FAMILIES INVOLVED NI

Our background

Families Involved NI (FINI) is an informal regional network of families in Northern Ireland supporting family members who have complex needs.

Our family member background

Our family member is likely to have one or more neurodevelopment conditions, including learning disability, autism, ADHD as well as sensory processing disorders and high levels of anxiety. He or she may have communication issues and, in some cases, may present with behaviours of distress which may impact their own safety or the safety of others. It is likely that they will be assessed as lacking the required mental capacity to make some decisions and choices about how they wish to lead their lives.

Current Services Provision in NI

The specialist services capable of diagnosis as early as possible, the skilled professionals who will help develop the required life plan and the specifically trained social care workers all of whom will partner with parents to develop the capable environment enabling our family member to live within their own communities close to relatives are far from being in place.

Therefore, in adulthood, the critical need to have skilled care provided by paid caregivers results in the placement of many of our family members in institutionalised settings.

These settings, increasingly, are being provided by independent providers, either from the voluntary and community sector or by private companies.

The statutory sector, however, specifically the five HSC Trusts, still deliver services in the form of nursing homes, residential care homes, day care settings and acute assessment and treatment units or learning disability hospitals or wards.

Background to NI Law

Currently there is no law in Northern Ireland providing for the safeguarding or protection of people at risk of harm nor is there any statutory guidance. From the public perspective, we understand that there is criminal law which has its own thresholds and sanctions. The 2015 Adult Safeguarding Prevention and Protection in Partnership Policy was produced jointly by the Department of Health and the Department of Justice, but our understanding is that agreement could not be reached on appropriate legislative proposals which would underpin operation procedures and through statutory guidance provide definitions. Ten years later, the effect of not doing this is a culture which has developed based on the professional judgment of health professionals, mainly social workers and that assumptions can made that incidents resulting in harm can be ignored as not being serious enough to consider protecting the affected person.

In the absence of statutory definitions which provide a meaning that everyone can understand for words like harm, serious harm, threshold for protection, 'reasonable cause', are being screened out' from further enquiry'. Therefore, what we, as families, see as harm does not meet the definition of harm applied under the policy and rarely reaches the point at which protection plans or alternatives are to be considered, or the possibility of multiple incidents providing a pattern of events which could be considered criminal in nature.

Background to the draft Adult Protection Bill (APB)

The consultation on the proposed Adult Protection Bill was published in Dec 2020 and closed in April 2021; analysis of responses and final proposals for the bill were completed in July 2021. The consultation document opens with:

Building on the response to the Commissioner for Older People's Home Truths Investigation into Dunmurry Manor Care Home and CPEA's Independent Review into Safeguarding and Care at Dunmurry Manor, the Department of Health ('the Department') is undertaking a public consultation to inform the development of an Adult Protection Bill, subject to the approval of the Northern Ireland Executive.

It is important to consider that the work leading up to the consultation for the draft **Adult Protection Bill** referenced an investigation into a care home owned by an independent provider and related to the abuse of elderly persons. The independent investigation into Muckamore Abbey commenced in May 2022 almost a year after this consultation was concluded. The Muckamore inquiry relates to the alleged abuse of people with learning disabilities in a facility in which services are delivered by an HSC Trust itself.

This Trust, in collaboration with the other Trusts, carries responsibility also for implementing safeguarding and protection procedures under the present policy for residents of its Trust area.

The findings from the Muckamore inquiry are not yet published but are likely to provide insight into serious failings int terms of safeguarding and protection within the statutory sector. These findings should cover both the delivery of services and also failures in its monitoring role.

These may include concerns about conflict of interest for the Trust in 'self-auditing' with no outside scrutiny, challenging the effectiveness of professional candour in the absence of a statutory duty of candour and create difficulties around he independence required for professionals investigating. The full implications of the failures by a **statutory body** in a **statutory facility** for people with **learning disabilities** are still to be fully understood.

We believe that this legislation should not proceed any further until the recommendations from the Muckamore Abbey Hospital Inquiry on the largest safeguarding investigation in British history are published and fully considered.

Context and Scope of Comments Following

The following comments reflect our current views on the Bill as presented in June 2025; drawn from our own lived experience and the safeguarding role we have in protecting our family member and keeping them from harm.

We extend our safeguarding role to attempting to oversee the safety of our loved one within the institutional setting where they have been placed. We carry our anxiety for their wellbeing even though we have little access, understanding or influence in how safeguarding and prevention of harm is monitored by the HSC Trust.

We are also informed by and acknowledge the quality of the responses to the original consultation particularly those provided by COPNI, NIHRC, RCOT, RCSLT, GMC and NMC. The final proposals for the Bill do not appear to have had regard to or taken account of many important recommendations. **The delay of four years in publishing the draft bill has had a dampening effect on much needed necessary and discussion These responses should be re-considered by the Health Committee and we hope that this conversation, albeit late, now bee overseen by the Committee**,

Comments on Principles

We agree with the principles outlined in the Bill and that they must be included within the Act and in the statutory guidance. These principles, however, must be seen to be grounded within the entire range of the framework of human rights within NI and UK so that already existing laws, conventions, declarations and accepted good practice in Human Rights are recognised as the standard by which law is implemented and is the bedrock of our present legal code. As new approaches are developed within the over-arching framework, those considerations can be more easily reflected within individual legislation. The duty to consider human rights and to train social and health professionals becomes an imperative.

Work is already going on in the Assembly to give legal status to the Convention on the Rights of People with disabilities. The Committee on the Rights of People with disabilities has provided guidance on discontinuance of institutionalised living. All these considerations empower our family members and enhance opportunities to live the life they choose or would choose,

Comments on Alignment of Adult Protection Bill with the 2016 Mental Capacity Act

Our family members with complex needs are likely to need support with making decisions or giving consent. The principles included in section 1 of this bill require social workers when considering an intervention to have regard not just to 'best interests' but also to 'ascertainable wishes (both past and present)' and to enable the adult to participate as fully as possible in the performance of the functions, the adult being provided with such information and support as is necessary to enable the adult to so participate This accords with the principles in the MCA in terms of empowerment and the need to support the person as far as is possible.

However, the majority of our family members may lack mental capacity and oral communication. The nature of the participation where intervention is being considered for safeguarding or protection is entirely different from the approach towards participation in decision-making. Specialist assistance from Speech and Language Therapists would be required to support the affected adult perhaps using other forms of communication but would require time invested in assessment and development of methodologies. Present culture in investigating a safeguarding concern, incident or harm to a person is to assume that the person lacks mental capacity and the competency to provide evidence. Evidence is then sought from other staff and CCTVs if available or self-harm is assumed.

The lived experience of family built on years of close contact with their relative and how they communicate is not considered. Family is told if an incident has occurred but skills as communication partners are not recognised.

The Mental Capacity Act allows for the appointment of a nominated person, by default the main family carer or next of kin. The Trust/provider of the services has a duty to consult the nominated person and take their views into account. However, sharing of information is limited. In the draft Adult Protection Bill there is no reference to the 'nominated person' but section 28 of the draft Bill allows for the Trust to 'involve relevant persons".

Other current limitations within the Mental Capacity Act include lack of a code of practice on how, in general 'best interests' decision-making should be managed and recorded. The existing Code of Practice is limited to decision making specifically within applications for in Deprivation of Liberty. Given that the MCA was passed in 2016 and, almost 10 years later, much of it has not been implemented, it is not surprising that 'best interests decision making; has now evolved into 'assisted decision making' which is now in statute in the republic of Ireland.

The right of the affected adult to support from family should be formally recognised through family engagement in evidence gathering, access to all relevant information, involvement in protection planning and unrestricted access to and communication with our family member.

Inevitably, this will require availability of financial resources for family to access independent legal advice and to advocacy support in their own right at 'best interest' decision meetings and other multidisciplinary team meetings.

Comments on elimination of Restrictive practices through legislation.

While restrictive practices are referenced in the Mental Capacity Act, in particular the issues around the use of restraint in section 12 for which a Code of Practice has been drafted but not approved due to human rights concerns, restrictive practices are not directly mentioned in the Draft Protection Bill.

Yet the use of these restrictive practices including seclusion, physical, psychological and chemical restraint together with use of Deprivation of Liberty safeguards that are more restrictive than necessary, have to be considered as practice which is causing harm, potentially traumatic in nature and for which safeguarding and protective measures have to be considered.

For so many of our family members, the presence of what used to be called 'challenging needs' and which is now recognised to be 'behaviours of distress' is the primary reason why we need to agree to their placement in what we hope should be safe environments while their needs are assessed. Sensory processing issues and intolerance of the

external environment create anxieties. Very often increased elation or agitation reflects a need to communicate, and this can be misread as challenging or aggressive behaviour. Skilled staff can respond with de-escalation techniques and helping the person self-regulate and develop coping strategies, but unskilled staff can react using prone restraint, seclusion and use of medication for sedation purposes.

A policy aimed at reducing the need for restrictive practices was issued in 2023 by the Department of Health where the HSC trusts were required to implement this policy and to train staff on pro-active and de-escalation approaches to avoid the use of restrictive practices within their own facilities and to ensure the contractual arrangements with care providers to reflect a similar approach. However, there does not appear to be any plan to legislate for elimination of these practices and the Restrictive Practices Policy has yet to be implemented by Trusts (no funding).

The lack of clearly defined statutory definitions identifying improper use of restrictive practices as instances of abuse or neglect in implementing appropriate care plans makes it difficult at present for staff to recognise these practices as abuse.

Comments on The Continuum of safeguarding and prevention of Harm

The Adult Safeguarding Prevention and Protection in Partnership Policy has been the tool for managing the continuum of adult safeguarding and prevention since 2015, Page 18 of that policy provides in Figure 4 a graphical representation of that continuum which is described as: Prevention to Protection. It clearly indicates the point at which a threshold is reached after which protection arrangements are considered. All actions before that point are covered by agreed policies and operational procedures which provide structures for safeguarding across all statutory provided or commissioned services for adults and for voluntary and community group activity.

It included a Regional Adult Safeguarding Partnership which was stood down in July 2020, five months prior to the commencement of the consultation and on this draft bill. Local adult safeguarding partnerships were also established under that policy and appear to be still operating. An Interim Adult Safeguarding Board was established.

A decision seems to have been made by the Department of Health in 2020 to proceed with legislative options only in relation to that part of the continuum relating to protection and to leave the part relating to safeguarding with its existing structures, policies and operational procedures intact without legislative underpinning based largely on the professional judgment of health professionals. No effort was made to review the outworkings of the policy. The evidence now in the public domain points unequivocally to the conclusion that it has not worked.

The criticisms made by us and others about the limitations in the scope of this Bill as reflected in its title still remain. We agree strongly with the former Commissioner for Older People in NI (COPNI) when he said:

Safeguarding and protection are defined in the consultation paper with much emphasis placed on the current regional Adult Safeguarding Prevention and Protection in Partnership Policy continuing to provide the framework for addressing safeguarding while the new Bill will "introduce additional protections to strengthen and underpin the adult protection process." This does not recognise or address the weaknesses of the current policy and the resulting abuse of older people that was formally investigated in both the Cherry Tree Review, and in the Commissioner's Home Truths report."

Neither will this approach recognise or address the likely findings in the Muckamore Inquiry of abuse towards adults with a learning disability.

The response of the Royal College of Occupational therapists includes comments on the proposed title for this bill and suggests that a title 'Adult Care and Protection" bill might be more appropriate. Occupational therapists are in a position to observe and assess care settings in terms of 'capable environment' in a way that most families cannot do due to time and access restrictions. RCOT also comments in their response:

There were serious care failings that led to what happened at Dunmurry and Muckamore (1.25) and we believe that these need to be kept in focus and must be addressed. Having an Adult Protection Bill and putting legislation in place in a dysfunctional system is not going to solve the issues but detract from them

We, as families need to know that, on admission of our family members for care and treatment or to placements commissioned by Trusts or where services continue to be delivered by the Trusts, they are safe from harm and can experience quality care and social wellbeing. Contractual arrangements with providers have to demonstrate safeguarding policies and the extent of resources applied towards safeguarding. The commissioning Trust must also identify with its own staff and with designated safeguarding staff the responsibility for safeguarding our family members.

Families need to be fully involved in the details of the care plan for their family member which should include scrutiny of financial resources being agreed and how far those will meet all the assessed needs of their family member. This should include how much is allocated to continuous training of staff in safeguarding and frequent monitoring of safeguarding procedures. Safeguarding should be on the agenda for all Care Management Reviews and Risk Assessment planning.

Comments on need for statutory definitions

We have already commented in the section **Background to NI Law** on how the absence of legislation underpinning terms of use has undermined attempts to implement the 2015 Safeguarding Policy.

Our families have had experience acting as informal advocates in engagement with HSC Trusts on safeguarding and protection for our family members over the years. It is clear to us that the present culture among many professionals is that it is professional judgment that matters, not the law. We have experienced professionals seeking definitions of harm or abuse from other professionals on the basis that a definition which has been reached through professional judgment and good practice 'is the law'.

Our current understanding is that statutory definitions are being considered by the Department of Health with legal assistance and will be part of statutory guidance to published potentially after the Bill has passed. The scope and intent of the state to protect extremely vulnerable people like our family members will depend on definitions which ultimately may require testing in our courts. The cumulative experience of the last number of years of institutional abuse and how to stop it may get lost if that experience of current safeguarding policy is not captured now.

We ask the Health Committee in conjunction with the Justice committee within the Assembly to take the lead immediately in considering these definitions. The definitions must be understandable by the public, including lay people and professionals, reflect human rights consideration and be considered in the context of law reform as is the approach in the Republic of Ireland which has assigned the Law Reform Commission to develop a Framework for safeguarding legislation.

Comments on independent advocacy

We are currently taking the views of families across the five HSC Trusts on their experience of independent advocacy which is funded by the Trusts. The Department of Health has not provided any review or research into the use of independent advocacy since 2010. However, the requirement for independent advocacy is referenced in legislation around Mental Health and Mental Capacity legislation.

We note that the Memorandum provided by the DOH to the Assembly in June 2025 there is a reference that they chose to endorse Option 5 rather than Option 4 because of the need for independent advocacy.

We would hope to follow up shortly with some comments from families on the present arrangements which cover Trust funded advocacy. It is clearly not desirable that decisions to fund independent advocacy should be controlled by Trusts.

Comments on the creation of an independent Adult Safeguarding Board.

As families, our experience tells us that a Board charged with safeguarding and protection for the most vulnerable members of our society should be independent in every sense of that word. Our understanding of the relevant sections in the draft Bill is that the Board would be similar to or by definition an Arm's Length Body (ALB) sponsored by the Department of Health.

We agree with COPNI that such an entity should be completely independent and outside of the Department of Health. We would not recommend either that the Department of Justice should sponsor a Safeguarding Board. However, an Independent Board should reflect in its membership representatives from those Departments.

The structure of this Board should be based around holding all others to account with the necessary powers to do so. It could provide the independence necessary to enable both regulatory and provider accountability and support independent advocacy.

It is essential that discussion take place immediately to anchor ownership of this Board and we would ask that both the Health Committee and the Justice Committee considering jointly leading on this discussion.

IN SUMMARY

We would like the opportunity to address the Health Committee on these comments and additional comments which we will continue to identify in conversation with our families.

26 September 2025

CAROLINE KELLY BRENDA AAROY

On behalf of Families Involved NI