

Response to the Ad Hoc Joint Committee on the Mental Capacity Bill

Association for Real Change (NI)

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ARC (NI) welcomes the ongoing consultation process being undertaken in relation to the Mental Capacity Bill and submitted evidence to the Department of Health, Social Services and Public Safety and the Department of Justice's Consultation on proposals for the Draft Mental Capacity Bill NI with recommendations (see Appendix One). This highlighted significant concerns on the impact for people with a learning disability.

ARC (NI) welcomes the opportunity to present to the Ad Hoc Committee on the Mental Capacity Bill a response to the clauses and schedules that have been introduced to the Northern Ireland Assembly.

On reflection of the Bill as introduced, there are significant improvements for protecting the rights of people with a learning disability, in particular that decisions around capacity are not permitted to be based on "age, appearance or any condition" or an "unjustified assumption about his or her ability".¹ Nonetheless, this immediately raises the key concerns surrounding enactment of the Bill and the reality of implementation throughout society.

The use of language such as "all practicable help" and "appropriate explanation" are extremely welcomed for meeting the range of needs of each individual.² However, again to ensure the Bill achieves true protection for people with a learning disability this would implicate a vast amount of staff training required to embed meaningfully this significant and positive value-based culture change. It is vital that the widest meaning available be attributed in order to accommodate the scope of additional needs.

In relation to the clause for nominated person, ARC (NI) questions that there remains only one nominated person. There are allowances within the Bill for people who care or have an interest in the wellbeing and welfare of an individual. However, during the consultation process it was strongly advocated by people with a learning disability that an individual should be able to nominate more than one person as their nominated representative.

It is imperative that process within the Bill be clear, transparent and accessible for people with a learning disability. In relation to tribunals and formal declarations there appear to be cumbersome hurdles for people to circumnavigate.³ ARC (NI) would welcome greater clarity on how awareness and knowledge exchange of the legal processes available to individuals through the Bill will be actively accessible to people with a learning disability.

ARC (NI) proposes an amendment to Section 12(4)(b) "is a use of force or a threat to use force and is done with the intention of securing the doing of an act which P

¹ Section 7(2)(a) and (b); Section 1(3)(b)

² Section 1(4) and Section 4(3)

³ Chapter 7 and Section 90



resists".⁴ The use of the word threat immediately creates an imbalance of power against a person with a learning disability. It is suggested that

the word threat should be removed and replaced with "is a use of force or informing the individual of the potential need for use of force and is done with the intention of securing the doing of an act which P resists".

ARC (NI) has concerns relating to the independent advocate; while it is agreed that having an unconnected and unbiased representative of an individual in relation to the Bill is a welcome introduction, ARC (NI) queries the true independence of an advocate being appointed and instructed by the HSC.⁵ This appears to contravene the objective of guaranteeing individuals an unbiased support. ARC (NI) proposes that the appointment and instruction of independent advocates should be commissioned at Departmental level, be widely accessible and not based on a postcode lottery. Furthermore advocacy provision should be reviewed to enshrine greater transparency.

The requisite training and awareness-raising required to make the Bill a working reality for people with a learning disability in Northern Ireland will be significant. ARC (NI) is concerned as to how governing body intends to meet the resourcing and funding needs for carrying out the value based training imperative to ensuring that individuals are truly protected under the Bill.

The Bill proposes welcomed changes designed to empower people with a learning disability to have control of their lives unless the clauses for incapacity are met.⁶ It is good to see that issues raised around safeguarding of vulnerable adults is not being used to limit their rights under the Bill. There must be appropriate and adequate infrastructure for informing people with a learning disability of their rights under the Bill.

In conclusion, ARC (NI) is committed to the Bill's proposals to redress stigma and barriers to equality that people with learning disabilities currently experience. While ARC (NI) welcomes the potential rights, support and protection afforded to people with a learning disability under the Bill, it is vital that the governing body continue to work with people with a learning disability and those in the learning disability sector to build the best practice guidelines for addressing the key operational issues raised in this response:

- Embedding a value based culture shift in society
- Set standard for value based training of all relevant Personnel
- Value based practices integrated into staff review meetings
- Shared understanding
- Rights awareness
- Allocation of adequate funding and resources
- Active and ongoing consultation with people with a learning disability

⁴ Section 12(4)(b)

⁵ Section 84

⁶ Section 1(2)

APPENDIX ONE



Association for Real Change (Northern Ireland): Response to the Department of Health, Social Services and Public Safety and the Department of Justice's Consultation on proposals for the Draft Mental Capacity Bill NI

RECOMMENDATIONS

Active and continuous engagement for reassessing proposals and practicalities of the impact of legislation

- The term "reasonable measures" must incorporate the broadest meaning in order to ensure that a person with learning disabilities, for whom decision-making is not a straight-forward process, is able to exercise their legal right to decisions in their life
- The Bill needs to be a workable reality for the people on the ground.
- Further discussions as to what time, resources, and mechanism are going to be available for supported decision-making
- Consideration to the questions, fears and difficulties being raised about how the Bill will work in practice.

Flexible and holistic approach to ensure that all members of society are being reached

- It needs to be clear that safeguards are there to support and protect, not bind people who are vulnerable. They are to be protected from exploitation, violence and abuse not decision-making
- People with learning disability should be involved at deciding the final draft of each clause within the Bill
- The Bill needs to be recognizing every individual as people with profound mental and physical disabilities are often a forgotten group within society
- There needs to be practical recognition and support for journey decision-making.

Strategic learning at national and international level

- Share and learn from best practice, taking and refining the successes and failures of other countries
- There needs to be an examination of models of support being utilized in different countries
- Counter measures and diverse and robust strategies of unique decision making limitations and situations be carried out to protect against immediate pitfalls.

Better co-ordination of government policy and local network

• Government needs to be engaged with vulnerable people, such as those with learning disability in a more substantial, continuous and genuine way so that they are able to access all areas of civil life



- Clear vision and strong leadership to drive the changes needed throughout society to ensure true equitable equality for all citizens
- Integrity of honest and realistic action for cultural shifts with genuine collaboration amongst the key stakeholders
- Frank examination must be made between the good intentions to the policy being proposed and to the reality in practice.

Strategic investment in preparing and enabling all stakeholders to engage in supported decision-making

- Equity in approach: for people who use non-verbal communication, or have limited physical and verbal expressions, it is vital to support unique decision making abilities
- Creatively supporting the individual in their personal circumstances, and those who care for them
- Bill should adopt a requirement of "best interpretation of a person's will and preference"
- Informed training and awareness raising driven by people with a learning disability to create a sustainable and genuine supported decision-making process.

Review and clarity on provisions

- Reassess the review procedures to a shorter timescale
- Option for person to choose more than one nominated person
- Clarity on where the money for taking further action comes from if individual, family or carers, disagree with the professional decision-maker
- Clarity on who decision makers are going to be, and who decides what constitutes a person of suitable qualified and relevant experience
- The availability of the advocate should be made available at the earliest possible stage. Furthermore, there needs to be clarity on who an advocate will be and where they will come from.

Recognition of the impact upon the individual and the support circle surrounding a person with learning disability

- The finding of incapacity should be the finding of the need for support
- The Bill needs to respond and understand the reality of what families face
- Empowerment and support systems need to be genuine and enforceable which will require training, time and patience

There needs to be Rights advisors to educate and raise awareness for people of their rights.