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**Decision-making capacity in mental health:
Exploratory research into the views of people with
personal experience**

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Executive Summary

The distinction between who does and does not have the capacity to make decisions lies at the root of Western conceptions of citizenship and rights. Most people receiving mental health care have capacity, but for a minority there are times when decision-making capacity is diminished. The recently adopted UN Convention on the Rights of Persons with Disabilities (CRPD) requires States to recognise that persons with disabilities (including persons who experience mental health problems) enjoy legal capacity on an equal basis with others. While Ireland has not yet ratified this Convention, the State is in the process of introducing new legislation in an effort to bring Ireland's law into line with Article 12 CRPD. Thus the Irish Government has published an outline of a mental capacity bill (the Scheme)¹ and is expected to publish the bill in early 2010. The issue of capacity is also at play in Ireland's mental health legislation, which refers to a person's 'impaired judgment' and also to being 'capable of consenting' to treatment. Because, as recognised by the Law Reform Commission, a finding of a lack of decision-making capacity can result in the restriction or removal of a person's human rights², Amnesty International Ireland (AI) has chosen to lobby Government about the capacity legislation as part of its current mental health campaign. The research presented below explored issues related to decision-making capacity from the perspective of people with experience of a mental health problem. The results will inform AI's lobbying position on upcoming capacity legislation as well as the Government's planned review of the Mental Health Act 2001.

The overall aim of the research was to explore issues related to decision-making capacity and advance directives with people who have had personal experience of impaired capacity in the context of a mental health issue. The research looked at three levels of decision-making capacity: in relation to decisions with legal consequences such as those about property, in relation to decisions about mental health treatment and in relation to decisions of daily living. The research was conducted through in-depth interviews with eight participants all of whom have experience of mental health treatment. The methodology was participatory: participants were involved in the research design and verified the transcripts and analysis. Ethical guidelines for survivor research were adhered to as well as the 'Ethics-As-Process' approach and the British Psychological Society Guidelines (1990) (see methodology section for further details on the approaches taken).

Overview of the Scheme of the Mental Capacity Bill 2008

The publication of the Scheme provides an immediate policy context for the research questions. The Scheme takes a new, 'functional' approach to capacity. It provides that determinations of a person's capacity must be time-specific and decision-specific. This contrasts with the traditional 'all-or-nothing' approach which exists under the current Ward of Court system. The Scheme takes an approach to best interests that seeks to maximise the autonomy of the individual, as well as respecting the individual's right to dignity, privacy and bodily integrity. It provides a basis for supported decision-making by requiring within its Guiding Principles that all practicable steps be taken to help a person to make a decision. However, it does not

¹ The Scheme of the Mental Capacity Bill 2008 (available at: http://www.justice.ie/en/JELR/Pages/Civil_law_reform_proposed_legislation)

² Law Reform Commission *Consultation Paper: Vulnerable Adults and the Law* (LRC CP 37-2005) para 1.26.

further spell out how supported decision-making should operate. Its main focus is on formal and informal *substitute* decision-making. It allows for informal substitute decision-making about healthcare but does not set a clear distinction about when formal decision-making should take over from informal. The Scheme also supports the provision of accessible information to individuals in the determination of incapacity.

The issue of mental capacity is hugely relevant in the context of the Mental Health Act 2001, which deals with the involuntary admission, detention and treatment of persons with mental health difficulties, in particular in the definition of 'mental disorder' (which is the criterion for involuntary admission and/or detention) and the treatment provisions set out in Part 4 of the 2001 Act. However, the Scheme is silent on how its provisions will operate vis-à-vis the Mental Health Act 2001.

Results

Participants' own descriptions of incapacity illuminate new understandings of it in the context of mental health. Participants described how in periods of mental distress, decisions could be 'impossible hills to climb'. Sometimes panic or fear inhibited decision-making, sometimes poor concentration, sometimes the loss of a pre-existing skill such as being able to be organised. This loss of decision-making capacity was described as 'horrible' by one participant and as 'the worst aspect' by another. For most participants, the experience of having others make decisions for them was at times distressing, frustrating and scary. However, some participants acknowledged that there were times when it was necessary for others to make decisions on a person's behalf, and one described it as being at some moments and to some extent a relief.

Participants also identified ways that they had learned to recognise when they were losing their capacity. One person recognised this through noticing when his/her mind was 'getting into a muddle again'. Another person saw it as recognising the plateau where 'if I step off that or slip off it then I know I need to take medication for a while,' but some participants didn't always know when they lacked capacity, particularly in the early years of their experience.

Participants' views on the proposed definition of capacity showed some support but also significant concerns about its relevance in mental health. Some statements made by participants concurred with aspects of the definition. Some discussed how incapacity is usually partial; one person discussed how there should be a presumption of capacity and that it is possible to behave inappropriately but still be capable of making decisions. These responses support the perspective taken in the Scheme that capacity is decision-specific and time-specific as well as the presumption that individuals have capacity. However, most participants disagreed with the proposed definition. Three participants expressed a strong desire for an alternative to the capacity/incapacity framework because it does not recognise the subtleties of continuing capacity in the context of a mental health crisis. Some participants were critical about an incapacity framework because the mental health system does not provide alternatives that might avoid the necessity for such determinations, e.g. crisis houses. Some participants also felt that the capacity framework did not suit because incapacity is so temporary in mental health.

In contrast, participants' descriptions of their approach to capacity suggest an approach in line with a strong social model of disability. Participants described how their decision-making capacity could be reduced by the lack of treatment options from which to choose. Capacity can be negated by the way that information is delivered if that manner is too heavy-handed, or if the person providing the information is not perceived as trustworthy by the individual concerned. Capacity can also be negated if the information about the decision is not in accessible language. In some participants' experience, capacity can be diminished through the effects of medication that literally "stops your ability to think". Capacity can be undermined if the individual is not given enough time to digest information and develop their decision.

Participants identified the personal support they are given during the decision-making process as one of the key enablers of their capacity. Two individuals felt that without the in-depth support of another person, they would not have been able to make decisions at key moments in their lives. The role of this person varied – sometimes it was described in terms of working through the available choices or minimising a surfeit of choices. Sometimes it was just having a trustworthy person with whom to talk things through. The majority of participants highlighted the importance of affirming an individual's capacity. Many emphasised the value of expressions of hope for their recovery and the belief in their innate, persistent capacity throughout times of difficulty that was conveyed by others.

These descriptions of the role of supportive relationships, accessible information and a positive environment point to a situated and relational conception of capacity. They open up a new perspective on capacity that can inform wider debates about a social approach to mental health.

Participants also provided a range of practical suggestions that can be taken into account in the process of implementing capacity or mental health legislation. With reference to the qualities of people who should assess capacity, participants thought that persons charged with this responsibility should be neutral, drawn from a wide range of professions and non-professionals, trained in determining capacity and/or in logic, knowledgeable about mental health/emotional distress/ emotional intelligence, friendly, respectful, wise and self-aware.

With regard to who should assist them to make everyday decisions, participants wanted someone they trusted and someone close to them. Participants wanted to be able to choose who would assist them to make mental health treatment decisions. Options included an advocate, a multidisciplinary team and a legal professional. Two participants emphasised the need for the role of the family to be clarified. For legal decisions, some participants wanted assistance from someone knowledgeable in the law, while others wanted assistance from trusted friends.

Participants were predominantly negative about the idea of going to court for the determination of capacity, with several indicating that at times of severe distress this would be impossible for them to face. They offered reasonable ways of thinking about the timeframe for reviewing capacity. Rather than set a specific timeframe, participants wanted any review to be responsive to changes in the individual's capacity. Some also wanted to be involved in determining the timeframe for review, either in a contemporary negotiation or in advance through an advance directive.

A diversity of views was expressed regarding an appeals process. One participant proposed a process of dialogue as a precursor to any formal review process. Other suggestions were for a court or a neutral oversight body as a forum for appeals.

The issue of advance directives was touched on briefly in this research. Advance directives can provide instructions for substitute decision-makers about mental health treatment and other decisions. Participants were asked whether they thought it would be helpful to be able to write down in advance what mental health treatment they would or would not want in situations where they would lack capacity. Responses were unanimously in favour, with a majority saying that such expressions should have a legal footing. The view was expressed that such a document would facilitate the individual's sharing their knowledge about what works for them and thereby have a positive impact on the type of treatment they receive in moments of crisis. Participants also had a realistic appreciation of how this might work in practice in relation to mental health, recognising that it was unlikely they could require a particular medication but with a strong desire to be able to refuse ECT, drugs that were known to cause them ill effects, or experimental drugs. In terms of scope, participants thought the directive should be either totally binding, binding for refusals of particular treatments, or binding unless there was clear justification to override it.

While these results cannot be taken as representative of a wide constituency, being the views of just eight individuals with experience of mental health problems, they can provide a basis for further research. The results will underpin future research questions regarding the definition of capacity, the facilitators and barriers to individual fulfilment of capacity and the role and operation of advance directives. In the meantime, the results will be of immediate benefit in providing useful evidence to inform AI's lobbying position and the wider Irish debate on capacity and mental health legislation.

Chapter One: Introduction

Amnesty International Ireland (AI) is a membership-based campaigning organisation, which has a mission to uphold and defend human rights. AI has been campaigning in the area of mental health in Ireland since 2003 and launched a new phase of its mental health campaign on 15 June 2009. As part of this campaign, AI will lobby to ensure that mental health and related legislation complies with human rights standards including in particular the UN Convention on the Rights of Persons with Disabilities (CRPD), which came into force in May 2008. Article 12 of the CRPD requires States to recognise that persons with disabilities (which includes persons experiencing mental health problems) enjoy legal capacity on an equal basis with others.

The Irish Government has published an outline of a ‘mental capacity’ bill (the Scheme)³ and is expected to publish the bill in late 2009. The Law Reform Commission (LRC) recognised the link between decision-making capacity and human rights insofar as a finding of incapacity will result in the restriction or removal of a person’s fundamental human rights.⁴ It is for this reason that as part of its mental health campaign, AI will be lobbying the Government about the capacity legislation. With a view to informing both AI’s lobbying position and the wider debate on capacity in Ireland, AI has conducted the research presented below that explores issues related to decision-making capacity from the perspective of people with experience of a mental health problem.

The distinction between who does and does not have the capacity to make decisions lies at the root of Western conceptions of citizenship and rights. In its Consultation Paper on Vulnerable Adults and the Law: Capacity (2005), the LRC acknowledged that:

“To be autonomous and capable of self-determination is a large part of what humans cherish in terms of liberty and independence. Part of being an adult is the right to make decisions independently, although in reality many of us make them interdependently by consulting with friends and family.”⁵

A rationalist conception of the person who has legal rights is also at play in much of Western discourse defining ‘legal personality’:

“To Rationalists...the true legal person is the rational human being; legal rights in essence derive from the human ability to reason.”⁶

Yet other conceptions of the subject of rights co-exist within Western law, including religious, naturalist and social constructionist perspectives.⁷ In light of the CRPD as

³ The Scheme of the Mental Capacity Bill 2008 (available at: http://www.justice.ie/en/JELR/Pages/Civil_law_reform_proposed_legislation)

⁴ Law Reform Commission (2005) para 1.26..

⁵ Ibid., para 1.04.

⁶ Naffine, N. (2009) *Law’s Meaning of Life: Philosophy, Religion, Darwin and the Legal Person*, Oxford: Hart Publishing.

⁷ Ibid.

well as the LRC's endorsement of a social and human rights model of disability,⁸ it is particularly appropriate to consider the social model of disability approach to capacity. The LRC identifies this approach as entailing an emphasis on ability rather than disability and as supporting human rights. However, going further than this, proponents of a social model of disability approach argue that individuals are disabled by their environment rather than by impairment. From this perspective, the individuals' capacity is not entirely determined by intrinsic mental faculties, but rather by interaction with the social world.⁹ The relevance of this approach to decision-making capacity in mental health will be shown in the below results.

This research is practical in its intent. The originating impetus for the project was to inform AI's lobbying submissions. The research therefore focuses on a number of practical questions that directly relate to elements of the proposed capacity legislation as evidenced in the published Scheme. However, narrative understandings of capacity can also inform practical application of the law. Stories can demonstrate the impact of incapacity on individuals' lives. They can evidence individuals' fulfilment of both capacity and incapacity. And they can articulate the meanings that individuals attribute to capacity/incapacity. In the interviews for this project, therefore, the opportunity was taken to explore individuals' experience of incapacity. These narrative understandings are reported in the latter section of the report.

Almost no research has been conducted to explore conceptions of decision-making capacity from the perspective of people with experience of a mental health problem. One study located as part of literature searches for this project was conducted for the Mental Health Foundation in the UK in advance of the enactment of their Mental Capacity Act 2005. The research explored service users' and carers' views of the new mental capacity legislation. The 14 service users interviewed included mostly those attached to mental health services with some engaged in learning disability services. It found that service users had varying preferences of how to express their wants and needs to others. Service users were less likely to express their needs and wishes in situations where they didn't feel confident. Prejudice and stigma also diminished service users' confidence in their own ability to express their wants and needs. The service users also identified important staff characteristics for those that would provide support in making a decision, including: good communication skills, flexibility and responsiveness, a positive outlook and a non-judgmental, caring disposition.¹⁰

Another small-scale study was conducted with 10 service users and carers, including individuals affected by mental health issues, intellectual disability or physical disability, and looked specifically at implementation of the UK's Mental Capacity Act 2005. Participants were largely in favour of the Act. Concerns were raised regarding the adequacy of training provided to professionals and whether professionals could

⁸ Law Reform Commission *Report: Vulnerable Adults and the Law* (LRC 83-2006) paras. 1.59-1.60.

⁹ Rapley, M. (2004) *The Social Construction of Intellectual Disability*, Cambridge: Cambridge University Press.

¹⁰ Myron, R., S. Gillespie, P. Swift and T. Williamson (2008) 'Whose Decision?: Preparation for and implementation of the Mental Capacity Act in Statutory and Non-Statutory Services in England and Wales', Mental Health Foundation, available at http://networks.csip.org.uk/_library/Resources/Housing/Support_materials/Other_reports_and_guidance/Whose_decision.pdf

fulfil the commitment to a presumption of capacity. There was also concern about the continued potential for abuse by proxy decision-makers. Advance decisions to refuse treatment were seen as 'sensible' and beneficial to those who wanted to refuse a particular treatment. There was some concern expressed that procedures to implement the Act could be intimidating to service users. There was also a suggestion to have user participation in monitoring implementation of the Act, and training for both service users and carers.¹¹

The research conducted to date is thus limited in both its scope and scale. The Mental Health Foundation research asked general questions of a relatively small, mixed group and therefore provides relatively basic information from service users' perspectives. The Manthorpe, et al. study involved more focussed discussion with a mixture of service users and carers and therefore provides some useful comparative information to the results presented below. Given the paucity of in-depth explorations to date, the research here presented is thus innovative in developing a detailed and reflective analysis of capacity from the perspective of individuals who have been the subject of mental health interventions.

Aim of the research

The overall aim of the research was to document views on decision-making capacity and advance directives from the perspective of people with direct experience of mental health treatment. The scope encompassed decisions with legal consequences such as those relating to property or mental health treatment as well as decisions of daily living. Both types of decisions are addressed in the Scheme.

The specific research questions were:

- How does the individual tell when he/she is having trouble making decisions?
- How does it feel when others make decisions for him/her?
- Who should assess capacity and how?
- Who would be preferred in providing representation in a formal assessment process?
- How often should capacity be reviewed?
- What kind of support to assist in decision-making would be valued?
- Who would be preferred to provide support in decision-making?
- What kind of information would assist in decision-making?
- How could advance directives or crisis plans work in mental health?

¹¹ Manthorpe, J., J. Rapaport and N. Stanley (2008) 'Expertise and Experience: People with Experiences of Using Services and Carers' Views of the Mental Capacity Act 2005', *British Journal of Social Work* 1-17.

These questions were developed in consultation with members of AI's Experts by Experience Advisory Group (EEAG) who helped to devise AI's mental health campaign strategy.¹² The questions reflect key components of the Scheme including:

- the definition of capacity
- the role of the assessor
- support during assessments of capacity
- support in making decisions
- where capacity should be determined
- how often a determination of incapacity should be reviewed

In addition, the issue of advance directives is relevant because the Scheme provides for substitute decision-making (situations where a person makes a decision on behalf of another person who is incapacitated) and requires substitute-decision makers to consider the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him or her when he or she had capacity) when deciding what course of action to take in the person's best interests (Head 3). For this reason the research also briefly considered advance directives.

Methodology

The research was conducted using a Human Rights Based Approach (HRBA). A HRBA uses human rights law as the basis on which to develop policy, deliver services and campaign for change. It assists actors in positions of responsibility (the duty bearers) to respect and foster human rights by incorporating rights promotion into both policy and delivery of policy. It also focuses on empowering the people who hold those rights to develop the skills and confidence so that they can ensure their rights are upheld and hold duty bearers to account.

The Human Rights Based Approach consists of five key principles:

- Express application of the human rights framework
- Empowerment
- Participation
- Non-discrimination and prioritisation of vulnerable groups
- Accountability

This research reflects an express application of the human rights framework by seeking to explore how capacity legislation can fulfil the commitment under the CRPD that 'persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life' (CRPD, Article 12(2)). The research findings will provide an initial basis for articulating how the Government can support individuals who are subject to mental health treatment to make decisions for themselves as well as protect individuals from abuse in relation to capacity, as provided for in Article 12, subsections 3 and 4 of the CRPD.

¹² The Experts by Experience Advisory Group is a committee made up of people in Ireland with direct experience of a mental health treatment as well as experience of advocacy. It has 10 members and decisions are taken by consensus along with the staff of AI's mental health campaign. The Group's purpose is to provide the policy direction for AI's mental health campaign.

The research findings will also provide a basis for the empowerment of EEAG members and other mental health rights holders. Emancipatory research seeks to bring about positive social change for disabled people through research.¹³ This project seeks to develop mental health rights holders' (people whose rights are at issue) own analysis of decision-making capacity as a basis for their own lobbying effort by collating the views of a group of rights holders into a single source and developing an analysis that reflects a consolidation of rights holders' perspectives. The results will be reflected in AI's lobbying submissions and will be attached to AI's submission on the capacity legislation.

The research has operated through a participatory methodology. Participatory research seeks to equalise research power relations by involving the participants in the research design, data collection, analysis and dissemination. This research was initiated through AI's EEAG, with whom the research aim and specific research questions were developed and agreed. The ethical standards utilised in the research were also chosen with the EEAG. The participants in the project were sent the interview transcriptions for their review and comment. The draft analysis was also presented to participants for feedback at a joint meeting with an academic advisory group (see below). Thus rights holders have been involved in all phases of the project apart from the dissemination phase.

Eight individuals with direct experience of mental health treatment were interviewed using a semi-structured topic guide (see Appendix 1). The participants were accessed through snowballing from individuals who are engaged in AI's mental health campaign. Of the ten people who were approached to participate, one individual refused to participate due to lack of time and one who expressed an interest was not able to due to personal circumstances. An equal number of men and women were interviewed and ages ranged from 42 to 62. All had completed at least a third-level diploma or certificate and therefore in total, this represents a relatively highly educated group in relation to the general population. Only one of the participants was unemployed with most of the remainder in employment and this is also unusual amongst people with a history of contact with the mental health service, for whom there is a very high unemployment rate in Ireland.

The sample for the study is therefore not representative of the general population of people with experience of a mental health intervention. For this exploratory study, the researchers considered that it was important to involve participants who had a relatively sophisticated understanding of their experience, that is, a group of people who have had both the opportunity and the expressed interest in reflecting on their mental health experiences, in order to generate a sufficiently nuanced and thorough analysis of the issue of capacity. Such a group is not necessarily un-representative – that is, their views do not necessarily reflect different experiences from others in the mental health system, but their ability to articulate these experiences is greater than would be expected from a larger, strictly representative sample. This presents certain limitations on the analysis which are acknowledged in the report's conclusion. The researchers also considered that it was valuable to focus in this exploratory research on participants who had a number of experiences over time and therefore

¹³ See Oliver, M. (2002) 'Emancipatory Research: A Vehicle for Social Transformation or Policy Development?', NDA Inaugural Disability Research Conference [proceedings]. Dublin: National Disability Authority.

could base their contributions on both more than one incident and also describe any change in their understanding of their own capacity over time. The value of this approach is shown in Chapter 3 under the sub-section on “self-recognition of capacity”.

Interviews were held in the location preferred by each participant, including the individual’s home, public restaurants and AI’s offices. One interview was held over the telephone. The transcription of each interview was circulated to the relevant participant for verification and amended with any corrections received. An initial coding framework was developed on the basis of the topic guide. Specific codes were then generated from the texts as these related to the research questions. This method follows the ‘Framework Approach’ developed by Ritchie and Spencer,¹⁴ which involves “a systematic process of sifting, charting and sorting material according to key issues and themes”.¹⁵ Additional codes were generated from thematic analysis of participants’ narrative descriptions. Two researchers carried out interviews and coding in order to establish inter-coder reliability. The resulting analysis was then presented to a joint meeting of the research participants and the academic advisory group for validation.

Ethics

Empowerment, human rights, participation, non-discrimination and accountability are all concepts that reflect democratic, egalitarian and human rights ethics. By adopting a Human Rights Based Approach, the researchers have addressed broad ethical concerns such as who should benefit from the research process, who should control the process and to whom and how researchers are accountable. However, research practice also recognises specific standards of ethics concerning issues such as confidentiality and protection from harm. In the absence of any national system of ethical approval for social research, for the purposes of this project an advisory committee of academic experts was formed to advise on the research design and review the draft report. The advisory group consisted of experts in disability/mental health research, mental health practice and/or expertise by personal experience of having used mental health services.

The researchers also followed three ethical guidance documents that were agreed with the EEAG in order to ensure ethical conduct of the research:

- The research process followed the guidelines for ‘survivor’ research developed by Alison Faulkner.¹⁶ The *Ethics of Survivor Research* guidelines emphasise equality between researchers and participants as well as an emancipatory intent. Much of this guidance supports participatory research practice as described above, that is, ‘everyone being involved from the start’, ‘taking the analysis back to the participants’, and providing participants with accessible feedback and a copy of the report. The guidelines recommend payment for service users/survivors who are actively involved as researchers. In this case, those service users/survivors who were engaged as experts on the

¹⁴ Ritchie, J. and L. Spencer (1994) ‘Qualitative data analysis for applied policy research’, in Alan Bryman and Robert G. Burgess (eds.) *Analyzing Qualitative Data*, London: Routledge, 173-194.

¹⁵ *ibid* 177.

¹⁶ Faulkner, Alison (2004) *The Ethics of Survivor Research: Guidelines for the Ethical Conduct of Research Carried out by Mental Health Service Users and Survivors*. Bristol: The Policy Press.

Academic Expert Advisory Group were paid a professional rate for their time. Participants were not paid for interviews or attendance at the validation meeting, but were offered expenses. Faulkner's guidelines also address standard concerns of research ethics including confidentiality and protection from harm. In terms of supports, all of the participants in this project were in regular contact with the researcher who was alert to signs of stress in the participants. When issues arose in this regard, the researcher contacted the participant concerned to ensure supports were in place. Most participants were also connected with Irish peer support or advocacy groups.

- The research process took account of the 'Ethics-as-Process' approach described by Cutcliffe and Ramcharan.¹⁷ This approach recognises that research is an ongoing process between participants and researcher. Rather than the traditional approach of once-off engagement in ethics through an initial consent form, the approach recommends a number of techniques to engage with ethics throughout the research, including:
 - 'member checks' for establishing the credibility of the findings
 - ongoing establishment of consent
 - ensuring the absence of pressure or coercion on participants to continue both within interviews and in the process as a whole
 - developing a 'theoretical response to upholding clients' autonomy' (this has been accomplished through adopting the Human Rights-Based Approach)
 - recognising when research becomes intrusive, and separating individual from group consent

In this project, the lead researcher took steps to ensure that all participants had the opportunity to reject or accept participation at each stage of the process. At all points during the process, participants were invited individually in order to maintain confidentiality and freedom from peer pressure. Participants were assured that the interview could be stopped at any time upon their request. They were invited to review the transcript of their interview but assured that this was their choice. Participants were also invited to a validation meeting for 'member checking' and were assured that it was also their choice whether or not to participate, with an alternative method of feedback offered to any participant who expressed an interest in this. Through these steps, the requirement to engage with participants' autonomy throughout the research process was met.

- The research was conducted in accordance with the British Psychological Society's ethical principles (1990). All participants completed a consent form reflecting these principles (see Appendix II).

During the research design phase, the lead researcher also suggested that the project follow the National Disability Authority's guidelines on research with people with disabilities, however these were rejected by the EEAG on the grounds that members did not see themselves as disabled people.

¹⁷ Cutcliffe, J.R. and P. Ramcharan (2002) 'Leveling the Playing Field? Exploring the Merits of the Ethics-as-Process Approach for Judging Qualitative Research Proposals', *Qualitative Health Research* 12:1000-1010.

The issue of confidentiality in a small-scale, participatory project such as this warrants special consideration. Confidentiality needed to be addressed in three directions. Firstly, the participants needed to have the opportunity to maintain confidentiality between each other. The participants were therefore not disclosed to each other until the validation meeting, and only upon their own choice to participate in that meeting. Secondly, the participants needed to have the opportunity to maintain confidentiality with other stakeholders related to the research process. For this reason, participants were asked, individually, whether or not they wanted the academic experts to attend the validation meeting. There was unanimous choice for having the academic experts attend the meeting and thereby to disclose participants to the academic experts. Finally, participants needed to be able to maintain their confidentiality to the general public. In order to maintain confidentiality in this direction, the results are presented in such a way as to avoid any identifying information for each participant. The results are presented in a gender-neutral form and no other demographic identifying information is attached to any individual quotes. The more subtle issue of whether or not individuals can and want to be identified through any other content in the text will have been negotiated with the participants at the validation meeting. Interview transcripts from the project are stored in a password-protected folder on AI's secure server, recordings have been destroyed and consent forms are maintained in a locked file.

Organisation of the report

The following report is organised into three further chapters. Chapter Two provides a brief discussion of the prevalence of capacity among people who are clients of the mental health system as well as an overview of the proposed Scheme and related conceptual issues. Chapter Three presents the detailed analysis of data obtained in one-to-one interviews. This chapter begins by reporting the narrative understandings of decision-making capacity arising out of participants' descriptions of their own experience. The latter sections of this chapter are broken down into sub-sections that relate to specific components of the proposed legislation. Chapter Four provides a discussion of the key findings and an overall conclusion.

Chapter Two: Background

Prevalence of incapacity in people diagnosed with a mental health problem

Estimates of how many people with a mental health diagnosis lack capacity are quite variable. They are often based on small sample sizes and inpatient populations. However, the limited evidence available supports the view that most inpatients in mental health services have decision-making capacity. Given the limitations of research into prevalence, the following discussion should be read with caution as to validity. Okai, et al.'s systematic review found a set of studies showing anywhere from 10 per cent to 95 per cent levels of incapacity amongst psychiatric inpatients, however most studies estimated that more than half of psychiatric inpatients had capacity, and the median estimate was 29 per cent.¹⁸ These studies were all based on small samples sizes of between 20 and 113 patients. The researchers found strong linkage between incapacity and severity of symptoms, psychosis, involuntary admission and treatment refusal. The issue of refusal is particularly important. Five studies showed that individuals who refused treatment were more likely to be assessed as lacking capacity. This presents a chicken and egg-type scenario: it is difficult to tell whether the treatment refusal reflects a condition of incapacity, or the clinician is presuming incapacity where the patient disagrees with the clinician's treatment regime. A related finding supports the latter interpretation: Okai, et al. found that clinicians were more likely to assess a patient as having capacity than a researcher. However, the authors speculate that this may be due to a tendency for clinicians to presume a patient has capacity where the patient accepts treatment. The issue of the relationship between 'insight' and capacity is also relevant. One study found that among patients diagnosed with psychotic disorders or mania, insight is the best discriminator of capacity, though this relationship did not hold for patients with non-psychotic disorders. However, at least one of the measures of 'insight' required agreement from the patient that they were ill and that their symptoms were abnormal, as well as that the patient was compliant.¹⁹ Therefore, the 'insight' assessment in this study was heavily biased in favour of patients who agreed with the clinician. Thus any estimates of capacity/incapacity, including those that link incapacity with lack of insight, must be viewed with caution given the possible bias in the assessment process. Also, it appears that the majority of capacity research has been conducted on in-patient populations. Reliable evidence is not available for levels of capacity among people with mental health problems living in the community.

There is no strong link between having a particular diagnosis and lacking capacity, though at least one study has shown that clinical and functional assessments of capacity produce similar results.²⁰ Almost all studies of capacity report that there is a heterogeneity in prevalence of capacity by diagnosis and by demographic

¹⁸ Okai, D., G. Owen, H. McGuire, S. Singh, R. Churchill and M. Hotopf (2007) 'Mental Capacity in Psychiatric Patients: Systematic Review', *British Journal of Psychiatry* 191:291-7.

¹⁹ Owen, G.S., A.S. David, G. Richardson, G. Szukler, P. Hayward and M. Hotopf (2008) 'Mental Capacity, Diagnosis and Insight in Psychiatric Patients: A Cross-Sectional Study', *Psychological Medicine* 1-10.

²⁰ Rutledge, E., M. Kennedy, H. O'Neill and H.G. Kennedy (2008) 'Capacity is not Independent of the Severity of Psychosis', *International Journal of Law and Psychiatry* 31:1:9-18.

categorisation. Palmer, et al. (2004) found “remarkable heterogeneity among patients”, while differences in capacity appeared more related to cognitive functions than to severity of illness.²¹ Appelbaum’s overview also found that the relationship between psychiatric symptoms and capacity has been inconsistent and that the capacity of psychiatric patients relates more to their level of cognitive functioning than any specific symptom or disorder.²² Thus lack of capacity should not be assumed in individuals with a particular psychiatric diagnosis, even those undergoing inpatient care.

Conceptual issues concerning decision-making capacity

The LRC identified three approaches to ‘mental capacity’: status, outcome and functional. The traditional approach conceptualises incapacity as arising from a status of the individual. In the status approach, the determination of incapacity is based on characteristics of the individual, e.g. their medical or psychiatric diagnosis. The status approach makes an “across-the-board” assessment of capacity or incapacity, rather than an assessment based on a particular decision at a particular time. The LRC noted that “[a] status approach to capacity has particular potential to operate inequitably in relation to persons whose capacity fluctuates, for example, persons who have long periods of capacity alternating with shorter periods where cognitive ability is significantly impaired by an episode of mental illness”.²³

In an outcomes approach, capacity is determined based on an assessment of the consequences of the decision. The result of the choice is taken as an indicator of the individual’s capacity.²⁴ The outcome approach suffers from the problem that its findings are necessarily based on evaluative judgments about whether the outcome is good or not. Thus it relies heavily on conventional standards of wisdom. Where a person is assessed as making an unwise decision, under an outcome approach they would be judged to lack capacity.

The third approach recognised by the LRC is the functional approach. According to the LRC, “the fundamental premise of the functional approach is that the fact that a person belongs to a category of people who are often unable to make decisions for their own wellbeing may open the possibility of a lack of decisional capacity - but it does not of itself resolve the matter”.²⁵ The functional approach conceives of capacity as both time-specific and decision-specific. That is, capacity of an individual is determined about a particular decision at a particular point in time. It also recognises that a person may be capable of some decisions while incapable of others.²⁶

The functional approach is in accord with the World Health Organization’s (WHO) approach to disability evidenced in the International Classification of Functioning, Disability and Health (ICF). The ICF recognises that disability is a universal

²¹ Palmer, B.W., L.B. Dunn, P.S. Appelbaum and D.V. Jeste (2004) ‘Correlates of Treatment-Related Decision-Making Capacity Among Middle-Aged and Older Patients With Schizophrenia’, *Archives of General Psychiatry* 61:230-236.

²² Appelbaum, P.S. (2006) ‘Decisional Capacity of Patients with Schizophrenia to Consent to Research: Taking Stock’, *Schizophrenia Bulletin* 32:1:22-25.

²³ LRC (2005) para 2.08. See also LRC (2006) para 1.65.

²⁴ *ibid*, para 2.11.

²⁵ *ibid*, para 2.16.

²⁶ *ibid*, paras. 2.16 and 2.19.

experience – everyone will experience a disabling decrement in their health at some point in their lives. It therefore focuses on the person’s level of functioning rather than on their impairment.²⁷ This approach also contains the potential to implement a social model of disability towards capacity. Tina Minkowitz has argued that from the perspective of a social model of disability, capacity is not an individual problem. Rather, incapacity arises from how society relates to the individual in such way that diminishes the individual’s capacity. Minkowitz says that in order to fulfil the CRPD supported decision-making must be understood as an essential component of capacity. She argues that “ the construction of capacity as being dependent on any cognitive, perceptual, physical, communication and relational capabilities discriminates based on disability,” while the support paradigm constructs legal capacity without reference to evaluation of capabilities.²⁸ By adopting a relatively strong interpretation of the social model, Minkowitz highlights the role that supports play in enabling a person to demonstrate their capacity. Assessments of cognitive function must take into account the effects that having appropriate support may have on an individual’s ability to demonstrate capacity in order to come to accurate conclusions. This has been recognised in the proposed Scheme of the capacity legislation, in so far as it says that “a person shall not be treated as unable to make a decision unless all practicable steps to help him or her to do so have been taken without success”, nor should they be assessed as lacking capacity to understand information if he or she is able to understand an explanation of it given to him or her in a way that is appropriate to his or her circumstances (see below).

It is the functional approach that the LRC recommended be adopted so that intervention is proportionate and autonomy maximised.²⁹ In doing so the LRC expressly rejected both the all-or-nothing status approach and the outcome approach.³⁰

“The functional approach best accommodates the reality that decision-making capacity is a continuum rather than an endpoint which can be neatly characterised as present or absent. This approach has been approved of by interested parties who expressed their views to the Commission. It is in line with the social model of disability and with the legal presumption of capacity.”³¹

The LRC went on to recommend that the capacity legislation include a presumption of capacity to the effect that every adult is presumed to have the capacity to make decisions affecting them, unless it is proved to the contrary.³² The Commission viewed this as necessary to promote legal certainty and also to reflect the human rights disability model, which assumes that all persons with disabilities have legal capacity on an equal basis with others.³³

²⁷ World Health Organization (2002) ‘Towards a Common Language for Functioning, Disability and Health: ICF’, WHO/EIP/GPE/CAS/01.3, Geneva: WHO.

²⁸ Minkowitz, T. (undated) ‘The Paradigm of Supported Decision-Making’, unpublished, available for download at www.barcsi.hu/letoltesek/.../Minkowitz_presentation.pdf

²⁹ LRC (2006) paras 2.27 - 2.30.

³⁰ *ibid* paras 2.24 - 2.26.

³¹ *ibid* para 2.28.

³² *ibid* paras 2.35 – 2.39.

³³ *ibid*. See also Article 12(2) CRPD.

In defining capacity, the LRC chose a positive definition of capacity as opposed to incapacity.³⁴ In adopting a truly functional approach, the Commission also rejected any strong linkage between lack of capacity and ‘mental disorder’. It focused on functional cognitive ability, that is, the ability to weigh relevant information in making a decision and acknowledged that a person could attain the level of cognitive ability required with the assistance of a third party, e.g. using simple language or drawings etc.³⁵ Furthermore, the Commission concluded that the fact that a person can only retain information for a short time should not of itself determine that the person lacks capacity.³⁶ The Commission also acknowledged that persons must be allowed to make what others may view as imprudent or unwise decisions.³⁷

Thus the LRC recommended the following definition of capacity:

“**Capacity** means the ability to understand the nature and consequences of a decision in the context of available choices at the time the decision is to be made.”

The Commission was of the view that the ability to communicate effectively had to be taken into account in the definition of capacity and so included the following text:

“Where a decision requires the act of a third party in order to be implemented, a person is to be treated as not having capacity if he or she is unable to communicate by any means.”

International Human Rights Law and Capacity

International human rights law is constantly evolving and the most recent iteration of the rights of persons with disabilities, including persons with mental health problems is the recently adopted CRPD. While Ireland has not yet ratified the CRPD, by signing the Convention it has indicated a clear intention to ratify in the future. The CRPD has widely been described as marking a ‘paradigm shift’ in how disability is perceived by moving towards a social model of disability, which recognises that “disability resides in society, not in the person”.³⁸ Its provisions on legal capacity are particularly relevant in the current context. Indeed the Department of Justice, Equality and Law Reform stated in its Regulatory Impact Assessment on proposed capacity legislation that “[t]he next step towards ratification of the Convention is to ensure that Ireland complies with obligations under the Convention. The Mental Capacity Bill is one of the significant steps to facilitate the ratification process.”³⁹

Article 12(2) of the CRPD expressly states that “persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life”. The Convention then goes on to clarify and expand upon the measures States Parties are required to take to

³⁴ *ibid* para 2.41.

³⁵ *ibid* para 2.43.

³⁶ *ibid* para 2.44.

³⁷ *ibid*

³⁸ United Nations *Disabilities – From Exclusion to Equality – Realizing the Rights of Persons with Disabilities* (2007) United Nations, New York) 4.

³⁹ Available at:

<http://www.justice.ie/en/JELR/Regulatory%20Impact%20Assessment.doc/Files/Regulatory%20Impact%20Assessment.doc>.

ensure that persons with disabilities may exercise their capacity to the fullest extent possible, while being safeguarded against abuse.

Article 12(3) requires States to put supports in place to assist persons with disabilities in making decisions for themselves, thereby maximising the autonomy of the person and placing substitute decision-making processes such as guardianship to the realm of last resort. In Article 12(4), the Convention calls for safeguards to be put in place to prevent abuse. It recognises that a lack of capacity does not equate with a loss of rights and demands that the rights, will and preferences of the person be respected. It also requires protections against conflicts of interest and undue influence, as well as requiring that any interventions on grounds of incapacity be proportionate, adapted to the individual's need and applicable for the shortest possible time period, as well as being subject to regular review by a 'competent, independent and impartial authority or judicial body'.

Overview of the Scheme of the Mental Capacity Bill 2008

The Government published an outline of proposed new legislation on decision-making capacity in September 2008 in the form of the Scheme. It is expected that the draft legislation will be published in early 2010.

The Scheme appears to be based in part on recommendations of the LRC (albeit with some important differences discussed further below), and in part on the approach to capacity laws in other jurisdictions. The Scheme is divided into four parts:

- Part 1 (Capacity, formal and informal decision-making)
- Part 2 (The Office of the Public Guardian)
- Part 3 (Enduring Powers of Attorney)
- Part 4 (Private International Law)⁴⁰.

The Scheme is intended to apply to adults and does not affect the existing law concerning the capacity of a person to make a will (Head 19) or the capacity and consent required in certain contexts including marriage or civil partnership, judicial separation, divorce or dissolution of marriage, adoption, sexual relations, voting or acting as a member of a jury (Head 20).

The Scheme sets out nine Guiding Principles, which must be taken into account by every person involved in the implementation of the Act when making any decision under the Act (Head 1).⁴¹ These include the principles suggested by the LRC as well as some additional principles which seem to have been helpfully borrowed from similar laws in other jurisdictions.⁴² After defining capacity in Head 2, Head 3 goes on to give a non-exhaustive list of matters to be taken into account when considering,

⁴⁰ Part 4 deals with the incorporation into Irish law of the Convention on the International Protection of Adults adopted at the Hague on 13 January 2000. This Convention regulates how States will co-operate on the mutual recognition and enforcement of protective measures for adults who lack capacity and does not warrant any discussion here.

⁴¹ The Guiding Principles set out in Head 1 of the Scheme are set out in Annex 1 to this Report.

⁴² See, in particular, section 1 of the Mental Capacity Act 2005 (England and Wales); see also section 5 of the Adults with Incapacity (Scotland) Act 2000.

for the purposes of the Act, what is in a person's best interests.⁴³ This list suggests an approach to best interests which seeks to maximise the autonomy of the individual, as well as respecting the individual's right to dignity, privacy and bodily integrity.

The Scheme grants jurisdiction to the Circuit and High Courts (to be known as the Circuit Court of Care and Protection and the High Court of Care and Protection, respectively) to hear applications for decisions on a person's capacity and for the appointment of personal guardians under the Act.

The Scheme adopts a tiered approach to substitute decision-making that starts with informal decision-making (Heads 16 and 17) and then moves to once off intervention orders by the Court (Heads 6 and 12) and Guardianship (Heads 6 – 11). The Scheme also seeks to update the existing law on Enduring Powers of Attorney (EPA), whereby a person can designate one or more people (called donee(s)) to make decisions on their behalf in the event that they one day lack the capacity to do so for themselves (Heads 44 – 57). Subject to the provisions of the Scheme, informal decision-makers may make decisions in connection with the personal care, health care or treatment⁴⁴ of the individual who lacks capacity. Personal guardians and donees of EPAs may be given the power to make both personal welfare decisions (including healthcare decisions⁴⁵) and decisions relating to the property and financial affairs of the individual who lacks capacity.

The Scheme also deals with the establishment and duties of the Office of the Public Guardian, whose functions include establishing and maintaining registers of EPAs and Court ordered personal guardians, supervising donees of EPAs and personal guardians, receiving reports from donees of EPAs and personal guardians, and dealing with representations (including complaints) about the way in which a donee of an EPA or a personal guardian is exercising his or her powers (Heads 28-43). The Scheme also anticipates the publication of codes of practice by the Public Guardian (Heads 39-40).

The issue of mental capacity is hugely relevant in the context of the Mental Health Act 2001, which deals with the involuntary admission, detention and treatment of persons with mental health difficulties. In particular, capacity is an important component of the definition of 'mental disorder' (which is the criterion for involuntary admission and/or detention) and the treatment provisions set out in Part 4 of the 2001 Act. However, the Scheme is silent on how its provisions will operate vis-à-vis the Mental Health Act.

The Scheme does not contain provisions to regulate situations where a person who lacks capacity is *de facto* deprived of their liberty without recourse to the Mental Health Act 2001. Such formal procedures are necessitated by Article 5 of the

⁴³ The 'Best Interests' provisions of the Scheme are set out in Annex 2 to this Report. They reflect, in some respects, the provisions of section 4 of the Mental Capacity Act 2005 (England and Wales).

⁴⁴ With the exception of refusal of consent to life-sustaining treatment.

⁴⁵ Again, with the exception of refusal of consent to life-sustaining treatment.

European Convention on Human Rights according to the decision of the European Court of Human Rights in *HL v the United Kingdom*⁴⁶.

Key issues in relation to the proposed scheme of the bill

The Scheme's approach to the definition of capacity

The Scheme adopts a functional and time-specific approach to capacity and uses the definition proposed by the LRC (see above), which it combines with provisions apparently borrowed from the Mental Capacity Act 2005 (England and Wales)⁴⁷. The definition under the Scheme is:

“... the ability to understand the nature and consequences of a decision in the context of available choices at the time the decision is to be made...” (Head 2(1))

The Scheme goes on to state that:

“a person *lacks* capacity if he or she is unable: (a) to understand the information relevant to the decision, (b) to retain that information, (c) to use or weigh that information as part of the process of making the decision, or (d) to communicate his or her decision (whether by talking, using sign language or other means) or, if the decision requires the act of a third party to be implemented, to communicate by any means with that third party.” (Head 2(2))

It can be seen that this definition incorporates the components of ‘understanding’, ‘reasoning’ and ‘evidencing a choice’. The definition adds an additional component related to memory (‘retaining’ the information) and excludes an ‘appreciation’ component. This is in accordance with the functional approach adopted by the LRC that focuses on the abilities of the individual.

Head 2 of the Scheme goes on to affirm that ‘a person is not to be regarded as unable to understand the information relevant to a decision⁴⁸ if he or she is able to understand an explanation of it given to him in a way that is appropriate to his or her circumstances (using simple language, visual aids or other means)’. The Scheme also recognises that the fact that a person may be able to retain relevant information for a short period only should not prevent him or her from being regarded as having the capacity to make a decision. The Scheme also contains a presumption of capacity and a number of other Guiding Principles in Head 1 (see Appendix 3).

Assistance with decision-making

As discussed in the introduction, the process of supported decision-making features large when considering incapacity from the perspective of a social model of disability.

⁴⁶ Application No. 45508/99 judgment of the European Court of Human Rights, 5 October 2004. For a discussion see: Donnelly, M (2008) ‘Legislating for Incapacity: Developing a Rights-Based Framework’, (2008) *Dublin University Law Journal* 30:395-438

⁴⁷ See section 3 of the Mental Capacity Act 2005 (England and Wales).

⁴⁸ The information relevant to a decision is defined as including ‘information about the reasonably foreseeable consequences of: (a) deciding one way or another, or failing to make the decision’ - Head 2(5).

Mary Donnelly has noted that the LRC failed to ‘impose any requirement to facilitate or develop the capacity of the person,’ in its Report. In its Regulatory Impact Assessment on the Scheme the Government acknowledged the need for access to supports, where required, to exercise capacity.⁴⁹ This is in line with Article 12 of the CRPD which places an obligation on States Parties to ‘take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity’. It also accords with the social model of disability.

However, there is very little in the Scheme on supported decision-making. While the Scheme touches on the concept of supported decision-making under the Guiding Principles where it states that “a person shall not be treated as unable to make a decision unless all practicable steps to help him or her to do so have been taken without success”, its main focus is on systems of substitute decision-making. The Scheme does not set out a framework for supported decision-making. Instead the emphasis is on procedures for substitute decision-making such as informal decision-making, Court appointed personal guardians and EPAs.

Furthermore, neither the LRC’s proposals for the capacity legislation nor the Scheme as published contain provisions relating to advocacy. This is despite the fact that the Government, in its Regulatory Impact Assessment on the Scheme acknowledged the need for access to supports where required to exercise capacity.⁵⁰

The Assessment process

Who should assess?

The Scheme assigns jurisdiction to declare that a person lacks capacity to make a decision or decisions concerning his or her personal welfare or his or her property or affairs to the Circuit and High Courts (Head 5). However, the Scheme does not require that the Court assess a person’s capacity in all circumstances. Under the provisions relating to ‘informal decision-making’, it appears that a person involved in the care and treatment of another person whose decision-making capacity is in doubt is effectively tasked with assessing capacity and deciding the best course of action in all circumstances, except as set out in the specific circumstances shown in Head 17 (Heads 16 and 17).⁵¹

While the Scheme requires informal decision-makers to act in accordance with the Guiding Principles and in the person’s best interests (as per Head 3 of the Scheme), it appears that the Scheme leaves it largely to Codes of Practice to determine when

⁴⁹ Available at:

<http://www.justice.ie/en/JELR/Regulatory%20Impact%20Assessment.doc/Files/Regulatory%20Impact%20Assessment.doc>

⁵⁰ Available at:

<http://www.justice.ie/en/JELR/Regulatory%20Impact%20Assessment.doc/Files/Regulatory%20Impact%20Assessment.doc>

⁵¹ Head 17 provides that an informal decision-maker is not authorised to do any act which (a) would require a court order or (b) would conflict with a decision of a donee of an EPA or a personal guardian. Major healthcare decisions concerning non-therapeutic sterilisation, withdrawal of artificial life-sustaining treatment and organ donation are confined to the jurisdiction of the High Court under Head 21. However, it is not clear to what extent informal capacity assessments and substitute decision-making are otherwise regulated by the Scheme.

formal assessments of capacity and substitute decision-making have to be used, including in the context of decisions regarding medical treatment.

The Scheme does not specify who should assess capacity. However, under Head 13 it provides that the Court may ‘request expert reports for the court by such experts as it considers necessary, whether medical (including reports concerning cognitive ability), social and health care (including care in the community) or financial (including reports on valuation of property).’

Court assessment process

Based on submissions received during its consultation process and a review of the approach adopted in other jurisdictions⁵², the LRC recommended the establishment of a multi-disciplinary Guardianship Board to consist of a High Court judge as chairperson, along with a registered medical doctor with expertise in the area and a health professional with the expertise and training to assess functional capacity (such as an occupational therapist or a clinical psychologist).

The main functions of the Guardianship Board were intended by the Commission to include determining issues of legal capacity, making guardianship orders (as well as extending, reviewing, varying or discharging such orders), making once-off intervention orders and supervising EPAs. In the exercise of its functions the LRC recommended that the Guardianship Board be given wide powers to obtain relevant expert reports (such as from clinical psychologists or behavioural psychologists).⁵³

The Government did not accept the LRC recommendation that a Guardianship Board be established. Instead the Scheme vests jurisdiction in the Circuit and High Courts (to be known as the Circuit Court of Care and Protection and the High Court of Care and Protection, respectively) to hear applications under the Act (Head 4). The question of which Court has jurisdiction depends on the rateable value of any land in respect of which an application is made to the Courts, except that major healthcare decisions concerning non-therapeutic sterilisation, withdrawal of artificial life-sustaining treatment and organ donation are confined to the jurisdiction of the High Court under Head 21. The powers of the Courts of Care and Protection are similar to what was recommended by the LRC.

As regards expert reports, the Scheme provides:

“... the court shall have such powers as are required to assist it in making a decision including the power to request expert reports for the court by such experts as it considers necessary, whether medical (including reports concerning cognitive ability), social and health care (including care in the community) or financial (including reports on valuation of property).”⁵⁴

⁵² Note, in particular, the Law Reform Commission’s review of the Australian approach, where a number of jurisdictions have adopted the tribunal model to determine capacity issues (Law Reform Commission (2006) paras 6.07 – 6.13).

⁵³ Law Reform Commission (2006) para 6.49.

⁵⁴ Head 13.

There is no automatic entitlement to legal representation, either at initial proceedings where their capacity is determined, or at any review proceedings⁵⁵ and applications may be dealt with without a full hearing or in the absence of the person to whom they relate in certain circumstances (to be dealt with in rules of court).

Timeframe for review of incapacity

Article 12(4) of the CRPD requires that measures relating to the exercise of legal capacity are subject to regular review and apply for the shortest time possible.

Head 14 of the Scheme provides that certain persons may, *with the permission of the Court*⁵⁶, apply at any time for a review of a declaration that a person lacks capacity. In addition, Head 14 provides that the Court is required to review decisions on capacity at such intervals as it considers appropriate, being not more than 36 months.

Appeals process

The LRC Report recommended that the High Court should be the ultimate appeal body in respect of any Order made by the Guardianship Board⁵⁷. The Scheme provides for a right of appeal *on a point of law only* from a decision of the Circuit Court of Care and Protection or the High Court of Care and Protection to the High Court and Supreme Court, respectively. Thus the right of appeal is limited to points of law, rather than the original court's decision/ finding on the facts. The Scheme does not specify the time period within which an appeal must be taken or who is entitled to lodge an appeal.

Advance directives

While there is no Irish legislation which deals with the validity of advance decisions/ directives/ living wills regarding medical treatment, it has been argued that some of the statements in the Supreme Court judgment in *Re a Ward of Court (No. 2)*⁵⁸ suggest that, in certain circumstances, if an individual expressed his or her wishes in an advance directive, the Irish Courts would uphold its validity.⁵⁹ However, there is no certainty on the law in this area, in particular in the area of advance directives in respect of psychiatric care.

The LRC did not deal with the area of advance care directives in its Report on *Vulnerable Adults and the Law* and while it subsequently published a Consultation Paper on Advance Directives, it expressly excluded *psychiatric* advance care directives from its scope.⁶⁰ While the Scheme seeks to update the existing law relating to EPAs (whereby a person can appoint someone to make decisions on their behalf (including certain healthcare decisions) in the event of incapacity), it contains very

⁵⁵ Head 15.

⁵⁶ Emphasis added.

⁵⁷ Law Reform Commission (2006) paras 6.69 - 6.70

⁵⁸ [1996] 2 IR 79.

⁵⁹ See: Campbell 'The Case for Living Wills in Ireland' (2006) 12(1) *Medico-Legal Journal of Ireland* 2, 6; Madden *Medicine, Ethics and the Law* (Tottel Publishing 2002) para 11.57, cited in the Law Reform Commission Consultation Paper *Bioethics: Advance Care Directives* LRC CP 51 2008, paras 2.07-2.08.

⁶⁰ Law Reform Commission (2008), Introduction, para. 11. It is worth noting that one of the Law Reform Commission's recommendations was that the proposed legislative framework should apply to advance care directives that involve *refusal* of treatment only. See Law Reform Commission Report *Bioethics: Advance Care Directives* (LRC 94-2009) para 5.05.

little in relation to advance decisions regarding medical treatment or other matters. The “Best Interests” provisions in Head 3 of the Scheme require that the person’s past and present wishes and feelings (and, in particular, any relevant written statement made by him or her when he or she had capacity), beliefs and values that would be likely to influence his or her decision and other factors he or she would be likely to consider be *considered* insofar as they are *reasonably ascertainable*.⁶¹ However, the Scheme does not go on to provide any framework regulating the creation and validity of advance decisions.

Conclusion

This Chapter has provided an overview of proposed capacity legislation in Ireland and discussed a set of relevant key issues. Many people in inpatient settings have capacity to make decisions. In order to protect individuals’ human rights, it is important to maximise their opportunities to demonstrate that capacity. There has been widespread support for a functionalist approach to assessment of capacity and this is reflected in the proposed Scheme for the legislation. The Scheme promotes a social model of disability approach by containing a presumption of capacity as well as through requiring that individuals are provided with accessible information. However, the Scheme fails to fully underpin supported decision-making and in this way falls short of a strong social model of disability approach. The Scheme also fails to provide for access to an independent advocate. In principle, the Scheme recognises taking account of the advance expressed wishes of the individual concerned, but does not provide a statutory framework for advance directives. In matters relating to capacity the Scheme grants jurisdiction to the Circuit and High Courts, rather than a specialist Guardianship Board, as was recommended by the Law Reform Commission. There remains some uncertainty regarding the limits of ‘informal decision-making’ under the Scheme. While the issue of capacity plays a central role in the context of the Mental Health Act 2001, the Scheme does not explain how its provisions will interplay with the provisions of that Act, nor does the Scheme address the issue of safeguards which should apply where incapacitated persons are *de facto* deprived of their liberty. These provisions as set out in the Scheme provide a backdrop for the views of people with direct experience of mental health problems that are reported below.

⁶¹ Emphasis added. A similar requirement is included in the Guiding Principles (Head 1(g)).

Chapter Three: Results of interviews

Overview

This chapter presents the analysis of data obtained through interviews with participants. The chapter begins with an exploration of the concept of capacity that draws on participants' personal experiences. Participants' personal stories illuminate the lived experience of assessed incapacity, the power that plays itself out over their experience and the ways that they have learned to identify their own periods of deteriorating capacity. Following this exploration, the next sections develop a new conception of capacity based on participants' responses to the Irish Government's proposed definition. The later sections relate participants' views on assistance with decision-making, the assessment process, review and appeals procedures and advance directives.

Experience-based understandings of decision-making incapacity: 'Impossible hills to climb'

Participants were asked how they know or have known in the past when they are having trouble making decisions. The purpose of this question was to generate scenarios that would illustrate the experience of incapacity. In response to this question, some participants articulated their understanding of incapacity through stories about their past experiences.

One person described the experience of being in a state of mind that made it impossible to make everyday decisions:

I suppose reaction would have been that I would have just stayed in bed all day. If I had to make the everyday decisions and I was very depressed, I just wouldn't make them for days and days on end ... and I probably would have difficulty having three square meals a day. I probably wouldn't have eaten very much. I would have had difficulty in eating when I was in that state of mind. I certainly wouldn't have gone out walking or meeting people. I would have had huge difficulty with that. (Participant 8)

And in describing another time, this participant explained how mental activity inhibited decision-making:

I suppose I would have had difficulty making those decisions as well, because at that juncture they would have been impossible hills to climb, even though they're just everyday decisions, and I let my parents do it for me, you know? My mother would bring meals up to the room or they would encourage me or they would, not coerce, mildly coerce you could say. In other words, I just left the decisions to my loved ones really. Now when I was in a bed-sit in _____ at one stage, coming out of the private system, so I had to make the decisions for myself, I would have had difficulty in forming a schedule. I would actually have to write down everything I would have to do during the day. And maybe I would only do one or two things and leave the rest alone. And it would have been done with much difficulty because my inclination was just to withdraw,

you know, not to do it. That's it, really. And it would have been an emotional strain for me because of the obsessionality, the obsessional thoughts and anxiety and tension that would have really inhibited me. I suppose to put it simply, the everyday decisions were like huge tasks at that stage. (Participant 8)

So too, another participant described a similar experience:

Well when you have depression, that's a continuous feeling of crisis. That's why depression is so bad because it's that moment of crisis extended, elongated into a period of months, and your mind is like a food mixer and your thoughts are racing at an enormous rate - you can't sleep, you can't relax, you can't find peace and somebody is asking you to fill out a tax form. (Participant 4)

Two participants articulated how fear could result in incapacity to make a decision:

So yes, there were times the phone would ring and I would get a panic attack. There were times when I would see a tax bill would come in and I would get a panic attack. To this day I have difficulty in filling out forms - the very challenge of it is a challenge. (Participant 4)

There was too much - if I say yes, that could bring about that and if I say no that will bring about that, and it was complete and utter fear. It wasn't that I didn't have the capacity. I obviously did deep down somewhere. But it was really around fear and actually not trusting myself anymore and not believing that I was capable of making a decision that was right for me. (Participant 7)

And in practice, the experience for this participant was described thus,

It got down to the simple day-to-day things. You know, I'd say to ____ [partner], you know, "I'm going to the shop. What do you think? Do you really think I need to go to the shop?" Now my first thing, I'm going to the shop, I knew I needed to go to the shop but the minute it was out, it was like, "Oh [exclamation], do I need to go to the shop?" (Participant 7)

Another person described incapacity as a sudden loss of the ability to be organised:

I remember my doctor was really great, and when I would go to her, I would bring a list of the things I couldn't make a decision about, very simple things, there was nothing too difficult in it. Now they would be decisions that I would [in the past] get out of bed every morning and make without even thinking about it, but at that time, I couldn't, maybe like, what to have for dinner or how to organise things - that was something that went, I was very organised. I had children and I was really organised and my house was organised and then all of a sudden over a period of time, it was happening, but all of a sudden that all went and I couldn't anymore. (Participant 3)

The above narratives describe different types of incapacity in relation to mental health problems. For these participants, sometimes it is panic or fear that inhibits decision-

making, sometimes difficulty in concentrating enough to be able to make the decision, sometimes a less definable loss of a pre-existing skill, such as organisational skills. The experience of the potential decision as being too large, as an ‘impossible hill to climb’ is hinted at by several people and directly articulated by one. As will be shown below, participants later made suggestions about how decisions could be made more manageable in scope, thus facilitating their decision-making capacity.

Self-recognition of incapacity: learning from experience

In response to this first question about ‘knowing’ incapacity, several participants identified the ways in which they recognise they are losing capacity.

Three participants spoke about being able to recognise when they were heading towards not being able to make decisions. For example, one person said,

Sometimes I start to get into a muddle again - I start to feel that, maybe I would get up in the morning and suddenly I realise that some of the things that had to be done that day weren't organised to be done that day, or I had forgotten about them, or worse still come night time and I had forgotten about them and there would be something that had to be done that day. I start to recognise then and I start then to go back...so that what I do when I start to see things that are not being done, that I'm not, I suppose, organised the way that I should be organised, then I realise that I have to go back to basics and if it gets really bad, I have to go back to my doctor, and that's where I go. I go back to my doctor. (Participant 3)

This recognition can include not only that the person is not thinking clearly, but also recognising in a self-protective way that he/ she should not make a decision that has significant consequences. So one participant said, “Uhm, well I think I know that if my thought becomes disturbed the way that it does when everything goes and I can't think clearly, uhm, then I know that this isn't the time to make any kind of decision” (Participant 1).

This same participant described how being able to recognise the point of losing capacity was a process of ‘learning’, something that had been learned over time and through experience. This participant learned not only to recognise the loss of capacity, but also what mental health treatment was needed to regain it:

So for me I know now to control my condition if there's a kind of a plateau, a stage where if I step off that or slip off it then I know I need to take medication for a while and that's a crucial decision for me, to know I need to take medication. And in fact I've learned that once I begin to wonder, oh, maybe I should be taking medication, that I shouldn't hesitate. That's the time I need to start taking heavy anti- psychotics. And for me that's been a learning that has to do with making decisions about taking the first step to help myself or prevent myself going down that slippery slope which becomes really difficult to negotiate or come back out of. (Participant 1)

Two participants said they would have the ‘insight’ to know when they could not make a legal decision. One said,

Well, I suppose all I can say to you is that when I was unwell, I realised that I wouldn't sign any contract because when I signed my contract at _____ that included terms and conditions, I realised that I had to have some kind of stability, for want of a better word, some wellness in yourself, the confidence in yourself to actually sign that contract. But if you had asked me to sign that contract ten years ago, no, I wouldn't have. (Participant 8)

On the other hand, several participants described times in the past when they did not have the 'insight' that they were unable to make decisions. This was contrasted with their current level of self-awareness when, through experience, they have learned to recognise the signs of lessening capacity.

One person described how they were resistant to others' feedback:

I thought everyone around me had a problem. So that makes it very difficult to see how, in the circumstances, at the time, I don't know that there were any other options. (Participant 1)

Being in a state of mind where you are unable to make decisions can itself have a distressing emotional impact. Two participants described how 'horrifying' it was to be unable to make decisions about their own daily lives. One said,

And it's a horrible, ... place to be because you don't want to hand over and yet you do, but you want someone to make the decision that it's all going to be right and fine and grand and yet it's a horrible place to be where you have to rely on another human being. I find it very sad, very, very sad. I used to get extremely frustrated. I used to get really mad with _____ [partner]. (Participant 7)

While another said,

I think when I was unwell the worst aspect of it was in and around that whole thing. I love the fact that I can run my own life and I had lost that for a period. One of the most disabling factors in and around mental health is the fact of that very issue. (Participant 4)

Participants' articulations of their own self-knowledge about incapacity suggest that incapacity in mental health can be a partial, rather than a total phenomenon. This will be explored further below, but at this point it is worth remarking on how some participants have developed self-awareness sufficient to be able to identify when they are beginning to lose capacity. These participants show how a person can have lost capacity to make some decisions, but retained enough capacity to recognise this situation and to act to prevent further deterioration. Some participants also articulated how they would be able to recognise when they did not have the capacity to make a legal decision. An important factor appears to be a process of learning through personal experience in order to develop this self-awareness. This suggests that an initial episode of incapacity should not be taken as precedent for later decisions about a person's incapacity; rather, in different episodes, the same person's level of capacity may be different. Assessments of capacity need to take account of how much the

person at that particular point in time is able to contribute to their own decision-making capacity rather than relying on past episodes to determine present incapacity.

The emotional aspect is also significant. Losing capacity is not simply a functional loss; it carries with it emotional effects. Working in a holistic way with people who are having difficulty making decisions will require, then, acknowledgement of their own emotions about their incapacity.

Experiencing others' decision-making

Participants were asked to describe what it was like for them when others have made decisions for them in the past. Five of the eight participants described this experience as horrible, frustrating and scary. One participant described it as a 'complete sense of powerlessness' in which,

I was in a situation where all the decisions were taken away from me. My clothes were taken away. I could only eat at certain times. I could only have tea when the tea trolley came around. I remember that time, the only control I felt I had over my situation was to stop smoking. I did that for a few weeks. And it was kind of a protest, you know? It was something I could have control over... (Participant 1)

and regarding another occasion, this same participant described the self-assertion of control in an otherwise powerless situation:

One of the first things I'd do when I'd get my money back from the lock up would be to make a phone call and then some of my friends would come in with clothes. After a day or two I'd put them on. It would be de facto of having my clothes before the consultant - they wouldn't take them off me again... So those were the kind of things where I was trying to take control of my situation, to counter the situation where all the control is taken away from you. And I was always trying to assert my own stamp, my own individuality on the situation. (Participant 1)

Another described annoyance at being the subject of other people's conversations:

And you know what I hated? How I was subject to conversations within the family and friends without ever being consulted myself. That really, really, in my heart of hearts I hated that! It was like I was an object to be discussed or somebody who was removed from the family circle and discussed about rather than talked to. (Participant 8)

However, for this participant, there were both positive and negative feelings about others making decisions on their behalf:

There were two reactions to that. One reaction - I felt like a rag doll being torn around the place, messed around the place, you know? Decisions were being made - I wasn't making them. But on the other hand, I was kind of happy that I was leaving it to other people. I was just so exhausted. So that was the two kinds of feelings I had. (Participant 8)

For another participant, it made a difference who was making the decisions. While the participant felt powerless and frustrated while in acute mental health care, the same participant appreciated when, on occasions, family members made decisions. For this participant and another, there were occasions when it was appropriate that others make decisions on behalf of the person. For one participant this was when a person was in danger of self-harm. For the other, this was when the person was not able to see that they needed mental health treatment.

Two participants described how difficult it is for individuals to challenge the decision-making authority within the mental health services. One said,

Now unfortunately for a lot of people that's not possible, you know, and they find that if they ask any questions or display any signs of having any kind of a voice of their own, they are immediately shot down as maybe getting unwell again or going into another episode. So, I'd like to see all that change as well. That would be important. (Participant 1)

The other described the negative feedback they had received when they tried to challenge their psychiatrist:

And then I didn't know enough about the system. I wasn't educated on how they were making decisions about me. Once or twice I did challenge but I got shot down. I remember one day there was a psychiatrist, a nice guy, and in 15 minutes he had three phone calls, three [expletive] phone calls. And I was full of anxiety - the old panic attacks were flying high - as I say, he had three phone calls and then he walked out of the room. So I spent the whole week thinking, it took me a whole week, and I went back into him and I said to him, "I need to say something to you," and he said, "What?," and I said, "I don't think that was okay, when I was talking to you to take three phone calls," and he said, "You're not the only one, _____. We have a busy schedule." So that just shot me down, and I thought, "Oh ..., don't rock the boat here. What's he going to tell the team now and what's going to happen now?" (Participant 7)

This participant also said that they would have been concerned about losing their mental health service if they had challenged the service providers further:

Because you see, I was dependent on the service and I was dependent on the drugs, so if they cut me loose, where was I? What had I got? So yeah, you always have that in the background that they have this power. (Participant 7)

Participants' experience of losing decision-making authority over their own lives was predominantly negative. Only one person had a positive statement about this, indicating that in some measure it was a relief to have others make decisions on their behalf at a point in time when they did not have the inner resources to make them. But for this participant, as well as for others, there were times when the experience was negative – causing severe frustration and deep annoyance. These emotional

consequences of taking away someone's authority to make decisions over their own lives need to be recognised as part of the assessment process.

Defining capacity: Does incapacity exist in relation to mental health?

Participants were asked for their opinion on the proposed definition of capacity contained in the Scheme. Under this definition, a person is judged to have capacity if they can understand the information relevant to the decision, retain that information, use or weigh that information as part of the process of making the decision, and communicate their decision. The Scheme presumes that individuals have capacity and incorporates a time-specific and decision-specific assessment of capacity. While a minority of participants (three out of eight) agreed with the proposed definition, more participants identified various ways that the definition did not adequately take account of the field of mental health.

Participants did identify aspects of capacity that accord with the proposed definition, including that in their experience, incapacity is usually partial, not total, that there should be a presumption of capacity, and that it is possible to behave inappropriately but still be capable of decision-making.

One participant described how they could make some decisions but not others:

Will I go to the shop? Will I get brown bread or white bread, I don't know! And yet, I could make a decision to go to the hospital every day and I could make the decision to engage in the services and the decisions to participate in different groups. (Participant 7)

Another described how they had known individuals who even in the midst of psychosis or while displaying unusual behaviour, still retained capacity:

I was in _____ [a support group] and they have a mixture of people with dual diagnosis and others blatantly psychotic, and the people who are psychotic would have a load of inappropriate behaviour but they could follow the whole doesn't have capacity. (Participant 2)

This point was echoed by another participant who said:

When you listen to someone who is psychotic you can understand what they want, so it's important to spend time listening to them in order to develop your understanding of their capacity. (Participant 4)

These experiences demonstrate how mental or emotional distress does not necessarily result in total incapacity and even within a distressed or delusional mental state, a person may have some capacity.

More participants than not disagreed with the proposed definition in various ways. The view was expressed that individuals always have capacity:

...because you see, you haven't lost your skills, they're all still there. It's just that you've lost your confidence in your capacity to make a decision. And it's just - we'd always say to people, you're not learning any new skills. You're going to remember the skills you have. (Participant 7)

Three participants expressed a strong desire for an alternative to the capacity/incapacity framework in that this was too narrow. One said,

I actually don't feel that there is a definition that could take away your capacity. I just feel that, I just can't put it into words, but I honestly believe that there has to be better way than deciding that because today I can't understand what you are saying to me, because I can't impart that information back to you, because I can't make a decision about my mental health, that I deserve to be brought in under a Mental Health Act and given treatment that I may not want. (Participant 3)

Part of the disagreement with a conception of incapacity was due to a view that in the area of mental health, if appropriate alternatives were offered, a person would be able to come to a point relatively quickly where he/ she could make the relevant decision. Two people mentioned crisis intervention services as a means of eliminating the need for capacity judgments for people with mental health problems.

And there are a lot of us out there that believe that before we start getting into the area of making a decision in an emergency situation on the person's capacity to react or act or make decisions maintaining information, that what we should have is a form of crisis intervention house where a person could go and be allowed to be in crisis without burying the crisis under huge doses of medication. (Participant 4)

A consistent concern of a number of participants was the relationship between incapacity and the temporary nature of mental health problems. In total, five participants raised the temporary nature of incapacity in the context of mental health. One participant expressed concern about any suggestion that incapacity in the context of mental or emotional distress would be a long-term state:

Again I think we should be using that in the context of possibly for some people, momentarily it might happen. And I'm using the word very carefully 'possibly' there because even in the worst case scenarios I still hear people saying that 'even in that case, if I was offered choice, or if they had dealt with me in a certain way, I certainly would have been able to demonstrate that I had capacity and some sort of authority to make a decision' but I think the danger here is that there's a slippery slope where we see this as almost a long-term thing for some people, where decisions have to be consistently, constantly made for people, not momentarily, which may help people in a certain circumstance... (Participant 6)

Others expressed concern that viewing incapacity as long-term engenders dependency on the part of the individual in distress, denies the individual 'dignity', undermines the person and inhibits their recovery.

Another participant made a link between belief in the medical model and incapacity:

The whole medical myth is that serious mental illness is a lifelong illness, and that's only one view, but if you believe that then you don't have capacity because you've been brainwashed into the medical model...If you define capacity as the ability to see the reality of things, then anyone framed in the medical model doesn't have capacity. (Participant 2)

This view shows how the very conceptualisation of mental or severe emotional distress as a medical phenomenon, as an 'illness' can, in itself, create incapacity. In a situation where the discussion about an individual's capacity/ incapacity occurs within a paradigm of mental disorder as a lifelong illness, it is unlikely that the individual concerned will rate his/ her capacity highly, nor conceive of regaining his/ her full capacity. This suggests that a one-sided, medical approach to mental health can construct incapacity.

One participant also thought that the definition of capacity should not include memory. This is relevant both for people who have received Electro-Convulsive Therapy (ECT), which can affect a person's memory and for people who are on medication that can affect memory. This participant said,

So the second question, can they retain the information - the point is again relevant - I couldn't remember my name when I was drugged. Only now am I beginning to get back the ability to remember your name! And I still have difficulty and I have to address it to people absolutely and clearly - I'm very sorry, I've had too many drugs and I can't remember things. And does that mean that I don't have the capacity to make a decision? So, you know, who is going to make this kind of judgement call? It's not about the ability of the person to retain the information. It's about who is making the judgement! And it shouldn't be about whether the person can retain the information or not because some people have good memories and some people have bad memories but that doesn't mean they have better capacity it just means that they have better memories. (Participant 4)

On the other hand, two participants said that they would be able to pass the definition even at times when they were not able to make good decisions:

Sometimes I think when I have been unwell, I can really seem to get information and really seem to use it, contrary to actually how well able I am to look after myself. (Participant 5)

I think that most people who are given treatment and they get the information, but they still don't get to make an informed decision because how do you give them the information that they don't have to be a cripple for life? I was diagnosed with pathological shyness and it certainly fit the bill and I could understand at college, when I was trying to get my [exams]. I could understand the lectures and I could understand the information in the lectures, so even though I could understand what I had to do, I didn't have the capacity to do it. (Participant 2)

Participants thus pointed to a range of difficulties with the proposed definition. For some participants, the point is that even within severe mental or emotional crises, some level of capacity is retained. For them, if the process facilitates recognising and maximising this capacity then the notion of 'incapacity' is irrelevant in mental health. Others emphasised that incapacity in those with mental health problems is a temporary phenomenon and arises out of the lack of alternative supports to hospitalisation. For them, if acceptable alternatives were in place, individuals would not need to have their authority to make decisions removed. On the other hand, some participants acknowledged that there were times when they were not able to make decisions that were in their long-term best interests. Yet at these times, in some cases they said they would have been able to pass the definition in the Scheme. Taken together, these perspectives point to the need for legislation to account specifically for incapacity in relation to mental health problems.

Situated and relational incapacity due to a mental health problem

The participants highlighted a number of aspects of capacity that are not in the current definition and that in their view, are necessary in the context of mental health in order to ensure that an individual's capacity to make decisions is recognised. Some of their comments point to a social model-type understanding of incapacity as a situated and relational concept. From their articulations, it is possible to see that capacity is not entirely an intrinsic state within the individual, an independent condition that can be assessed objectively nor a simple state of functioning of the mind. Rather, the individual's capacity is influenced by a range of physical, environmental and social factors that influence their mental capacity. These include the medications administered for treatment, the way information is provided, the available options for care and how assessors and support people relate to the individual being assessed.

Two participants highlighted how incapacity can be created by the medications used to treat mental health problems. One described the effect that medication had on his ability to think and to communicate:

...so have I been given medications or not before I'm being given the information? Because that's the most pertinent question that needs to be asked before anybody can answer these questions here. Because if you inject me with Haldol or you inject me with any other psychotic medication, the first function it has is to stop your ability to think. That's the very first function it has. It's designed by the pharmaceutical companies to stop your ability to think and now you're going to be asked the relevant questions about decision making after you've been forced, in that emergency moment that you're in, to take anti-psychotic drugs and I can only demonstrate it for you on the tape, but when I was on such drugs my speech pattern was like this [demonstrates], my hands shook and if you asked me the time the of day I would get a panic attack - not because there was any thing wrong with my capacity but something was radically wrong with the way I was being treated. (Participant 4)

This participant also made the point that the medication administered in an emergency situation has the effect of reducing capacity and therefore this must be taken into account in the context of capacity assessments.

Two participants described how capacity can be affected by the available options for care. One participant said,

You see there's no alternative to the medical model, so how can you have a frank and even discussion about something when there's only one door in the room. In theory, we should have doors all over the place, and that's what *A Vision for Change* states, but of course they're never there. (Participant 4)

Decision-making capacity is also affected by how decisions are presented, how accessible the information is, and whether or not the person presenting the information is considered trustworthy. Three participants expressed that their own capacity to understand information is affected by how that information is presented. One participant described this in terms of the accessibility of the information:

Can you understand the information relevant to the decision - that has got nothing to do with the person receiving the information! That has got a huge amount to do with the person dispensing the information! And what language is he going to use? I mean is he going to come in with a big load of scientific waffle to tell you what's going on or is he going to use language that's relevant to the person on the street. So that's got nothing to do with my capacity to understand the language and if somebody talks to me in a big load of psycho babble and I say that I don't understand what you're saying, is he now going to decide that I don't have the capacity or is he going to be honourable enough to say I didn't explain it properly? So it is very relevant that somebody says what language is this language that we're going to be asked to understand? ...because I have very often had to challenge my doctors about the language that they are addressing me because I don't understand what you're saying doctor - what does that mean? Now is that a sign that I have no capacity? (Participant 4)

The accessibility of information provided is reflected in the Scheme under Head 2, subparagraph 3, which states that 'a person is not to be regarded as unable to understand the information relevant to a decision if he or she is able to understand an explanation of it given to him or her in a way that is appropriate to his or her circumstances (using simple language, visual aids or any other means).'

One participant also identified that lack of comprehensive information could stop a person from being able to make a decision:

... or if they feel the information isn't comprehensive - doesn't take their whole situation into account, well then, people can feel mistrustful that the information actually captures their whole situation. And if it doesn't address all of the concerns that people have or all of the issues in their circumstances, then perhaps people might feel they don't have - that they'd hesitate over making the decision that doesn't take all of their situation into account. (Participant 1)

The trustworthiness of the information provider was also identified as a factor in being able to make a decision:

Well in a normal situation I think that if people trust the person conveying the information, it's going to make it much easier to come to a decision than if people don't trust or are suspicious or have reason to be suspicious of the information that comes down to them, (Participant 1)

While another participant articulated that the general way others involved in the process are relating to the individual can impact on capacity:

You know capacity, it really depends on how people relate to you and what environment is created to look at decisions to be made or not to be made. But if I'm pushed or if people are being aggressive and that this is it, sure, I'm going to react. And then, you know, I often hear people saying, oh they got distressed, and we felt it was in their best interests, but of course they got distressed! Sure, they were being badgered! You know, I mean, _____! [exclamation], the amount of people I've spoken to, I mean, working with people, and they've said, "Yeah, I did start shouting and I did start giving out because nobody was listening." (Participant 7)

Finally, one participant described how they way that the options were framed would make a difference to being able to make a decision:

I think I could have made a decision that I needed help if it had been presented in a very different way ... It's very different to what it would have been like twenty years ago on my first encounter and it was a completely crazy situation that was not addressing any of the real issues for me, that brought me to the distress that I was in. There was no recognition of the pain that I was in and the confusion and the despair. So none of that was ever in the picture. It was just, you're ill, and this is it. Where if an empathetic understanding approach had included recognition of the emotional distress and pain and offered me a safe place to go and heal from that, well then that's something I probably would have wanted to accept that offer. (Participant 1)

The need to allow time for understanding

One participant said that the concept of 'understanding' in the proposed definition needs to take account of a length of time that may be required to understand the information.

I think for me one of the things that I found difficult in terms of the communications aspect is that it takes me a while to understand things. I don't understand very quickly... (Participant 8)

In this section, participants' contributions point to the influence that both social and environmental factors can have on a person's capacity to make mental healthcare decisions. Participants highlighted how the introduction of medication into a person's system, the available treatment options and the accessibility of information can hinder their capacity. They also described how social factors including the trustworthiness of

the information-provider and the manner of relating to the individual can have an impact. More than one participant highlighted how a paradigm that sees mental and emotional distress as a purely medical phenomenon can itself create incapacity. These comments support a 'social model of disability' approach to incapacity. Rather than being a condition that is purely intrinsic to the individual, they point to a range of barriers that can diminish an individual's capacity and show the ways that incapacity is impacted by social and environmental factors. The significance of trustworthy relationships for an individual's capacity, articulated by some participants, raises the prospect that a socialised understanding of capacity must incorporate a critical analysis of the relationships involved in an individual's decision, including family members, friends, advocates and mental health professionals, with a view to determining the extent that they help or hinder the individual's exercise of their capacity.

Assistance with decision-making

In more than a few interviews, participants articulated a link between support from others and the capacity to make decisions. In some cases, the participant described how the support of a key individual enabled them to continue to make decisions when they were at a point where they were having difficulty. In some cases, the participant described how support could have helped them even though they did not get it. These articulations identify a strong valuing of supported decision-making. On the other hand, as stated earlier, some of these same participants also described moments when they would have been relieved to have others make decisions for them, identifying a role for substitute decision-making. Participants' articulations point to a complex relationship between supported and substitute decision-making.

Two participants emphasised that without the in-depth support of a particular individual during the time when they were in severe difficulty, they would not have been able to make decisions. One participant described going to a GP regularly over a period of months for assistance with making decisions. The GP would allow time for talking through choices, affirm the individual's ability and facilitate the individual to make decisions. The other participant described how significant an intimate partner was in being able to make both everyday decisions and those around mental health treatment:

I actually remember because I had to turn around to _____ [the partner] and I was so upset about it, and I had to start asking ____ to help me with decisions because, I just, it was too much.... the only one I would have turned to would have been, say, _____ in that situation because I trusted _____. So it had to be someone that had a good sense of me. (Participant 7)

And regarding mental health treatment, this participant said,

Well again I would have talked to _____ [the partner] a lot around my health and what was going on. I wouldn't have really showed that part of myself [to mental health professionals]. I would have been a bit afraid to let them know... I was afraid of them making decisions that were wrong for me. (Participant 7)

One participant described how support was missing in experiencing a severe mental health problem:

You know, I think that what can happen for me is that I am then kind of, you know, left off to live my life howsoever I choose, and I have found myself very isolated in that particular circumstance...What I've had is a kind of a one-time community psychiatric nurse calling around and after having left hospital under extremely bad relations with them, and I thought she was being very sarcastic about my library books, you know, so I said, go away and leave me! But then, for one thing, it wasn't enough. It wasn't enough to have a community psychiatric nurse calling out two weeks after I'd been in hospital. (Participant 5)

This participant described how support seemed to be 'all or nothing - all as in, you hand over your life and your soul or nothing, you just kind of manage away on your own.' The type of support that this participant would have wanted, on the other hand, was someone to check in regularly when the participant was living in the community and provide reminders of day-to-day living responsibilities that needed to be attended to, as well as a counsellor to talk through larger decisions such as whether to leave or remain in a job.

Some of the same participants also indicated that there were times when they were content to let others make decisions for them, sometimes welcoming the assistance. One person praised the support in managing day-to-day tasks received from the participant's mother. This participant also described how at some points in time, leaving decisions to either parents or, when appropriate, mental health professionals had been the preferred option:

You know, at certain points I just left it to the professionals to make the decisions for me because I couldn't make them myself. (Participant 8)

This participant in addition to some others indicated a complex view on support and decision-making. On the one hand, some participants greatly valued the support they had received in the past and articulated that without this support, they would not have been able to make decisions. Some articulated a role for substitute decision-making, that is, those occasions when they were content to leave the decision-making to others. On the other hand, some of these same participants said that they would want to make their own decisions and that the experience of having others make decisions for them, either mental health professionals or family, was in itself frustrating and 'horrible'. One participant emphasised that they would never want to get into a position again where they did not make their own decisions. These ambivalent perspectives show that the distinctive roles for supported and substitute decision-making need to be carefully negotiated. Also, since a few participants describe how their current wishes differ from their wishes when they were first in distress, this suggests that any arrangement on substituted or supported decision-making would need to be reviewed in line with the changing experience of the individual.

Types of assistance

Participants described a variety of types of assistance that would help them to be able to make decisions. Practical help in working through the decision-making process was

identified by five participants. This took different forms: having someone who would work through the choices with the person, using 'creative ways' of talking through the choices, using practical 'tools and techniques' and sometimes helping the person to minimise the choices as a way of helping them to focus their decision-making.

Someone to listen

One simple type of assistance that was mentioned in response to this question was just someone who would listen:

Well, first and foremost I would want someone who would listen to me. You know, if it was felt that I needed to go to a psychiatrist, I would want one that would listen to me. I would want one that I could be honest with. (Participant 7)

Minimising choices

Two participants described the value of having someone to work through the available choices for everyday decisions.

Well I'd like somebody around that I trust, a friend to minimise the range of choices and say, take one or two choices, take one or the other rather than twenty possibilities out of the wardrobe. (Participant 1)

What she used to say to me was, let's look at the list and prioritise, what's important, what really has to be done today, what has to be done today that can't be put off until tomorrow. From that we would make a list for what I had to do today. And that could go on for about a week or two weeks, where we do that, and gradually I would start to make my own decisions, and I would only need to go to her every two or three weeks and then it would be a month. (Participant 3)

Another participant emphasised the value of using practical tools and techniques and creative methods for facilitating decision-making:

We do it in our skills [class] and it's really just very, very simple and it's just four boxes with a circle in the middle and you can work it and you can be included in remembering your skills. And I know if someone had done that with me it would have made a difference. (Participant 7)

Affirmations

Five participants said that affirmation of their capacity was significant for them. One participant described this 'unconditional love' as central to their recovery.

It's an enormous thing - the reason I recovered, and I'm cutting to the solution rather than the problem because I think it's important - the reason I recovered is that my [partner's] belief in my capability in making decisions never stopped and ____ [partner] always believed that the transition between my losing my capacity to make decisions and regaining my capacity to make decisions was a very temporary thing and so it was. I think that had ____ [partner] made a different decision I would never have recovered because

without the ability, the capacity to make a decision I would never have found my dignity again, as a human being, as a worthwhile member of my family, as an equal partner in my marriage. (Participant 4)

and further on, this participant re-stated this emphatically:

No, it's just one word that you used there, that ____ [partner] 'thought', no, letting me know that ____ [partner] knew - that's the difference. ____ [Partner] *knew* I had the capacity. I always had it and ____ [partner] just had this innate belief that it was there. I had just put it aside on a temporary basis, but even when I was at my worst, when I was suicidal, ____ [partner] knew - ____ [partner] didn't think, ____ [partner] knew. It was that conviction that carried us through, that belief in me that carried us through. (Participant 4)

Other comments emphasised the importance of hope:

And it's most important when a person is in so much distress and isolation that they have something to believe in and something to hope for. (Participant 8)

...so part of the capacity for me is building people's belief in themselves that they can make decisions in the first place, and they can have influence and empowerment and all those kind of things, you know? (Participant 6)

While another participant said that affirmation of the participant's ability was a component of regaining capacity:

One other thing I appreciate with her as well is that she will always, always tell me how great I am, and how far I have come, and if I feel that things are a mess and I can't get out of them she will very gently say to me, "no, no this is not like before and you have come so far, and this is just a hitch and it will be gone in a day or two - it will be all right and you will be back on track". (Participant 3)

The prevalence of these comments about affirmation by five out of the eight participants suggests that this is a key association with the concept of capacity.

Drawing on their own experience, participants have shown how affirming an individual's capacity can enable that person to have capacity. This supports the idea that capacity is socially constructed and relational, showing how capacity or incapacity can be constructed in a relational process where one individual affirms or denies the capacity of another.

This analysis is also supported by participants' comments about gradual transfer of control from others to the participant. Two participants identified the importance of giving control over decisions back to the individual so that they can regain their capacity quickly. For example, one participant described how important it was to their recovery that a doctor had encouraged them to take back their decision-making role. The participant contrasted this with how other people have been treated:

It wasn't until I started to meet other people who were acutely unwell and they were starting to get better, and as they were starting to get better, they wanted to make certain decisions, and suddenly they were stopped. They were stopped by their psychiatrist, or they were stopped by well-meaning people - nobody who actually wanted to take control of their lives and live it for them, but people who felt that they still weren't ready - that I began to realise that at the time when I was unwell, my doctor actually used to start to give me back that control, as we were going along. She would say to me, "Now I think you can do this today" and gradually she was giving it back. And it was then I realised that at the time I couldn't make a decision, she discussed it with me, and we made the decisions together, even though she would be the one prioritising. But as I was getting stronger and better, I was the one prioritising and I was the one making that decision and eventually I was the one living that life. That's something that I really appreciate now, that I had that kind of help. (Participant 3)

One participant thought that the best assistance they could have received when they were lacking capacity was simply someone to talk to:

I think at that stage I would have liked somebody to come in and talk to me. Not to be living in that loneliness and isolation for all the time... (Participant 8)

Similarly, another participant thought that the assistance they required when they were unable to make decisions was just someone to assist them with the practical activities of daily living, to remind them of the decisions they needed to make:

I would have liked somebody who was, you know, capable, which wouldn't have had to be too highly capable considering where I'd been at! But who would knock on my door every day and say, _____, how are you doing, what are you doing today, you know, have you made plans to meet anybody, are you going to go out, are you going to stay in all day, have you got around to doing that job you said you were going to do, do you know? Something along those lines - have you paid the bills? Have you got food in the house? But I've never had that. (Participant 5)

One person described the value of having flexibility about when support was available so that it can be accessed when needed.

Information

Participants were also asked what kind of information they thought would help them to make decisions. The most common responses were information about alternative treatment options and about medication. Participants wanted to know what the intended effects of their medication were as well as about potential side effects. Alongside this information, they wanted to know about possible alternatives to medication so that they could explore options and make informed decisions about treatment. Participants also wanted information that was easily accessible. They wanted 'jargon-free', 'simple' information that was also 'full and complete'.

The Scheme address the issue of how the information is presented in Head 2(3) where it states:

A person is not to be regarded as unable to understand the information relevant to a decision if he or she is able to understand an explanation of it given to him or her in a way that is appropriate to his or her circumstances (using simple language, visual aids or any other means).

One participant emphasised how the expression of hope needed to be incorporated into information provision:

I think that most people who are given treatment and they get the information, but they still don't get to make an informed decision because how do you give them the information that they don't have to be a cripple for life?
(Participant 2)

Summary of assistance with decision-making

The variety of comments reported in this section demonstrate a strong connection between the availability of assistance and the capacity of an individual to make decisions. This is the case with reference to all three levels of decision-making: everyday, mental health treatment and legal. Participants articulated how support is an intrinsic component of an individual's capacity. Again, their own capacity is not, for these participants, an intrinsic function of their own minds but a phenomenon that arises out of the supports and information available to them. In one sense, this relational nature of capacity even extends to those occasions when others make decisions on their behalf insofar as this substitute decision-making has arisen out of the individual's own choice and self-recognition of its need. Affirmation of the individual's capacity emerged as a central type of assistance and this again underscores the value of support. The value of having complete and accessible information was also identified. These insights point to necessary components of implementation of any capacity legislation.

Who is preferred to assist with decisions

In addition to these types of assistance, participants were asked who they would like to assist them in three levels of decision-making: everyday decisions, decisions about mental health treatment and legal decisions.

For everyday decisions, a consensus from participants was that they wanted someone they trusted and someone close to them to assist. Family members and friends were mentioned by different participants and this depended on the type of decision. One participant captured a range of qualities for the person who would assist them – trust and good knowledge of the individual, but also someone who is themselves capable, understanding, encouraging and has the individual's best interests as a priority:

You see, my decision-making was probably one of the biggest problems I had in the sense that I just needed somebody - well I had _____ [the partner] - you need someone you can trust. You need someone that is mature enough and capable enough to have your best interests but doesn't take over, talks everything through, understands your frustration, really listens and tries as

much as they can to encourage you to make decisions yourself and that there is no right and wrong and that they're there to support you. (Participant 7)

When it came to who should assist in making a decision about mental health treatment some of the same qualities were identified including trustworthiness, knowledge of the participant and being a good listener. Three participants wanted to be able to choose the person who would assist them with a treatment decision. Participants were also more specific about who they would want to assist. Two participants suggested an advocate while one wanted a multidisciplinary team. One participant wanted a legal professional because "you can't make decisions about your mental treatment without looking at how the law impacts on you, from a legal perspective." (Participant 4).

One participant identified a particular sibling as the preferred person to provide substitute decision-making, while expressing a negative view about other family members making such decisions. Another participant said it was important that the legislation clarify the role of the family:

It's a complex picture, and there are big issues with that, you know? But I suppose the capacity bill would have to be clear in and of itself, you know, about what impact can kin, for instance, family have on this, because I've even heard some carers admit after struggling with their own conscience that they have maybe had people committed or whatever because it was convenient, or they didn't know what to do themselves, so I probably have no words of wisdom on that one but I can see it is a complex picture and the capacity bill would certainly have to be very clear on that, you know? (Participant 6)

While another emphasised that the role of the family should not be presumed:

But in the overall of this, I have many, many friends who wouldn't want their family involved in any shape or form. So it shouldn't be presumed that it's going to be the wife or the mother or the father. Like for instance, if I wasn't married, the last person in the world I would want taking on that role is my mother, the very last person in this world. I have brothers and sisters that I would be absolutely afraid of my life if they were involved in making that decision. I wouldn't want them anywhere near it. (Participant 4)

When it came to legal decisions, diverse views were expressed. Four participants wanted assistance from someone knowledgeable in the law, i.e. a solicitor. Three participants said they would seek assistance from trusted friends. One person described how a GP had been very important in assisting with a court case:

But because of my doctor, as I said, she dealt with it, now I didn't. And it really came about as a result of that, and she got in and she rang people who would have had authority, rather than people who had no authority who were saying they were going to do all this. And it was never even mentioned in court. (Participant 3)

Taken together, these responses show a high level of appreciation by participants about who would be appropriate to assist in different situations. For everyday

decisions, someone close to the individual was the preferred option, whereas for mental health treatment decisions more clarity and designation of a particular advocate was wanted. Similarly, in the case of legal decisions a number of participants recognised that they would want assistance from a legal professional. In order to ensure that people who develop a mental health problem can avail of their own preferences for assistance, Irish law on capacity will need to provide a statutory underpinning for their choice.

The Assessment Process

Participants were asked about their past experience of having their capacity assessed. Two participants indicated that they had never had their capacity assessed. One participant said she had no recollection of being formally assessed – she described the assessment process in this way:

...it would have been during the interviews that are conducted by the doctors. And I think the question was asked, “will you come in voluntarily?” and when I said no, that was the decision. That was the assessment: “We think you need to be here.” “I don’t.” Therefore, that’s the answer to the assessment process! (Participant 1)

While another participant also said that they had no involvement in a capacity assessment and no awareness of how this was done. Describing the experience, the participant said “I felt like a child”:

Well, you see, half the time you don’t know what’s going on because it’s all going on behind closed doors anyway, because like, when I attempted suicide and ended up in the hospital, I hadn’t a clue what information they had up there. (Participant 7)

Another participant recollected a distressing experience of ending up lying on the floor with a parent answering ‘bizarre’ questions:

I hadn’t slept in days and I was just wiped out. And I was lying on the ground and there were two doctors there and they were talking to my mother and they asked her the most bizarre questions! (Participant 5)

These narratives show what it can be like when the service user is not involved in the assessment process.

Who should assess

Participants were asked who they thought would be appropriate to assess their capacity. The responses addressed assessors’ personal qualities, their qualifications and training and which types of roles would be suitable to conduct assessments.

The most common response was the need for the assessor to be a neutral party. One participant commented that the assessor should be ‘independent or independently-minded’ (Participant 1). Another participant defined neutral in this way:

Well, that they're not necessarily for the service user or for the psychiatric services. Now, they could have come from either one but that they have the capacity, the expertise and wisdom of either side or both sides, but that they're able to use that information and that knowledge in a way that best meets my needs. (Participant 7).

Another participant defined neutral in terms of being 'outside the mental health system' (Participant 4).

Four participants expressed concern that the power inequality between patients and mental health professionals would impact on the assessment of a person's capacity. For one participant, this was about the medical perspective dominating over the assessment process:

...we need to disempower them [medical professionals] and empower neutral bodies to go in to assess it from the human point of view rather than from the medical point of view, because no one is looking at this from the human point of view. Everybody is looking at it from the medical point of view and it's not a medical decision. It's a human decision that we're talking about here. There is a role for the medical view, of course there is, but it's an equal role with others and it should not be given the exclusive power to make the decision in this scenario, which it is. (Participant 4)

For another person, it was about the power of a doctor to detain the individual, and this overriding the potential for an equal communication in the assessment process:

You see, I just don't know how a psychiatrist is the best placed person. I'm not saying they are or aren't. I don't know how they are, because how can they remain neutral? How can you if you're caught in - there's an imbalance of power in the relationship because you can actually have me signed in, you can have me signed out, you can have me signed away, upside down and inside out, right? Now, there's an imbalance. So how could you be the right person to decide whether I'm capable of making a decision or not? (Participant 7)

This same participant thought that no assessor could make an accurate assessment without the input of the individual concerned:

When people do a once off assessment, they cannot know what's best for me unless they include me in it. (Participant 6)

Another participant was also concerned about possible bias by the assessor:

Because I would still be a bit suspicious of who's doing the assessment, and what that person's relationship is and all the rest of it with the individual, they might have met them before they might have an idea of who they are, etc., etc. and that may be biased, and they may also be biased with an illness model, let's put it that way. If this person is diagnosed with schizophrenia for instance, then maybe they're less likely to have capacity than someone who has depression, so I'd still be a bit suspicious as to who the person is, and even if they're [a] very independent person within the services themselves, I would

still be a bit suspicious of them in the sense of they still have to toe the line to an extent, and the whole issue of risk is tied up with that so they have to cover their own back. (Participant 6)

Participants suggested that a range of professionals and non-professionals be empowered to conduct capacity assessments. One participant emphasised that assessment should involve more than doctors:

I'm thinking of whether it should be seen as only psychiatrists and I would disagree with that. I think that there's a range of professions who can judge whether somebody can make a decision or not and I don't think it even necessarily needs to be a professional. I think that a wise person with experience of distress can estimate or judge whether somebody's capable of making a decision. But in terms of pinning it down in legislation, why should doctors be the ones to assess people's ability to think? Why not a philosopher? Or somebody who can actually understand the process of logic, and not just logic, but emotional intelligence. I don't think that medical training gives people that necessarily, but psychologists, obviously have studied human cognition, but I definitely think it needs to be far more than a medical doctor, even if it's to be an approved social worker like they have in the States or England even. There it's more than the psychiatrist's say-so, it includes other professional perspectives in the decision about detaining somebody. So if you're assessing capacity, I think it needs to be certainly more than just the medical profession. (Participant 1)

This same participant said that people with direct experience of their own impaired capacity should be involved in assessing capacity. One participant preferred a GP to assess capacity both because of trusting the GP and also because the participant believes that the GP would take more time over the assessment process. Another participant said it would be a counsellor with whom the participant had developed a trusting relationship.

Several other participants raised the importance that the assessor be someone they trust. This was described in terms of 'getting to know' the assessor as well as that the assessor had taken the time to get to know the individual's situation. Others talked about the assessor being someone 'close to me' and someone who is 'looking after my best interests'.

Participants identified personal qualities that assessors should have: they should be friendly people, people with 'the right human qualities':

...I really do believe it's down to human qualities, not so much the kind of professional background you're coming from. If you've the right human qualities you can work with people and that's where I'd be coming from ... (Participant 4)

Participants said that the assessor should also be 'respectful', should have 'wisdom' and be 'self-aware'.

Finally, participants said that assessors should have adequate knowledge to be able to carry out assessments. This was expressed by one participant in terms of knowledge

about mental health, i.e. having wide clinical experience, and by others as knowledge about emotional distress, about emotional intelligence or about logic.

Somebody who knows that people become ill and that it's a part of the human condition but that it's not a permanent state. Distress is part of the human condition and when people are in distress sometimes they need tough help, but it should be done kindly. That they're not shocked by it, so they can say, look mate, like someone who is really drunk, you have to get them to leave the pub, and you can do it roughly or softly, it's the same with mental illness. (Participant 2)

Some participants talked about the need for assessors to be adequately trained so that they both understand the mental health system but also have the skill of assessing capacity. One participant said that service users should be involved in delivering this training.

...so I still think that yeah, it depends how we train people up and all the rest, prepare them for what this assessment is, and I think if it comes to the capacity bill and we do have to provide training to the professionals who might have to carry out some assessments, I think some of that training should be carried out by service users actually as well, who have had that experience and of course I'm hoping that this will have a big impact on it as well. (Participant 6)

Participants made a range of other comments about the assessment process. One person was concerned that coercion could influence the assessment of capacity:

and sometimes capacity, we also take that away through coercion and things like that and sometimes we don't even realise we're doing it... (Participant 6)

and similarly, this person thought that the assessment process needed to distinguish between those who lack capacity and those who appear to lack capacity because they are choosing to go along with a decision:

And I think one of the things within defining capacity for me is... people who will just go along, if that makes any sense to you, there's a distinction to be made there. Because even when you offer choice sometimes we just say "well I'll hand it over, you tell me, because you're the expert," you know? So I think we have to make that distinction in defining what capacity is, is it the inability of a person to make a choice, or is it that the person just goes along all the time, and they're perceived as if they have no capacity, because of that. (Participant 6)

Contrasting views were expressed about whether a person's history should be taken into account in assessing capacity. Two participants thought that a person's past history could 'go against them' in a capacity assessment. For example, one person said,

if he [the judge] took all my case history into account, he might rule not in favour of me, and that would be upsetting to me now because I don't have the file, I don't have my information, I don't know exactly how I've been perceived by the system and maybe that's something I should look at as well. (Participant 8)

On the other hand, another participant thought that ‘knowing their history’ could assist in determining whether, at this moment, the person had tipped over into incapacity (Participant 5). In this case, the knowledge of the person’s history was important in the context of those people familiar with the individual who would know whether they were going into an acute episode. This participant also emphasised in the same context that it is important to allow people to take risks:

There’s also the thing about people have to be allowed to take the risks that they want to take and I’d be abhorred at the thought that somebody was going to take those choices from me. (Participant 5).

Taking into account a person’s past history can be viewed as a positive thing when it is used to understand the person’s current situation better, however some participants are concerned that history could be misused in an assessment process to bias a judgment towards incapacity even when currently capacity is evident.

Court assessment process

Participants were asked how they would feel about going to court to have their capacity assessed. This question was asked because at the formal decision-making level, the Scheme proposes that the courts be given jurisdiction to deal with issues relating to capacity. Some views were expressed that going to court could be a positive, empowering experience. On the other hand, others said that going to court actually would be impossible for them when they are in a state of severe emotional distress or could exacerbate their mental health difficulty. Concern was also expressed that the process could be too slow to take account of urgent mental health support needs.

On the positive side, one participant said,

...the flip side of that is that I have seen people who have challenged things in court and who have actually felt so empowered because they’ve won through the process that they’ve actually gone on and done very well, and I think it is useful for some things to be challenged in the court in that sense. (Participant 6)

On the negative side, several participants thought that having to go to court would be horrific. One person said,

I would have passed away! My anxiety would have been so sky high, I’d have passed away, and that is just purely around panic attacks that I could not go into arenas. I just couldn’t because that was my biggest fear. (Participant 7)

While another participant described how emotionally draining it was to have gone through a court process in the past:

... I had actually started to recover and then there was this crisis in my life and as part of that crisis it meant that I had to go to a solicitor and as part of that then we had to go to court, and then there were some legal decisions that had to be made. And it absolutely took every shred of emotional energy that I

possessed away from me and I just felt like I was going to die. And that's the words that I would use - I felt that I was going to die. (Participant 3)

This participant also emphasised the need for support in order to be able to proceed with a court process:

But honestly, if I hadn't have had that, I couldn't have done it. I couldn't have signed a legal document. I couldn't have gone into court. I couldn't have dealt with solicitors or barristers or anything else. Oh, even thinking about it, my heart is shaking! I can just feel all that emotion from then, you know? So for me personally, without the support I just couldn't have, no. (Participant 3)

Another participant expressed concern about undue delay from a court procedure:

Well if it's a fast and speedy and appropriate judgment, but I think it could be very cumbersome and awkward and very expensive to do that in a situation for somebody ... I would see a problem where I couldn't be given medication - if I couldn't get treatment until I had been through a court process, well that could be a huge delay and obstacle. (Participant 1)

These comments reflect how daunting the experience of going to court can be for an individual who is emotionally vulnerable as well as the value of support in that environment. They also demonstrate that for some people, the court procedure would not be conducive to facilitating their maximum capacity.

Timeframe for Review

Participants were asked how often they thought capacity should be reviewed. Five of the eight participants thought that the three-year timeframe proposed in the Scheme was too long. One person proposed six weeks as a reasonable timeframe, while another person highlighted how his incapacity was 'momentary'. Several participants thought that the review timeframe needed to be individualised with reference to the person's own recovery.

...so on an individual basis maybe, and I know people don't like that because it's too broad, but I still think that it should be on an individual basis. (Participant 6)

While another participant said,

There would have to be some open-ended way that they can demonstrate that they have capacity - as soon as they can demonstrate it. (Participant 2)

And one participant thought that individuals should be able to request a review:

Maybe there should be something in it that the person can request a review, and it should be a simple procedure. (Participant 3)

Several participants also thought that the review timeframe should be negotiated with the individual concerned or should be part of a dialogue with the individual about his/her own recovery:

... Because on the assessment it should be asking “ok we’ve kind of discussed that sometimes you struggle with capacity, so how often does that happen? And how often would you like this to be [reviewed]?” The individual should have some input into that. (Participant 6)

Now if the review is being done for my benefit, you know, to help me, then let me decide with you, you know? “Okay, we’ve made a decision here, when would be a good time to review it again?” So we can see, “Is this still okay or do I now need to look at things or do things differently?” But if you’re doing a review to see if I’m off my head or not, no, what benefit is that? That’s of no ... benefit. The reviews should be so much around helping a person. The review should be about that a decision is made collectively and you were okay with it at the time, but that’s six weeks ago now. “Are you happy with it still? Do we need to look at it again? I have more information. I noticed over the last six weeks x, y and z. How about now?” (Participant 7)

It’s back to the fact that I would feel that I should have the power to make that decision for myself in the advance directive as to who is going to decide when my capacity should next be assessed. (Participant 4)

Participants thus identified new ways of thinking about the timeframe for reviewing capacity. Rather than a set timeframe, participants wanted the review to be quickly responsive to changes in their capacity. They also wanted to be involved in the process of determining the timeframe for review, either in the context of a negotiated process around their capacity and their recovery or in an advance directive that they would determine.

Appeals process

Participants were asked what options they would like to have if they were not happy with the decision made about their capacity. Some suggestions were made about a process of dialogue where questions can be answered. Other suggestions were for court procedures or a neutral, oversight body to be able to take appeals. Some concern was expressed that the legal profession could take advantage of a legal process.

Two participants preferred having recourse to an independent watchdog. One said:

There really needs to be an independent watchdog over the system so that people who for social control reasons and people who don’t fit into the neat boxes that everybody is supposed to fit into, so that if they fall victim of this situation, I’d think they’d want an independent commission or an independent watchdog. That’s the way I would be comfortable, knowing that there was a strong and independent body. (Participant 1)

And this latter participant preferred the watchdog to a court procedure.

While another participant thought there should be an option to appeal to a higher court, expressing the desire to be able to challenge the court's assessment:

They should be able to take it to a higher court and have financial assistance to do that. I know that's a consideration for some people who want to challenge their detention under the Mental Health Act, or maybe a tribunal, but I don't think they're any better. But there should be some way of challenging it. It would also be good for there to be an easy way for people under the Mental Health Act to challenge their decision. (Participant 3)

And another participant felt, simply, that the person should have "the same right of appeal as anybody else." (Participant 2)

One participant thought that it was important to have some kind of explanatory process before the appeal option:

Okay, first and foremost there needs to be someone in the room that will shut up and listen to them and listen to why they're dissatisfied. And not to listen to affirm the decision that was made or not to listen to challenge them initially. Just someone who will listen, who will take down all their points and validate those points and say, "Right, this is what I heard you saying, this is what I heard you saying. Is this correct? Is this where you feel that this decision isn't right?" So, say for example, this would be my way, say for instance we've made a decision that it is in your best interest to be kept in hospital. Okay. How did you make that decision? Who made the decision? What was it that brought that? And then for me to be asked then, "Right, if this isn't the right decision, what other options have you got available? Okay, so you're not going to stay in hospital. So what have you got in place? What are you going to do?" So that there's a debate where I'm able to go, "Right, this is why I feel I shouldn't be in hospital and these are some of the reasons and this is what I've put in place." And then to allow that discussion to happen. (Participant 7)

These responses show a diversity of preferences even among a small group of people with direct experience about how they want to appeal a capacity decision. For one person, it is important to have a space for dialogue with the service provider before making any challenge. Some want to be able to appeal to a higher court, while others prefer an independent watchdog that would perhaps be more accessible than a court system.

Advance Directives

Participants were asked two questions about advance directives. They were asked generally whether they thought it would be helpful to have their preferences for mental health treatment written down in advance. They were also asked to what extent such a document should be binding upon medical professionals.

All the participants were in favour of the idea of an advance directive and this is the only question where there was complete unanimity.

I do think it would be helpful. I know that there is a lot of debate and discussion about this, but I do think it would be helpful because nobody knows your mental health better than you. (Participant 3)

So what would I want on reflection? I would want a very clear and concise advance directive put in place that had legal standing... (Participant 4)

If you are taking risks and you are pushing yourself, and saying, I will try that training course, and you might take on too much, it would give you more confidence if you knew that you were going to be treated in the way that you wanted. (Participant 2)

I think especially if you know what works for you and what doesn't work for you and options that you want to try and that you don't want to try, I think it can be very, very helpful because if you've already written down that you want this done or that done then it becomes easier for it to happen in a situation where it should be happening, and likewise if you said that you don't want something, then I would probably be even more strongly resistant to them doing something that I didn't want done. So I definitely think it would be good to be able to put down the way that I want to be treated or don't want to be treated, particularly that I wouldn't want ECT. (Participant 1)

Participants had helpful perspectives on how advance directives should work. Two felt that it was important they could refuse ECT, while one person thought it was important that they be able to refuse certain drugs that they knew had an adverse effect on them:

And in a lucid moment I've turned around and said I do not want to take this certain medication because they have had adverse effects on me - for instance I would refuse to take lithium ever again because it gave me severe psoriasis which is troubling me all my life ... so I would want to be able to sign an advance directive to say that because of the adverse effects I have experienced I do not want to take lithium. (Participant 4)

Though this participant recognised that a directive should not be too prescriptive:

Now the psychiatric profession would disagree with that because it would limit, according to them, their ability to treat. And they have a point - there is a point in it. If I were to make an exhaustive list of every medication known to man, then they would have nothing with which to treat me. It's a point. (Participant 4)

Another participant agreed that it would be 'problematic' to set down a requirement to use specific drugs in an advance directive. However, this participant wanted to be able to ensure through an advance directive that they did not receive experimental medication:

I wouldn't want people experimenting on me with new drugs, certainly not when I wasn't capable of making the decision. (Participant 1)

A few participants described how the advance directive should be discussed and agreed with their doctor. For example,

So I think the solution to it is probably that if I was to make out an advance directive now based on my experience, I would want to say that I have discussed this with doctor x and these are the conclusions I have come to with doctor x that this is the type of treatment I want to undertake if I have a psychotic attack or whatever, and this only, and having discussed it with a medical professional, these are the conclusions that we have come to jointly. (Participant 4)

While another participant thought it was important that mental health services promote advance directives and include them in discharge planning.

One person thought it would be useful for the advance directive to set out the role of family involvement, to be able to assign family members to be involved in decision-making about their mental health treatment. This participant also thought it would be useful for the directive to be given to his solicitor. Another participant thought the directive should designate an advocate for the person:

I think it should be around things like if there are drugs that are particularly unpleasant or if they don't want ECT or if they don't want medication, they should be able to appoint someone who can advocate that their wishes are [to be] respected even when they're going into hospital... (Participant 2)

Two participants wanted the advance directive to cover their life responsibilities as well:

I think it's also the other areas that are important to decide who will take care of the other responsibilities of having a life, how to deal with the job or college, or who will get the house keys or whatever, who will feed the fish. (Participant 1)

And I also want to be able to say that any savings or property or money that I have is kept safe, so that kind of a way. I think it's very important. (Participant 8)

In terms of enforcement, there was a strong sense among five participants that the advance directive must have legal weight:

I don't like the legal but again I don't think the services will take it seriously unless it has some kind of legal force behind it, because they'll just pick out the wee tiny bits that they like and just discard the rest. (Participant 6)

Two participants thought the directive should be totally binding. Three people thought it should be binding unless there was clear justification, while one participant thought that there should be some flexibility, but the directive should be absolutely binding in the case of a refusal of a particular treatment.

Participant responses in this section show that they have a clear but commonsense conception of how advance directives should work. There is a strong consensus that individuals should be able to set out in advance their preferences on mental health treatment and be able to refuse certain treatments, but also to be able to state what they know works for them. Participants want this document to have legal weight and to be binding unless there are clear reasons why it cannot be in a particular instance. For individuals with experience of a medication that works effectively for them, there is particular concern raised that doctors should not be able to try out a new medication without informed consent, while the helpful suggestion was made that advance directives on medication be negotiated with the individual's mental health professional. Participants also wanted to be able to set down in advance how their daily life responsibilities would be covered and their property protected during a period of incapacity.

Chapter Four: Discussion

In psychiatric discourse the concept of decision-making capacity has traditionally been framed in terms of an objective determination by an expert psychiatrist about a patient (the subject). This framework accorded with a broader tendency amongst medical professions to position themselves as experts over a range of human needs.⁶² This approach is also embodied in Ireland's Mental Health Act 2001 which ascribes responsibility to psychiatrists for determining if a person's judgment is impaired to an extent that requires their involuntary detention and for determining if the patient is capable of consenting to treatment.

However, a social model of disability approach to mental health implies the recognition that capacity is constructed between society and the individual in a process of dialogue and negotiation. It implies that the disabling aspects of incapacity arise out of the environment within which the individual's capacity is determined. From the perspective of a social model of disability, incapacity is not simply an intrinsic attribute of the individual that can be determined objectively through expert testing. Rather, it is a relational phenomenon developed between the individual and his/ her environment. Incapacity arises not essentially from impairment but in the relationship between impairment and social barriers.

In the results of this research project, participants' descriptions of their approach to capacity articulate this type of social model of disability understanding. Participants described how their decision-making capacity can be reduced by the lack of treatment options available for them to choose from. It can be negated by the way that information is presented if that manner is too heavy-handed, or if the person providing the information is not perceived as trustworthy by the individual concerned. Capacity can also be negated if the information about the decision is not accessible. If information is not provided that is in clear English and free of jargon, the individual will not be able to make an informed decision. In some participants' experience, capacity can be diminished through the effects of medication that literally "stops your ability to think". Capacity can be negated if the individual is not given enough time to digest information and develop their decision.

Participants identified the personal support they are given during the decision-making process as one of the key enablers of their capacity. Two individuals felt that without the in-depth support of another person, they would not have been able to make decisions at key moments in their lives. The role of this person varied – sometimes it was described in terms of working through the available choices or minimising a surfeit of choices. Sometimes it was just having a trustworthy person with whom to talk things through. The majority of participants highlighted the importance of affirming an individual's capacity. Many emphasised the value of expressions of hope for their recovery and the belief conveyed by others in their innate, persistent capacity throughout times of difficulty.

The Scheme goes some way to recognising the social and environmental factors that can affect decision-making capacity. The Scheme sets out that a person is not to be

⁶² See Ivan Illich (1977) 'Disabling Professions' in I. Illich, K. I.K. Zola, J. McKnight, J. Caplan and H. Shaiken, *Disabling Professions*, London: Marion Boyars Publishing Ltd.

regarded as unable to understand information if “he or she is able to understand an explanation of it given to him or her in a way that is appropriate to his or her circumstances (using simple language, visual aids or any other means).” This section thus supports the provision of accessible information to the individual. The Scheme also recognises the principle of supported decision-making under the Guiding Principles where it states that “a person shall not be treated as unable to make a decision unless all practicable steps to help him or her to do so have been taken without success.” However, the Scheme does not contain any further specific provisions underpinning the supported decision-making process and so it is unclear how this principle would be implemented in practice. The Scheme also fails to set out clearly the boundaries between informal substitute and informal supported decision-making. It merely requires informal decision-makers to act in accordance with the Guiding Principles and in the person’s best interests (as per Head 3 of the Scheme).

Three participants expressed dissatisfaction with the capacity/ incapacity dichotomy. Two individuals said that if crisis intervention services were available, this could largely eliminate the need for capacity judgments about people with mental health problems. Their suggestion illustrates the wider point that in the absence of a choice of treatments, patients are faced with a ‘Hobson’s Choice’ between, for example, inpatient treatment and no treatment at all, a situation which may effectively result in their being unable to make a decision. The current availability of choice of treatments in Ireland is poor, as has been evidenced most recently in the Indecon report on progress in implementing *A Vision for Change*, the national mental health policy.⁶³ This report found that there is a continued over-reliance on inpatient treatment in Irish public mental health services and that there is a shortage of 56 per cent of staff required for Community Mental Health Teams as recommended in the Government’s mental health policy. Much of the staff shortage relates to the disciplines of Occupational Therapy, Psychology and Social Work. Thus the current reality for Irish mental health service users is that they often do not have choices about their treatment that would enable them to be treated at home instead of in inpatient units, or to have alternative therapies such as counselling or Cognitive Behavioural Therapy.

There was also a strong and persistent view among participants that capacity is fundamentally different in mental health than in other areas of disability due to the temporary nature of impairment. One participant articulated this in the following way:

“...What I’m saying here is that there’s a slippery slope where we see this as almost a long-term thing for some people, where decisions have to be consistently, constantly made for people, not momentarily, which may help people in a certain circumstances...” (Participant 6)

The temporary nature of incapacity in relation to mental health problems can fit with the Scheme’s emphasis on a time-specific and decision-specific approach to incapacity. However, it may be necessary to recognise in the law the very short-term nature of incapacity in relation to mental health problems.

⁶³ Indecon (2009) *Review of Spending on Mental Health Services and Progress Towards Implementation of A Vision for Change*. Dublin: Amnesty International Ireland.

Participants also provided a range of practical suggestions that can be taken into account in the process of implementing any capacity or mental health legislation. These suggestions addressed:

- The **qualities of people who should assess** decision-making. Persons charged with this responsibility should be neutral, drawn from a wide range of professions and non-professionals, trained in determining capacity and/ or in logic, knowledgeable about mental health/ emotional distress/ emotional intelligence, friendly, respectful, wise and self-aware.
- **Who is preferred to assist with decision-making.** In relation to everyday decisions, a consensus from participants was that they wanted someone they trusted and someone close to them, with different individuals to be chosen depending on the decision. As regards mental health treatment, participants wanted to be able to choose who would assist them, with options including an advocate, a multidisciplinary team and a legal professional. The need for the role of the family to be clarified was emphasised by two participants. For legal decisions, some participants wanted assistance from someone knowledgeable in the law, while others wanted assistance from trusted friends. These perspectives point to the need for Irish law to provide for the right to an advocate of the individual's choice, particularly in the context of both mental health care and legal decisions.
- Participants viewed negatively the idea of **going to court** as part of the assessment process, with several indicating this would be impossible for them to face.
- Participants offered reasonable ways of thinking about the **timeframe for reviewing capacity**. Rather than set a specific timeframe, participants wanted the review to be responsive to changes in the individual's capacity. Some also wanted to be involved in determining the timeframe for review, either in a contemporary negotiation or in advance through an advance directive.
- A diversity of views were expressed regarding an **appeals process**. One participant proposed a process of dialogue as a precursor to any formal review process. Other suggestions were for a court or a neutral oversight body as a forum for appeals.

The issue of advance directives was touched on briefly in this research. While the "Best Interests" provisions in Head 3 of the Scheme require that the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him or her when he or she had capacity), beliefs and values that would be likely to influence his or her decision and other factors he or she would be likely to consider be *considered* insofar as they are *reasonably ascertainable*,⁶⁴ the Scheme does not go on

⁶⁴ Emphasis added. A similar requirement is included in the Guiding Principles (Head 1(g)).

to provide any framework regulating the creation and validity of advance decisions. Participants were asked whether they thought it would be helpful to be able to write down in advance what mental health treatment they would or would not want in situations where they would lack capacity. Responses were unanimously in favour, with a strong view that such expressions should have a legislative underpinning. The view was expressed that such a document would facilitate the individual to share their knowledge about what works for them and thereby have a positive impact on the type of treatment they receive in moments of crisis. Participants also had a realistic appreciation of how this might work in practice in relation to mental health, recognising that it was unlikely they could require a particular medication but with a strong desire to be able to refuse ECT, drugs that were known to cause them ill effects, or experimental drugs. In terms of scope, most participants thought the directive should be either totally binding or binding unless there was clear justification to override it. One participant thought that it should be binding in the case of a refusal of a particular treatment. Participants' perspectives about advance directives provide valuable, initial evidence in the Irish context about the demand for advance directives in mental health as well as how these could operate.

Limitations of the research

This project involved a small-scale, in-depth exploratory study with eight participants who had long-term experience of their own mental health issue. The participants also had a high education level overall. Therefore, its results cannot be taken as representative of the wider population of people who have had a mental health intervention. It is possible that other types of assistance, supports and even interpretations of incapacity would arise amongst different age groups or amongst those with a lower level of education. However, the results do provide useful insights to be taken into account in discussions of incapacity in the context of mental health. The narratives reported provide valuable qualitative illustration of the impact that incapacity can have on an individual. The results have opened up new interpretations of incapacity and new considerations for addressing it. These interpretations and considerations can be seen as particularly relevant for individuals who are middle-aged and have lengthy experience of their own mental health issues over time since that is the situation of the participants. However, there is an argument that the findings have wider application. If, as is proposed by the Scheme, all individuals are presumed to have capacity until demonstrated otherwise, then every client should have the opportunity to maximise the demonstration of their capacity. The suggestions made here about assistance and advocacy, affirmation, accessible information and other supports all have the potential to increase the capacity of any client and therefore should be explored with any client in order to ensure that their capacity is maximised. Thus these results provide a basis or foundation from which the development of appropriate supports can begin. The results will also provide a basis for further research by setting out a framework for future research questions amongst a wider sample.

Conclusion

This research has sought to explore the views of people with mental health problems about decision-making capacity and advance directives. In in-depth interviews with participants, a set of useful insights have been articulated. Participants have contributed to a social model approach to mental health in relation to decision-making capacity by describing how a range of barriers and facilitators inhibit or support their

decision-making capacity. The results of this exploratory research can provide a basis for further discussion with a wider constituency of individuals affected by mental health issues. The results will be of immediate benefit in providing practically useful evidence to inform AI's lobbying position and the wider Irish debate on capacity and mental health legislation. In addition, the varied and sophisticated perspectives reported on here can inform the international development of a social approach to mental health in relation to capacity.

Appendix 1: Interview Topic Guide

Introduction and discussion of informed consent.

Questions:

- Defining capacity
 - How do you tell when you are having trouble making everyday decisions?
 - How do you tell when you are having trouble making decisions about your mental health treatment?
 - How do you tell when you are having trouble making decisions that have legal consequences, such as entering into a contract?
 - In the Scheme, a person has capacity if they can understand the information relevant to the decision, retain that information, use or weigh that information as part of the process of making the decision, and communicate his or her decision. What do you think about this definition of capacity?

- Experience of having authority to make decisions removed
 - What has it been like for you when others have made decisions for you?
 - [Prompt for interviewer
 - a) What has been your own experience?
 - b) What do you think about this in general?]

- Supported decision-making
 - What kind of support would you like to assist you in making everyday decisions? By whom?
 - [Interviewer – prompt for reasons why]
 - What kind of support would you like to assist you in making decisions about your mental health treatment? By whom?
 - [Interviewer – prompt for reasons why]
 - What kind of support would you like to assist you in making decisions that have legal consequences, such as entering into a contract? By whom?
 - [Interviewer – prompt for reasons why]
 - What kind of information do you think would help you to make decisions?

- Assessment process
 - What has it been like for you when someone has assessed your capacity to make decisions?
 - In your opinion, did the person correctly assess whether you had capacity or not?
 - When your capacity to make decisions is in doubt, who do you think would be the appropriate person to assess your capacity?
 - [Interviewer – prompt for any others – anyone else?]
 - [Prompt – who would you prefer to assist you during a formal assessment process?]
 - How would you feel about going to court to have your capacity assessed?
 - Once a person is assessed as lacking capacity, how often do you think this decision should be reviewed?
 - If you are dissatisfied with the decision on capacity, what options should be available to you to challenge that decision?

- Advance directives
 - This refers to writing down in advance what mental health treatment you do or do not want to have in situations when you do not have the capacity to make the decision. Do you think that this would be helpful in situations where others make decisions for you?
 - [Interviewer – prompt for reasons why]
 - To what extent should your doctor be bound by an advance directive?

- Any other questions
 - Are there any questions you would like to ask me?

Appendix 2: Consent form

Thank you for expressing an interest in being a participant for this research project. The Irish Government is expected to publish a bill on 'mental capacity' in late 2009. Amnesty International Ireland (AI) conducts action-orientated research to support its campaigning work. With a view to informing both AI's lobbying position and the wider debate on capacity in Ireland, AI is conducting research with rights-holders on their views about decision-making capacity. The aim is to produce results and policy recommendations that can inform both the legislation and ensuing policy and practice, including codes of practice.

Researchers: Shari McDaid and Sarah Delaney

Publication: The research results will be used in AI's lobbying materials on the capacity legislation and ensuing implementation. AI also publishes an e-bulletin on its mental health campaign, sent to members of AI's Mental Health Lobbying Network, in which the results can be published. The dissemination strategy will also be further developed in partnership with AI's Experts by Experience Advisory Group.

1. You have the right to refuse to participate in this research, or to stop the interview at any time.
2. You have the right to request that the data collected be destroyed.
3. You have the right to refuse to be tape-recorded. Tape-recording will, however, help to make the research results more accurate.
4. All information obtained in the interview is strictly confidential information and is stored securely at the researcher's office. Only the researchers will have access to this information. Your name will be retained only in order to prevent duplication of data and will not appear in any published research document.

At the conclusion of the interview, I will be happy to answer any questions you have about the research. If you would like to contact me after the interview, please call me at 01 863 8314.

Participant's Name: _____

Participant's Signature: _____

This Consent Form has been prepared according to the British Psychological Society Statement of Ethical Principles (1990)

Appendix 3: Guiding Principles of the Scheme

Guiding Principles as set out in Head 1 of the Scheme of the Mental Capacity Bill 2008

Head 1 Guiding principles of this Act

The following principles apply for the purposes of this Act and every person (including the court) concerned in the implementation of the Act or in making any decision, declaration or order or giving any direction under the Act shall have regard to them:

- (a) it shall be presumed unless the contrary is established that a person has capacity,
- (b) no intervention is to take place unless it is necessary having regard to the needs and individual circumstances of the person, including whether the person is likely to increase or regain capacity,
- (c) a person shall not be treated as unable to make a decision unless all practicable steps to help him or her to do so have been taken without success,
- (d) a person is not to be treated as unable to make a decision merely because he or she makes an unwise decision,
- (e) any act done or decision made under this Act must be done or made in the way which is least restrictive of the person's rights and freedom of action,
- (f) due regard must be given to the need to respect the right of a person to his or her dignity, bodily integrity, privacy and autonomy,
- (g) account must be taken of a person's past and present wishes, where ascertainable,
- (h) account must be taken of the views of any person with an interest in the welfare of a person who lacks capacity, where these views have been made known, and
- (i) any act done or decision made under this Act for or on behalf of a person who lacks capacity must be done or made in his or her best interests.

Appendix 4: Best Interests

‘Best Interests’ as set out in Head 3 of the Scheme of the Mental Capacity Bill 2008

Head 3 - Best interests

(1) In determining for the purposes of this Act what is in a person's best interests, the person making the determination, including the court exercising jurisdiction under the Act, must consider all the relevant circumstances and in particular the following -

(i) he or she must consider –

(a) whether it is likely that the person will at some time have capacity in relation to the matter in question, and

(b) if it appears likely that he or she will, when that is likely to be;

(ii) he or she must, so far as reasonably practicable, permit and encourage the person to participate, or to improve his or her ability to participate, as fully as possible in any act done for him or her and any decision affecting him or her;

(iii) he or she must consider as far as is reasonably ascertainable -

(a) the person's past and present wishes and feelings (and , in particular, any relevant written statement made by him or her when he or she had capacity),

(b) the beliefs and values that would be likely to influence his or her decision if he or she had capacity, and

(c) the other factors he or she would be likely to consider if he or she were able to do so;

(iv) he or she must take into account, if it is practicable and appropriate to consult, the views of

(a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,

(b) anyone engaged in caring for the person or interested in his or her welfare,

(c) any donee of an enduring power of attorney granted by the person, and

(d) any personal guardian appointed for the person by the court,

as to what would be in the person's best interests, and in particular, as to the matters mentioned in the previous paragraph;

(v) the duties imposed under this head also apply in relation to the exercise of any powers under an enduring power of attorney or are exercisable by a person under this Act where he or she reasonably believes that another person lacks capacity.

(2) In the case of an act done or a decision made by a person other than the court there is sufficient compliance with this section if having complied with the requirements of this Head he or she reasonably believes that what he or she does or decides is in the best interests of the person concerned.

"relevant circumstances" for the purposes of this Head are those

(a) of which the person making the determination is aware, and

(b) which it would be reasonable to regard as relevant.