

Consultation Response submitted by

Association for Real Change, Northern Ireland (ARC NI)

March 2025

Being Open Framework – Department of Health

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.

Understanding Openness and Culture

Q1 The framework looks at openness at three levels:

- Routine openness: Being honest in everyday care and communication.
- Learning from mistakes: Reflecting on errors to improve and avoid repeating them.
- When things go wrong: Clear communication and accountability when harm is caused.

ARC NI **agrees** with this.

Q2 The framework focuses on three areas of culture in an organisation:

- Infrastructure (e.g., policies and systems to support openness).
- Behaviours (e.g., how staff interact and communicate).
- Beliefs and stories (e.g., shared values and lessons from the past).

ARC NI **agrees** with this.

However we would add that leadership plays a crucial role in fostering a being open culture within an organisation. Leaders shape organisational culture through their own attitudes behaviours, decisions, and communication. If leaders demonstrate openness, honesty, and accountability, employees are more likely to follow suit. A leader who models candour in their actions sends a clear message that integrity is a core value.

Effective leaders create a psychologically safe environment where staff feel supported in speaking up and learning from errors. This kind of culture promotes transparency, honesty, and accountability, particularly in health and social care, including corporate governance, where ethical responsibilities are paramount.

ARC NI does not feel that this features strongly enough and would encourage a more explicit reference to setting the tone from the top of the organisation and the quality of leadership.

Supporting Openness in everyday care

Q3 To support staff in being open it is proposed that organisations:

- Provide regular training for staff to promote openness.
- Share real-life examples of openness and what was learned.
- Recognise and celebrate examples of good practice in being open.
- Provide supervision that is supportive of openness.

ARC NI **agrees** with this.

However we would add that ARC NI would advocate the opportunity of developing a regional standardised training programme that is co-produced by those with lived experience (including staff; people supported; carers etc) may benefit for a number of reasons including:

* consistency of expectation from the framework across the HSC system

* case studies (film and written) of positive, and more so not so positive personal stories to reduce the number of times a person has to tell this

ARC NI would also encourage the necessary freedom for individual organisations to create supplementary training, relevant to their culture, work environment/services, inter-linked policies and procedures e.g. safeguarding; whistleblowing etc; the people they support and wider staff continued professional development framework (training; staff meetings; and supervision).

Openness with a focus on learning

Q4 To improve learning it is proposed that organisations should:

- Encourage staff to talk openly about mistakes without fear of unfair retribution.
- Understand the circumstances that may contribute to failures and mistakes.

- Share lessons across teams to improve safety and care.
- Make improvements visible to the public, so people know what has changed.

ARC NI **agrees** with this however as referenced previously, the leadership is critical to the success of achieving this.

Openness when things go wrong

Q5 When things go wrong, it is proposed that organisations immediately:

- Inform patients and families as soon as possible after an incident.
- Offer apologies and explanations early.
- Provide emotional or therapeutic support to all those affected (patients; carers; staff).

ARC NI **agrees** with this.

Q6 For all involved in serious incidents, it is proposed that they have:

- Timely access to information about the incident.
- Regular updates on progress and outcomes of any investigations.
- Counselling or emotional support as and when needed for all involved.
- Debriefs to discuss what happened and how to improve.

ARC NI **agrees** with this and would encourage full consideration of the following:

* Clear, simple and accessible communication throughout - honest, and free of jargon (simple) so people understand what's going on and the type of support they can avail of.

* Well documented records of process, detailing what steps are being taken; when people can expect answers; decisions taken including a rationale for why and following de-brief records

* Documented and most importantly communicated evidence of the organisation acting on feedback so people can see that their experiences are leading to real changes.

Duty of Candour to support Openness

Q7 Do you think that the introduction of a statutory organisational Duty of Candour would support organisations in their development of a more open culture?

ARC NI **agrees** with this.

Q8 Do you think that the introduction of a statutory individual Duty of Candour would support individuals to be more open?

ARC NI **agrees** with this.

Q9 Do you think that including a “Duty of Candour” clause in staff contracts will improve openness?

ARC NI **agrees** with this.

However a culture of candour does not happen by accident—it is cultivated by strong leadership, robust policies and good governance. Leaders must actively promote transparency, encourage honest communication, and ensure employees feel safe to admit mistakes. By embedding these values into everyday practices, organisations can build trust, improve accountability, and ultimately enhance overall performance and reputation.

Whilst ARC NI is supportive of any changes that will strengthen the legal basis of acting with integrity on both an individual and organisational level, we believe that the majority of people working in HSC operate with good intent. We are unsure that the inclusion within employment contracts is required if an organisation can demonstrate that it has truly invested in embedding a culture and expectation of openness, transparency and honesty. In line with other required ways of working, we would question why typical disciplinary procedures would not apply if an issue was identified.

Leadership and oversight to promote Openness

Q10 Should Boards of organisations and Chief Executives, through their Board Patient Safety and Quality Committee, be held responsible for creating an open culture?

ARC NI **agrees** with this.

Q11 Proposals for monitoring openness in organisations

- Organisations should report and publish regularly on their progress in being open.
- Organisations should be held accountable for supporting openness by the Department of Health and regulators.

- Independent audits should assess whether organisations are meeting openness standards.

ARC NI does **not fully agree** with the proposals to monitor openness.

Q12 Would the introduction of an Independent Patient Safety Commissioner improve openness and patient safety? (Further information is provided in Section 6.2).

ARC NI does **not fully agree** with the proposals to monitor openness.

ARC NI believes the suggested monitoring is overly complicated, potentially onerous, could become a 'tick box' exercise. It also includes some processes (e.g. use of Datix) that are relevant to statutory health and care organisations rather than all organisations (including those in the community and voluntary sector).

The monitoring only notes the 'What will be collated', e.g. 'Analysis and Reports on Staff Surveys /Service User Feedback'. It does not focus on what are the outcomes of the measures in place to improve openness e.g. do staff feel able to speak up about concerns, are concerns raised by people supported/families addressed within policy timeframes? etc.

The Framework references the introduction of a Patient Safety Commissioner in England but provides no evidence as to whether this position has or has not resulted in the planned improvements. Whilst ARC NI sees the benefit of independent challenge for the purpose of scrutiny and accountability we would urge the analysis of intelligence to prove this as a cost-effective use of public fund.

We have seen in other initiatives, e.g. Regional Adult Safeguarding Policy, the implementation has been flawed by inconsistent implementation of the Policy across the 5 HSCTs and overly complex paperwork that undermines rather than supports the process of keeping people safe. We need to learn from this and focus on what would be the most straight forward way of monitoring e.g.

- Development of a short self-assessment tool for organisations to use to self-audit and inform improvements plans.

- Agreement of a small number of key outcomes metrics that could be used by organisations in staff / 'user' surveys, as part of existing internal audits/external inspections. Outcome metrics need to focus on whether staff and those being supported by the organisation feel listened to, feel safe, feel able to speak up and feel that actions are taken when there are mistakes/ errors or concerns raised.

The Framework includes proposals regarding how the DoH and bodies such as RQIA will hold organisations accountable in terms of openness and candour, there is no explicit reference to how the DoH and bodies such as RQIA will in turn be held to account and will report on clear measures and progress in terms of sectoral leadership, organisational change, improvement and reform.

For the reasons outlined above, ARC NI is not convinced that the proposed monitoring will result in an increase in openness, rather a risk of increased bureaucracy.

Training and education to support Openness

Q13 Organisations should support and train staff in being open in different situations so they can:

- Be open and honest in everyday care.
- Learn from mistakes and failures to share lessons.
- Support patients and families when things go wrong.

ARC NI **agrees** with this.

Q14 Organisations should provide support and train staff at different times using a range of training methods

- Training for openness at induction and as refresher training for all staff.
- Provision of a range of different opportunities for learning such as online or in person.
- Provision of support through mentorship, coaching and supervision.
- Learning provided in way appropriate to the staff role and the most effective training method.

ARC NI **agrees** with this and further thoughts have already been provided as per response to Q3.

Concluding Comments

ARC NI would advocate that the Framework is too long and detailed for 'general use'. We suggest the development of a short, accessible summary to aid communication and implementation of the Framework.

It is of concern to us that the consultation does not include an Easy Read version of the Framework to aid consultation with people with a learning disability, autism and other support needs. Without high quality engagement, it is not possible to ensure that those most affected by proposals are central to shaping future reforms that will deliver transformative change.

Therefore ARC NI urges the Department of Health to:

* Use plain English in all consultations and not use jargon or terms that are not widely understood.

* Use existing Personal and Public involvement guides to plan and complete future consultations.

* Work with the Community and Voluntary Sector and the PHA (that has the lead role for PPI Policy across the statutory health care services) to develop a more consistent and accessible approach to all DoH consultations to aid meaningful stakeholder engagement, particularly from marginalised groups such as people with a disability.

* Reduce the reliance on over long, complex documents to produce more meaningful and accessible summary information (that will be both more effective in terms of engaging with stakeholders and more cost efficient).

ARC NI would also point out that neither 'Disability' nor 'Health inequalities' are mentioned once in the Framework. ARC NI would therefore question whether the needs of people with a learning disability, autism and other support needs whether they be a staff member or a person accessing support from a health and care provider, have been fully considered as part of the Framework. Specifically, in terms of what difference the Framework would make to their lives. The accompanying Equality Assessment states:

'... the policy includes safeguards and protections to ensure that all individuals, including those with a disability, are able to experience openness from health and social care services.'

We can see no explicit 'safeguards and protections' to ensure that people with a learning disability, autism or other support needs who are routinely marginalised in their lives, will experience openness from health and social care sector services.

ARC NI would urge the revisiting of the Framework to ensure it is more inclusive, applicable to, and accessible by, marginalised Section 75 groups (as per (Northern Ireland Act 1998), including people with a learning disability.

The key role this Framework needs to play, as part of the range of measures to address significant health inequalities, has not been fully considered i.e. to address inequalities. There has to be a clear understanding of 'what the problem is' to identify solutions that will affect change, and this can only happen when there is openness and transparency. For people with a learning disability who face significantly poorer health outcomes, including much lower life expectancy than the general public, the need for this openness, transparency and willingness to change practice may literally be a life or death matter.

In conclusion, ARC NI fully support the development of this Framework, taking on board the feedback received and look forward to supporting the implementation to raise the standard of care received by people with a learning disability and their family carers.