

# **Citizens Information Board Submission on *Assisted Decision-Making (Capacity) Bill 2013***

## **1. Introduction**

The Citizens Information Board (CIB) very much welcomes the publication of the *Assisted Decision-Making (Capacity) Bill 2013*. The CIB acknowledges the change to the title of the legislation which we had called for in a submission made in 2010 in response to the Scheme of Mental Capacity Bill<sup>1</sup> and in a 2011 submission to the Oireachtas Committee on Justice, Defence and Equality.

In previous submissions, the Board identified a number of aspects of assisted decision-making legislation as important in keeping with the provisions of Article 12 of the UN Convention on the Rights of Persons with Disabilities, in particular:

- The presumption of legal capacity
- Equality of access to justice
- The right to self-determination
- Assessment of capacity as time specific and issue specific
- The right to participate
- The right to make choices
- The right to be supported in making decisions, including the provision of all practicable steps to help a person to make a decision before regarding him/her as unable to do so.

These aspects are to a large extent accommodated in the current Bill.

### **The National Advocacy Service**

The CIB has experience of the difficulties faced by people who require support in articulating and communicating their views from its involvement in delivering the National Advocacy Service (NAS)<sup>2</sup>. In 2012, NAS dealt with 1068 cases in total. Of these, 29% had an intellectual disability, 19% had mental health difficulties and 9% were those with an acquired brain injury. The present (and previous submissions on the topic) are informed by feedback from NAS in relation to the vacuum created by the absence of assisted decision-making legislation and which highlights difficulties encountered in day to day decisions. In particular, there is evidence from NAS advocates around the country to suggest that there continues to be insufficient attention by some residential services to maximising capacity in respect of a range of decisions made about people's lives, for example, decisions in relation to how

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<sup>1</sup><http://www.citizensinformationboard.ie/publications/social/downloads/submissiononforthcomingmentalcapacitylegislation.doc>

<sup>2</sup> The National Advocacy Service provides independent, representative advocacy for vulnerable people with disabilities. The service is funded and supported by the Citizens Information Board.

money is managed and how charges for services are levied.<sup>3</sup> It is also unclear to what extent the right of people to be supported by an independent advocate, as set out in the *HIQA National Standards for Residential Services for Children and Adults with Disabilities*, is being put into practice. The NAS Annual Report 2012 noted that, while many services are engaging very positively with NAS advocates, there is still a lack of understanding of advocacy in some services and a level of resistance at times.

NAS involvement with people with disabilities to date highlights the need for improved legal provisions in a range of areas of living. For example, the need for people to be assisted in exercising choice and living independently arises in some instances (see Case Example 1/Appendix). The need for support for a person in challenging the continuation of a Ward of Court provision is illustrated in Case Example 2 (see Appendix) and helping a person to put in place an individually-tailored supported decision-making mechanism is illustrated in Case Example 3 (see Appendix).

A need for advocacy support for some parents with an intellectual disability and/or mental health difficulties in articulating their views in the context of child care court proceedings has been identified by NAS. These child care related court cases, while representing only 2% of issues, have absorbed much of NAS advocacy time.<sup>4</sup>

### **Key Provisions of the Bill Identified by the CIB**

The CIB notes that under the guiding principles of the proposed legislation (Section 8) capacity is always presumed unless the contrary can be shown (Section 8 (2)). Other important core underlying principles set out in respect of outside decision-making interventions and supports highlight the need to:

- Reflect the right of the person being supported to his/her dignity, bodily integrity, privacy and autonomy (Section 8(6))
- Permit, encourage and facilitate the person to participate as fully as possible (Section 8 (7))
- Give effect to the past and present will and preferences of the person, (Section 8 (7) and
- Take into account the beliefs and values of the person (Section 8 (7))

Two specific provisions in the current Bill are identified by the CIB as particularly important in terms of enabling people to manage to the fullest extent possible their own affairs, including their money and where they live.

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<sup>3</sup> A Discussion Document highlighting issues around the way charges are levied and how people with reduced capacity are supported to manage their personal finances is currently being finalised by the CIB.

<sup>4</sup> The CIB is currently in the process of finalising a report on the topic of *Advocacy Support for Parents with an Intellectual Disability and/or Mental Health Difficulties Involved in Child Care Proceedings*

- Provision for individuals to make legally binding agreements with others to assist and support them in making their own decisions (Section 10)
- The requirement for decision-making assistants and co-decision-makers to ascertain and to give effect to the will and preferences of the person in all decision-making in so far as this is reasonably practicable

The CIB believes that the Bill should give greater consideration to how the principle of respecting the will and preferences of persons with disabilities is to be supported and facilitated in practice.

The proposal for the establishment of an Office of Public Guardian (Part 8) is significant. The Office of the Public Guardian will supervise decision-making assistants, co-decision makers, decision-making representatives and persons holding enduring powers of attorney. The Law Society<sup>5</sup> has expressed the view that the Public Guardian should also be given a supervisory role in relation to the operation of Patient Private Property Accounts for persons who lack capacity to operate the accounts and in relation to the Nursing Home Support Act 2009 where relevant to decision-making capacity. The CIB supports this view. The CIB also agrees with the view expressed by other agencies<sup>6</sup> that the name of this Office should be changed to reflect more accurately its primary role in facilitating decision-making in the context of maximising capacity.

The provisions in the Bill for the integration of the enduring powers of attorney (Section 40) and wardship (Part 5) into one legal framework is welcome. The provision for the review of all wards of court (Section 35) is particularly important (see Case Example 2/Appendix).

The Bill provides for the making of applications to court in respect of persons whose capacity may be in question to seek a declaration as to whether those persons lack capacity and for the making of consequent orders approving co decision-making agreement or appointing decision-making representatives. These are necessary provisions but ones which, in the view of the CIB, need to be carefully monitored in their implementation to ensure that a person's decision-making capacity is never undermined by inappropriate mechanisms.

The main protections required from this legislation relate to people who need assistance in making their views known and who need support to participate fully in decisions about their lives and daily living arrangements. Protection for people engaging in bona fides informal decision-making in connection with the personal care, health care and financial expenditure on behalf of people who need support with decision-making and where no formal decision-making arrangements are in place (Part 7) is also a necessary inclusion in the Bill. However, in order to ensure that such informal decision-making does not become another form of substitute decision-making, the Bill should include

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<sup>5</sup> [http://www.lawsociety.ie/Documents/members/policy\\_docs/MentalCapacity\\_SubmissionAug11.pdf](http://www.lawsociety.ie/Documents/members/policy_docs/MentalCapacity_SubmissionAug11.pdf)

<sup>6</sup> See <http://www.nuigalway.ie/cdlp/>

inbuilt legislative safeguards in the form of oversight by the Office of Public Guardian (see below).

The Bill contains two sections which may have a bearing on the way court proceedings are managed in respect of people with reduced capacity.

Section 60 provides for the Public Guardian to appoint a court friend to assist the relevant person in court proceedings where the relevant person has not instructed a barrister or solicitor and there is no other provision for supported decision-making during the course of a hearing. Subsection (6) allows a court friend to attend and represent the relevant person at meetings, consultations or discussions as required.

Section 61 (Panels to be established by Public Guardian) requires the Public Guardian to establish panels of suitable persons willing and able to act as court friends (as well as in other support roles) from which the Public Guardian must nominate persons to be appointed as a court friend as the case requires.

These provisions may, for example, be relevant in the context of supporting parents with an intellectual disability and/or mental health difficulties in articulating their rights as parents in child care court proceedings where the primary focus is understandably on ensuring that children are fully protected.

### **Shortcomings of Bill Identified**

While there has been a general welcome for the Bill<sup>7</sup>, some shortcomings have been identified by various stakeholders. It has been suggested, for example, that a necessary distinction has not been made in the Bill between the concept of mental capacity (decision-making ability) and that of legal capacity (recognition of a person's right to make legally binding decisions).<sup>8</sup>

The CIB identifies four other aspects of the Bill that require further attention and relevant amendments:

- The need to include a role for independent advocates
- Safeguards for informal decision-makers
- Assistant decision-making
- Co decision-making and representative decision-making

### ***The Role of Independent Advocates***

Section 60 allows the Public Guardian to appoint a court friend to assist a person to make an application to court. The court friend can attend court with the person, speak on behalf of the person in court, examine health records about the person, and interview the person.

Consideration could be given to including provision in the assisted decision-

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<sup>7</sup> See <http://www.nuigalway.ie/cdlp/news.html>

<sup>8</sup> For example, see Flynn (2013), <http://humanrights.ie/mental-health-law-and-disability-law/assisted-decision-making-capacity-bill-2013-finally-published/>

making legislation for people having access to independent advocacy to support and maximise the decision-making capacity of the individual. The National Standards for Residential Services for Children and Adults with Disabilities includes provision for access to an advocate as a criterion underpinning informed decision making and consent. The Standards contain multiple references to the role of advocacy and the need to make provision for people to have access to independent advocates. *Vision for Change* recommends that “all users of the mental health services – whether in hospitals, day centres, training centres, clinics, or elsewhere – should have the right to use the services of a mental health advocate” (p.25). Some consideration of a definition of independent advocacy is required in the context of the legislation and the standards underpinning service provision.

The provision in the Bill (Part 7) which gives legal effect to the daily decisions made by ‘informal decision-makers’ in relation to the welfare of individuals who lack capacity grants a wide range of powers to individuals. The Office of Public Guardian should have a role in overseeing informal decision making so as to ensure full transparency and to facilitate meaningful involvement by independent advocates where appropriate.

While the Bill includes a provision to give effect to the will and preferences of the person, e.g., in the context of co decision-making (Section 17), it is likely that the full implementation of this principle would be enhanced by the availability of a skilled advocate to support an individual in situations where the process as envisaged in the legislation is not being adhered to and the person would benefit from independent advocacy. For example, an independent advocate could play a critical role in supporting a person going through the courts system by helping him/her to make a complaint, lodge an appeal or seek a review.

### ***Informal Decision-making***

The scope of powers given to informal decision-makers under Part 7 of the Bill requires further consideration. In particular, there is a need to balance the requirement to provide protection for people (e.g. family carers) making informal decisions on a daily basis on behalf of those being cared for with the need to ensure that human rights of individuals are fully respected. Care is required to ensure that legal protection for informal decision-making does not result in substitute decision-making in the sense that the decision-maker is not chosen by the person, and is not subject to scrutiny by the court. As already stated, independent advocates would potentially have an important role to play in this key area of daily living. This role, however, needs to be supported by the Office of Public Guardian in order to ensure that Article 12 (4) of the UN Convention is adhered to, *viz.*

States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or

judicial body.

Amendments to the Bill are, therefore, required to build clear parameters around informal decision-making so as to provide safeguards where it does occur and to ensure that people have the option of using assisted decision-making agreements where these are feasible. In this regard, those acting in good faith (e.g., carers, family members, professionals) should be required to support as far as practicable individuals to create assisted decision-making agreements, rather than resorting to what is in effect substitute decision-making and contrary to the supported decision-making principle.

The CIB thus believes that Part 7 of the Bill should be amended to ensure that substitute decision-making does not continue to occur by default in the important domain of informal decision-making.

### ***Assisted Decision-making***

The provision in the Bill for the introduction of 'assisted decision-making agreements' which allow people to choose others they trust to help them with making decisions is an important one. This is innovative and reflective of the provisions of the UN Convention and a significant departure from the previous focus on the 'best interests' principle. However, the Bill must ensure that the primary focus is on supported decision-making where possible in accordance with the provisions of Article 12 (3) of the UN Convention, *viz. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.*

Further clarity is required in the legislation about the need to ensure that these assisted decision-making agreements are open to anyone to make, are legally binding, and, therefore must be respected by third parties, e.g., family members, health care professionals and financial institutions.

In order to optimise the impact of the assisted decision-making provision in the Bill, it is important that:

- Those appointing assisted decision-makers should not have to pass a test of functional mental capacity set out in Section 3;
- There should be provision in the Bill for people to have flexibility to appoint more than one assistant for each type of decision, e.g., living arrangements, financial matters, health care.

Clarity is also required about the legally binding nature of assisted decision-making agreements. In particular, the obligations on third parties to respect decisions made using an agreement must be clearly stated.

### ***Co decision-making and Representative Decision-making***

Section 16 of the Bill sets out how individuals can make co decision-making agreements, the powers of courts to make co decision-making orders and

safeguards. Section 23 allows the court to appoint decision-making representatives where a person is found to lack mental capacity for a decision, and either the court is unable to appoint a co-decision maker, or the person would not have mental capacity for that decision even with a co-decision maker.

There are five aspects of these provisions which the CIB believes require further consideration:

- As with assisted decision-making, individuals should be able to appoint more than one co decision-maker for each area of decision-making;
- There is a need for more emphasis on the responsibility of co decision-makers to support the will and preferences of the person;
- The individual should have as much control as possible in the appointment and *modus operandi* of co or representative decision-makers – consideration should be given to including provision for a role for independent advocacy in relevant court processes;
- Co and representative decision-makers (decision-makers of last resort) should only be appointed where the will and preferences of the person are unknown, and their role should only be to act in a manner that represents their best understanding of the person’s will and preferences;
- The least restrictive measure should always be explored fully and exhaustively before the next measure is explored – the legislation needs to state this explicitly.

## **Implementing the Legislation**

### ***Instigating appropriate mechanisms***

Guidance on implementing the legislation needs to take cognisance of how the various decision making or support mechanisms are to be triggered in respect of individuals with different needs. It is not clear where responsibility will lie for initiating the appropriate process for each individual. Some consideration is required of how different measures will work in practice in different scenarios.

### ***Coherence with Other Measures***

As well as the legislation on assisted decision-making, a number of other measures need to be in place. In addition to the HIQA National Standards for Residential Services for Children and Adults with Disabilities, published earlier this year, there is an urgent need for the introduction of a similar set of mandatory standards for community-based services. In this regard, the concerns set out in the Law Reform Commission’s *Consultation Paper on the Legal Aspects of Carers* which dealt with the regulation of home care for vulnerable adults should be taken into account. This is particularly important

in the context of the new provision in the Bill for the protection of informal decision-makers.

While the Bill contains some important amendments to the law on capacity which could benefit significantly people with mental health difficulties, further clarification is required as to how the provisions of the Bill will interact with the Mental Health Act 2001. The relationship between the two pieces of legislation and how they apply to different individuals should be a key consideration. Of particular importance in this regard is the development of integrated Codes of Practice.

While the main focus of the Bill is on the courts system, in practice, social care decisions are made, and will continue to be made, by different people in people's homes or in care settings. So the key challenge for the effective implementation of the legislation is that people making decisions or supporting decision-making all work according to the same protocols to optimise supported decision-making.

### ***Guidance and Codes of Practice***

There is a need to put in place mechanisms and protocols for information provision, training and guidance for individuals who require support – family carers, health and welfare services delivery personnel and banks/financial institutions. The purposeful implementation of the legislation when enacted will require the development of codes of practice to cover a range of areas. Guidance and protocols will be required in the context of informal decision-making, assisted decision-making, co-decision-making and representative decision-making in respect of:

- How to ensure that the will and preferences of individuals are clearly understood and respected as far as is practicable
- How to assess capacity and how to determine the most appropriate (and least restrictive) decision-making mechanism
- Management of people's financial affairs
- Matters that are required to be referred to the Office of Public Guardian and related responsibilities of people in different support roles
- Welfare and health matters, including, in particular:
  - Where and with whom a person is to live
  - Health interventions
  - Advance care directives, including end-of-life care
- How to deal with situations where there may be divergent views and possible conflicts of interest



- The respective roles and responsibilities of different stakeholders – the individual with the disability, relatives, advocates/support persons, service providers

The effective implementation of the legislation will require that those involved have the information and training they need to enable, facilitate and make the best decisions. This requires interagency collaboration between, for example, the proposed Office of Public Guardian, the Department of Justice and Equality, the Department of Health, the Department of Children and Youth Affairs, the HSE, the Office for Disability and Mental Health and NGO service providers.

It will also be important, the CIB believes, that the reform of other areas of law affected by legal capacity but not included in this Bill, for example, the Criminal Law (Sexual Offences) Act 1993 and the Juries Act 1976 is expedited.

### ***Information Dissemination***

A key factor in the effectiveness of the proposed legislation will be the extent that people – citizens (including people with disabilities), families, support workers, advocates, service providers and legal personnel – are aware of its provisions. This will require the proactive dissemination of information on the legislative provisions and the related regulations and implementation guidelines. The involvement of the proposed Office of Public Guardian, the Department of Justice and Equality, the Department of Health, the Department of Children and Youth Affairs, the HSE and the Office for Disability and Mental Health will be necessary in this regard.

### **Overview**

The Bill represents a significant shift away from ‘best interests’ decision-making towards respect for the will and preferences of persons with disabilities and to ensuring that, as far as is practicable, such will and preference is reflected in all decisions made by or on behalf of the person. In order to be effective, the legislation must ensure that the principle of decision-making remaining with the individual informs all supports and interventions. Great care is, therefore, required to ensure that substitute decision-making is not operating under another name, e.g. in informal decision-making. The making of applications to court in respect of persons whose capacity may be in question to seek a declaration as to whether those persons lack capacity and for the making of consequent orders approving a co decision-making agreement or appointing decision-making representatives is an important and necessary provision but one which needs to be carefully monitored in order to ensure that a person’s decision-making capacity is never undermined by inappropriate and/or unnecessarily restrictive mechanisms.

## APPENDIX *Case Examples*

### ***National Advocacy Service Case Examples***

#### *Case Example 1: Supporting a Person to Live Independently*

The person with Downs Syndrome is in her 30s and was referred to NAS by a family member. The initial meeting with the woman included her siblings. The woman had experienced substantial change in her circumstances in recent months. She had previously resided with her parents in the family home and attended a Day Service. However, her father had recently died and her mother had moved to a nursing home. She had previously relied on her parents for day to day living assistance and support.

A crisis situation had arisen as the woman's family found it difficult to cope with the changed circumstances and the issue of care of their sibling. It appeared that the family embarked on the process of deciding what they deemed to be in their sibling's best interests without involving the woman herself.

It also appeared that the woman's legal and financial interest in the family home had not been secured and that she required support from NAS around this issue.

#### *Advocacy Plan*

The Advocacy Plan for this woman involved ensuring that the woman's voice was listened to and that the tools to assist her to live in an autonomous independent way were put in place. This included seeking supports to assist in the transition period, including medical assessments in respect of the woman's capacity and devising ways to enhance her capacity. It also involved supporting the woman in claiming her inheritance. The advocate worked to ensure that she was aware of options available and helped with exploring independent living options and developing the skills required to achieve this.

#### *Outcome*

The advocate worked on the presumption of the woman having capacity and sought to include her in the decision-making process and to put processes in place to assess and enhance her independent living skills in accordance with her wishes. The advocate sought short term placement for the woman through *Share a Break* to assist in the transition stages for both the woman and her family. This was organised through the social worker and is presently ongoing. It took time for the woman's family to agree to their sibling entering into this alternative model of care as they had concerns regarding trusting other people with their sibling and were uneasy about involving a substitute family in place of their own.

The woman was provided with all information regarding the will/inheritance and was involved in liaison with FLAC, solicitor and psychologist on the matter. Again, the advocate worked closely with her to ensure that she understood the effect of the decisions that she made and that undue influence was not exercised by other parties.

Relationships with the family were developed and the family now see the woman in a more positive manner – as an independent person who requires support and assistance. The woman's financial independence was enhanced through helping her get her own bank account. This was a somewhat more complex process than it would be for many other people as the woman had no ID and application forms had to be completed by Gardai. The woman is presently on a supported accommodation shortlist for housing and so, according to the advocate involved, should be able to live in the manner that she wishes with her friends.

### *Case Example 2: Ward of Court*

The person is aged 50 years and has been a Ward of Court for over 20 years. As a young professional having begun a teaching career, the woman was involved in a severe road traffic accident and sustained head injuries. As a result of the brain injuries sustained, she had to learn to read, write, walk and talk all over again. She was made a Ward of Court and as time progressed began to establish herself as an individual once again. She faced opposition when she began to question her situation and her lack of autonomy. As a result she claims she was viewed as difficult and was admitted to a psychiatric unit where she remained for 14 years.

Early on in the woman's rehabilitation she remembered her old life and how it used to be. She informed NAS that she had applied to the Courts to have the Wardship lifted a number of years ago. However, the family objected and this was declined. She has now approached the NAS for assistance is making a new application to the courts to have the Wardship lifted as she feels it is no longer merited.

While the woman agreed that initially it was appropriate that she was made a Ward of Court due to her injuries, she began to believe that it was no longer warranted. She fought to establish an independent life and despite opposition from her family she eventually moved from the psychiatric unit to supported living and then to independent living. She has been living independently for over three years; she manages her finances, cooks, cleans, bakes and enjoys her autonomous lifestyle. She has worked hard to establish a social network for herself in the community and now works part-time.

This case illustrates the archaic nature of the current Ward of Court system. This all or nothing system diminishes the autonomy of the individual. Despite the fact that the woman has demonstrated the ability to live independently, manage her finances and hold a position of responsibility through employment; she is still prohibited from making decisions about her finances or even choosing to go on holiday. The onus lies with the woman to initiate proceedings for review of her case and the appropriateness of the Wardship. Without the energy and determination to fight her case this woman could remain a Ward of Court for many years to come even though it may not be warranted.

This case highlights the need for the capacity legislation to make provision for mandatory review of the situation of all people who are Wards of Court.

### *Case Example 3: A Partnership Approach*

This man has a large sum of money being held by his solicitor. Although he has been assessed as being in the moderate range of intellectual disability and lacking capacity to make decisions in relation to his money, it has emerged that he is able to communicate with people whom he trusts and knows, thus demonstrating more ability and capacity than had been originally thought. Discussions were held in relation to whether an application for Ward of Court should be made but this was not progressed. It was agreed that a viable alternative would be to form a support network around him including HSE staff, nursing home staff, an advocate, his solicitor and family members. This group meets to discuss the man's wishes and needs and to agree how his money might be spent. The advocate involved works towards ensuring that his solicitor and family members whom he trusts understand his views on how he wants to spend his money.