

Consultation response submitted by

Association for Real Change, Northern Ireland (ARC NI)

SEPTEMBER 2021

Future Planning Model – Integrated Care System NI Draft Framework

ARC NI is a representative organisation supporting 48 cross-sector learning disability providers. ARC NI welcomes the opportunity to respond to this consultation.

The principle of an Integrated Care System (ICS) model - Section 3

Collaboration, integration, partnership

ARC NI agrees with the potential opportunity an integrated care system can offer to people living in Northern Ireland. Specifically, as referenced on page 3 in the Department of Health's 'Targeted Stakeholder Consultation Document' that an Integrated Care Model will:

- Observe the principles of increased autonomy and accountability at local decision making levels;
- See the delegation of decision-making and funding to local levels, with the exception of regional and specialised services;
- Allow for planning, management and delivery of specialised services at a regional level; and
- Be supported underpinned by an outcomes-based approach.

Collaboration is referenced as key which ARC NI endorses, however, to really achieve what is outlined in the blueprint will require a change in culture and existing systems. It is our experience that the current system, excludes the voice of non-statutory providers of services and those that are in receipt of services. Furthermore, a significant cultural shift in the power balance within decision-making will be required.

When referring to partners within the framework, there is reference to private, voluntary and community organisations. There is ambiguity, however, as to what exactly is understood or meant by these. For example, page 8 states:

2.1.1 Local providers and communities must be empowered to work in partnership, including Health and Social Care (HSC) Trusts, independent practitioners, and the voluntary and community sectors.

Does the term 'independent practitioners', mean staff employed in private sector provider organisations? When Trusts are referenced in 2.1.1 above, is it to differentiate their role as provider rather than commissioner? This ambiguity tends to result in mistrust and power remaining with statutory colleagues. ARC NI is particularly interested in what plans are in place to practically foster a culture of openness, transparency and trust between all stakeholders.

ARC NI recommends further work is undertaken to explore and develop principles which will underpin true partnership working.

Health versus Social Care

Northern Ireland has had an integrated structure of health and social care since 1973 however as referenced in a Kings Fund Report (p5; 2013)¹, "...reform and development of policy was virtually non-existent ... with Social Care operating under the vision and principles set out in the 1990 White Paper, *People First: Community care in Northern Ireland.*" In 2013, consultation concluded the need to reform adult social care and the 2016 'Power to People' report recommended this reform of adult social care led by the Department of Health be fully aligned with community planning. The proposed framework does therefore demonstrate efforts to empower planning of services and support at a local level.

The inequity of Government per capita expenditure on health care in comparison to social care is not unique to Northern Ireland, however the expenditure on social care in NI is appreciably less than Scotland and Wales. "... social care values and priorities are overshadowed by a dominant health agenda, with social care relegated to the role of poor relation" (Kings Fund, page 17).

The recent introduction of a Health & Social Care tax must be used to address the historic underfunding of adult social care in Northern Ireland.

ARC NI welcomes a commitment to rebalance the resource allocation to social care in recognition of the emerging demand on social care support and in valuing its role in early intervention and prevention.

Competing Programme of Care Areas

Learning disability is a life-long condition that affects cognitive and social functioning resulting in the need for ongoing support and supervision throughout the life cycle. In Northern Ireland, many people live with family carers often into their old age. They too require support.

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"².

People with a learning disability experience health inequality. 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;" (p.2)³.

Evidence suggests that 40% of this population experience additional mental health issues⁴.

They also experience poor educational attainment, loneliness and social isolation and can live in poverty⁵.

There are currently nine Programme of Care areas, one of which is learning disability, to which resource procurement and finance are assigned. The HSC Trust expenditure on learning disability services is currently inadequate in meeting real need. We welcome

¹ https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/integrated-care-in-northern-ireland-scotland-and-wales-kingsfund-jul13.pdf

² http://www.niassembly.gov.uk/globalassets/documents/raise/publications/2014/employment_learning/5014.pdf

³ <https://www.nice.org.uk/Media/Default/About/COVID-19/Specialty-guides/learning-disability-autism-during-pandemic.pdf>

⁴ <https://www.assemblyresearchmatters.org/2017/08/22/learning-disability-northern-ireland-now/>

⁵ https://arcuk.org.uk/northernireland/files/2018/06/2018-050-APGLD-report_Final-May-2018.pdf

however the opportunity an ICS model presents for better support to those with dual diagnosis.

ARC NI welcomes further detail on the process for identifying and devolving flexible budgets to a local level, which ensures the needs of local communities, specifically those marginalised groups are equally met and furthermore support dual diagnosis.

Holistic health & well being versus medical model of care

There is no accurate data set confirming the learning disability population in Northern Ireland and this presents a concern when thinking about planning services and support at a local level.

However, ARC NI welcomes this move from what has traditionally been a medical model of support to a more holistic approach of health and well-being as noted within the Programme for Government. This will require cross-departmental collaboration. This includes the need to link a multitude of strategies such as HSC workforce strategy; housing supply; education; employment; and mental health for example. This will also necessitate resource allocation from multiple departments.

ARC NI would welcome further clarification of:

- **the dataset that will be used to plan for people with a learning disability; and**
- **the roles and responsibilities of Government Departments (in addition to Health) in this model**

Values and Principles – Section 5

Within the parameters and queries outlined above, ARC NI welcomes the values and principles as outlined in the framework. We would however stress that the issues raised above are historic barriers that must be overcome to aid an ICS Model becoming a successful reality.

Strategic Direction - Section 7

ARC NI agrees with the Minister and Department setting the overarching strategic direction and welcomes the proposed development of a Strategic Outcomes Framework. The principle of equity must be applied when measuring the impact of services, regardless of provider. It is well documented that the charitable sector delivers high quality services more efficiently and cost-effectively than their statutory counterparts. It is also well documented that the HSC sector is no longer sustainable and requires transformation. Introducing an ICS model is one way to empower true transformation.

ARC NI advocates the need to include an outcomes measurement for the effectiveness and efficiency of statutory services.

ICS NI Model – Section 8

Regional Group

ARC NI agrees with the tasks to be undertaken by the Regional Group, as outlined, however we would seek clarity on the membership of this group. To embed the significant cultural shift that is referred to throughout the framework of partnership will, in our view require evidence from the top down, of true partnership working and how this is demonstrated in the makeup of oversight committees and other working groups.

We are aware that this consultation is phase 1 of a 3-stage project, and there is still need to clarify a number of issues.

One question that needs further clarification is what constitutes a regional specialised service. Is this a specialist POC area such as learning disability, or an area of specialism such as assessment & treatment for people with a learning disability, or neither? The answer to this is critical to any response to the sub-structures below the regional group.

As such ARC NI feels unable to comment on the 'area', 'locality' and 'community' structures in the absence of this clarity, however, we would reiterate the challenges identified in our response to section 3 above e.g., marginalised groups.

ARC NI would recommend that:

- **the Regional Group includes diverse stakeholders other than statutory representatives; and**
- **further clarification is provided to define a regional specialist service.**

Umbrella representation / Partnership Forum

Association for Real Change has been in Northern Ireland since 1999 and has played a critical role in supporting the Government to improve the lives of people with a learning disability through policy change. We have fostered and achieved successful partnership working between stakeholders.

In November 2020, an independent review⁶ completed by Professor Roy McConkey, into the impact of COVID on the learning disability sector in Northern Ireland acknowledged the support lent by ARC NI to the sector. The sector felt listened to by the Department of Health and the Department of Health utilised intelligence gathered by ARC NI to influence policy making. However, this partnership was not formalised nor was it resourced.

ARC NI recommends this relationship is formalised within the proposed ICS Model.

⁶ <https://arcuk.org.uk/northernireland/files/2021/02/Final-report-ARC-Review-17th-November-2020.pdf>