 2021. Steps to address the lowest paid in social care have been offered to some but not all services, creating a risk of hierarchy of service value.

Uplifts to terms and conditions through Agenda for Change is not applied to non-statutory providers of social care. And inflationary uplifts are inconsistently applied by individual Trusts, if at all.

ARC NI looks forward to the development of a Social Care workforce strategy to address longer-term change however urgent steps are required now to ensure support can be maintained for those that require it.

ARC NI would urge that the social care workforce strategy be expedited with the urgent priority to focus on parity of terms and conditions for all workforce, regardless of employer.

We fully support initiatives around leadership, training and development and would encourage a cross-sectoral approach, enabling the social care workforce to come together to demonstrate the value of partnership working.

The heavy focus on training is not new and while we do strongly advocate the need for enabling continued professional development, we would note that the mandating of particular qualifications e.g. leadership qualification, does not guarantee good leaders. Historically training requirements has come at a significant cost, with commissioners refusing to meet these.

ARC NI would advocate the need to acknowledge training needs of social care workforce within the true cost of a social care service.

Individual Choice & Control

Currently choice and control is a concept rather than a reality for people with a learning disability and their family carers. Different Trusts have different processes and many examples have been cited by members, whereby family carers have been discouraged from seeing possible options of support for fear of having their hopes and expectations raised.

Furthermore, the assessment process (NIAST) is not understandable for many people supported and their family carers, which immediately limits the concept of 'choice and control'.

ARC NI strongly agrees with the need for accessible information to empower individual choice and control. We also agree with the need to address the care planning process, including the meaningful co-production of an individuals' care plan.

ARC NI also supports the need to address the barriers in achieving full implementation of Self-Directed Support. It is our experience that the greatest barrier to SDS is that choice and control remains largely with Health & Social Care Trusts.

We therefore welcome the proposed development of an 'In Control' action plan, including the adopting of the 'Making It Real' outcome measurement framework.

ARC NI is in full agreement with the ethos and direction of travel as outlined to address Individual Choice & Control.

We acknowledge the statement within the consultation that individual choice and control will be supported by the full implementation of the Mental Capacity Act 2016, and hence the assumption of assumed capacity as the starting point within social care practice. ARC NI members are however concerned that the plan for full implementation is unknown and that timescales have drifted. Whilst this is understandable, the Act plays a critical role in any reform.

ARC NI would strongly welcome the Department renewing their commitment to full implementation of the Mental Capacity Act, with a clear and transparent plan with timescales published.

Prevention & Early Intervention

Strengthening a System / Supporting Community

As outlined in much of the feedback above we are unsure this chapter reflects the reality of the challenge in reform required, to truly acknowledge, let alone support the role of our members in their prevention and early intervention services.

The majority of our members offer services to maintain a meaningful life, such as home, learning, employment, inclusion and maintaining good relationships. However, the extent of their role in identifying signs of additional supports to maintain an individuals' mental, emotional and physical well being are huge. This expertise tends not to be the 'commissioned service/support'.

For many people with a learning disability, they have been failed by mainstream services. For example, mental health services in community have on many occasions been unable to meet their needs, resulting in an over-extended admission to a hospital for treatment. We strongly articulated this case and the need to develop expert skill in community teams to meet the mental health needs of people with a learning disability in our response to the Mental Health Strategy. To date we see no plans to rectify this and two of the three hospitals are at full capacity, leaving in many cases, our members managing, without any recognition or additional resources, the mental well being of the people they support.

Whilst other policy areas talk about the meaningful inclusion of people with a learning disability in community life such as employment, recent funding pressures such as the exiting of European Funding, are placing this at significant risk and with no apparent recognition of the impact on physical, emotional, or mental well being.

This consultation document does not, in our opinion equally acknowledge the needs of people with a learning disability. This is what we regularly experience as a community, who are repeatedly treated as the forgotten, or less relevant. Therefore, we have very little faith and confidence that community planning partnerships led by local councils would have more understanding than our usual commissioners, the Health & Social Care Trusts.

Finally, as a consequence of unsustainable commissioning and the existing workforce crisis, our members have more recently had to pause or delay new referrals. To propose that prevention and early intervention can be accessed regardless of a statutory threshold of need, has not been the experience for people with a learning disability and their family carers.

The lynchpin in our view to resolve this is a cross-departmental strategy to meet the needs of people with a learning disability in Northern Ireland.

ARC NI would advocate a costed cradle to grave learning disability strategy with an outcomes based action plan be expedited, supporting various transition points in a person's life that includes cross-departmental commitments and financial support.

ARC NI would advocate that 'learning disability' be held at a regional level within the new proposed 'Integrated Care System' structure.

ARC NI would urge that the social care workforce strategy be expedited with the urgent priority to focus on parity of terms and conditions for all workforce, regardless of employer.

Supporting Carers

We agree with the principles acknowledged within the consultation document that family carers are in need of their own support, in addition to that of their loved one. We agree with the principle of co-production and empowering individual choice and control.

However, we feel that a relationship of trust needs to be better developed which is based on rhetoric becoming a reality, by not only having an assessment of their needs undertaken but support actually being put in place. Furthermore, a relationship based on trust will enable family carers discussing issues that they fear, such as future planning, an area that tends to result in a crisis for the person with a learning disability.

ARC NI would urge the “Preparing for the Future: A training manual for staff working with family carers of adults with learning disabilities” developed by Ulster University to form part of typical family carers’ assessments

Primacy of Home

This chapter of consultation is the most disappointing to ARC NI and its members as many people with a learning disability need support to live well in their communities.

The concept of Supported Living continues to be poorly understood as recently demonstrated within the Reform of Adult Social Care consultation.

Supported Living is not domiciliary care, nor is it a smaller scale residential setting. It is a range of bespoke person-centred services and supports designed to help people with a wide range of support needs retain their independence by being supported to live in their own home.

This lack of understanding is further compounded by its commissioning contracts and regulatory framework falling within Domiciliary Care. Some years ago, a working group was established comprising members from the Department of Health, Department for Communities (NIHE), RQIA and providers. This group was unfortunately stood down due to a change in personnel.

Cross-departmental responsibility for making the principle of primacy of home a reality for people with a learning disability is presenting real problems. As a result of the pandemic the Department of Health and Department for Communities have begun to strengthen their collaboration however the recent ‘Supporting People’ strategy presents real risks for people with a learning disability.

ARC NI would strongly advocate the Department of Health revisit the work of this group with a view to developing bespoke Regulatory Standards to govern the provision of Supported Living services.

Yet the consultation refers to expanding this support, in particular to meet the needs of those with complex needs. Our members have extensive experience in making this a reality for many people, resettled from long-stay hospital.

ARC NI would urge the Department of Health to reiterate its commitment to the resettlement of all people from Muckamore, Dorsey and Lakeview hospitals. This commitment needs to be accompanied by an action plan which needs adequate resources, timeframes, and measures of accountability.

2022/23 MEMBERSHIP

Action Mental Health	Livability
Ann's Care Homes	Live Life Well-Being Centre
Apex	Mainstay DRP
Autism Initiatives	Manor Healthcare Ltd
Belfast Central Mission	Mencap NI
Belfast Health & Social Care Trust	MindWise
Bolster Community	Northern Health & Social Care Trust
Camphill Community, Clanabogan	Orchardville Society Ltd
Camphill Community, Glencraig	Parkanaur College
Camphill Community, Holywood	Positive Futures
Camphill Community, Mourne Grange	Potens
CAN	Praxis Care
Caring Breaks	Presbyterian Council for Social Witness
Castleview Private Nursing Home	Priory Adult Care
Cedar Foundation	South-Eastern Health & Social Care Trust
Clanmil Housing Association	Stepping Stones NI
Conerstone Care 212 Ltd	The Beeches Professional & Therapeutic Services Ltd
Derg Valley Care	Triangle Housing Association
Extra Care	Western Health & Social Care Trust
Four Seasons Healthcare	
Friendship & Caring Trust Ltd (FACT Ltd)	
Harmoni	
Home Instead (Down & Lisburn)	
incredABLE	
Informing Choices NI	
Inspire Wellbeing	
Kilcreggan Homes Ltd	
Kingdom Healthcare	
L'Arche Belfast	
Leonard Cheshire	