A Citizens' Jury on Legal Capacity Law

A Citizens’ Jury on Legal Capacity Law

© Amnesty International Ireland

Sean MacBride House
48 Fleet Street
Dublin 2
Ireland

www.amnesty.ie

Even the kindest doctor is fearful
written by Rosy Wilson

Typeset in Simplon BP
Design by Distinctive Repetition

Even the kindest doctor is fearful

when his patient goes mad
tears grey hair, knows she’s all bad
lets her family starve, fires the first shots
of the War on Iraq

her mind dive-bombed by swallows
is all-over dark, a white labrador barks
a playful dolphin is damaged
by hammer-head sharks

her doctor dares not explore
snake-infested places, over-grown gardens
at the root of such ravings where
he may uncover more

even touch his own weeds,
tarantula spiders, hidden under
wall-flowers where bumble bees hum
on his tidy, cultivated borders.

With a solid desk between them
not reaching to touch in case it is catching
he diagnoses faulty brain chemistry,
late onset in her sixties, genetic.

He invites her to stay in his hospital on the coast
where they’ll mind her, cure her with currents
for the brain, drugs for bad moods -
when she resists he commits her.

Ten years after, although she’s as docile
as a couple-coloured cow chewing the cud,
he still fears Old Nick will come back
if she leaves off her lithium, runs out.

Citizens' Juries

A citizens' jury consists of a small panel of non-specialists, modelled on the structure of a criminal jury. In an independent setting, the 'jury' examines an issue of public significance and on the final day delivers a 'verdict' based on a charge.

A citizens' jury provides people with an opportunity to learn about an issue, deliberate together and develop common ground solutions to the issue. It assists decision-makers and legislators in acquiring both a comprehensive understanding of what public opinion might be on an issue, and realistic solutions to the issue and any problems it poses, based on the recommendations made by informed members of the public.

It is a deliberative and participatory process and the jury is given information from a number of different sources about the issue for discussion, including expert witnesses and case studies. It is a four-day process and juries do not necessarily have to work towards agreement, but there is usually a movement towards some sort of shared opinion. The aim is not to achieve unanimous agreement but to discuss the issue and arrive at recommendations.

In May and June 2012 Amnesty International Ireland used the citizens' jury model to facilitate the involvement of people with experience of mental health problems to analyse new capacity law.

Contents

Executive summary 11
Introduction 15
What the jury discussed 21
The charge 35
Personal testimonies 45
Appendices 51

> “
>
> **We have the opportunity to create a future where rights, equality and justice are realised.**
>
> ”

This citizens' jury was convened by Amnesty International Ireland (AI) to inform the Government's proposals to reform the 2001 Mental Health Act and to introduce capacity legislation to replace the Lunacy Act of 1871 which is still law in Ireland. The intention of the proposed reforms is to ensure the legislation is compliant with the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The Irish Government has signalled its intention to fully ratify the CRPD, but says it cannot do so until Ireland has the new capacity law enacted.

Since 2003 AI has been campaigning for a human rights focus to mental health in Ireland. In 2008 the campaign convened an Experts by Experience Advisory Group (EEAG) composed of individuals who have personal experience of mental health problems and some experience of advocacy. It was a member of this group who suggested AI use the citizens' jury model to facilitate the analysis of the new capacity law by people with experience of mental health problems.

So in early summer 2012 AI convened a citizens' jury, comprising 16 users of mental health services and three practitioners, to study, discuss and make recommendations which form the body of this report. The aim of the report is to present these proposals to the Ministers who are drawing up the new capacity legislation. The jury met for four full days during May and June 2012 with AI staff acting as facilitators. During this time the following expert witnesses addressed the jury:

- Dr Siobhán McHale, a consultant liaison psychiatrist in Beaumont Hospital;
- Áine Hynes, a partner of St. Johns Solicitors and Chair of the Irish Mental Health Lawyers Association;
- Kara Madden, the mother of an expert by experience;
- Jim Walsh, a member of the Irish Advocacy Network;
- Dr Mary Keys, mental health and human rights academic from NUI Galway; and
- Dr Pat Devitt, the Inspector of Mental Health Services.

The jury was unanimous in its support of the CRPD, particularly Article 12.2 that says:

> "States shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life."

The jury recognised that occasionally and for a limited time an individual's decision-making ability may be lessened and Article 12.4 requires that states should put in place safeguards "to ensure respect for the rights, will and preferences of the person". The jury agreed these principles should be at the heart of new capacity legislation.

The jury agreed that capacity assessments should be made by a team (not by just one individual). This team may include a legal adviser and an independent health adviser, an advocate or friend, as well as a psychiatrist, all on an equal footing. The will and preferences of the person must be the most important consideration.

When a person's decision-making ability is in question, the new capacity law must recognise and respect safeguards such as advance directives, independent advocacy, enduring power of attorney and supported decision-making.

During the jury discussion all the members of the jury who had experienced mental health problems reported they had experienced situations when decisions regarding assessment and treatment were taken primarily or solely by the psychiatrist treating the person. Although the issues of medication, treatment and the power imbalance between the person and the treating mental health professional are issues beyond the remit of the capacity law, the jury felt it was important this power imbalance was addressed within this report.

It must be noted that while the discussions on these issues were wide-ranging, a collective agreement was not always reached. All members of the jury have endorsed the reflections, discussions and recommendations recorded in this report.

> “
>
> **Mental health law and capacity legislation must reflect… a vision for a fairer future and uphold our commitment to progressing human rights for all people.**
>
> ”

One of the priorities of AI's overall mental health and human rights campaign is to ensure that capacity legislation in Ireland is in line with international human rights standards. The Government is currently drafting new capacity legislation and the organisation wanted to elicit the opinions of people with experience of mental health problems on this new law.

Over the course of four days in May and June 2012, AI's mental health campaign facilitated a citizens' jury on the issue of law and decision-making capacity. A citizens' jury consists of a small panel of non-specialists, modelled on the structure of a criminal jury. In an independent setting, the group examines an issue of public significance and, on the final day, delivers a 'verdict' based on a charge.[1]

This jury examined the issue of legal capacity with a specific focus on the role of decision-making, assessments and risk and dangerousness in the context of mental health. The jury was tasked with debating the key issues, listening to the views of expert witnesses and analysing case studies.[2] Following these discussions the jury then made a series of recommendations in relation to the upcoming capacity legislation.

The objectives of the citizens' jury were:

- To empower a group of persons with mental health problems to engage in the law reform process on legal capacity in Ireland.
- To inform key officials in the Department of Justice, Equality and Defence [the key department with responsibility for capacity legislation] of the views of persons with mental health problems on legal capacity.
- To inform key officials in the Department of Health conducting the review of the Mental Health Act 2001 of the views of persons with mental health problems on legal capacity and to inform the Department's Review.

[1] For a more detailed explanation of what a citizens' jury is, please see appendix a.

[2] The six case studies debated are included in appendix d.

The jury comprised 12 women and seven men. Of the participants, 16 have used or continue to use mental health services, while three work in the area of mental health. The participants were self-selected in response to event notices which were issued to a number of mental health organisations, informal support groups and individuals already involved with AI's campaign. We recognise this report represents the views of only a small group of people and cannot represent the views of the general population of people with a direct experience of mental health services. For the purpose of this report the jury voted to remain anonymous.

The expert witnesses to the jury were;

- Dr Siobhán McHale, a consultant in liaison psychiatry in Beaumont Hospital;
- Kara Madden, the mother of an expert by experience;
- Jim Walsh, a board member of the Irish Advocacy Network;
- Dr Mary Keys, mental health and human rights academic from NUI Galway and member of the Mental Health Commission;
- Dr Pat Devitt, the Inspector of Mental Health Services; and
- Áine Hynes, a partner of St Johns Solicitors and Chair of the Irish Mental Health Lawyers Association.

What is the difference between legal and mental capacity?

- The current approach of the law here in Ireland (and elsewhere in the world) is to focus on 'mental capacity'. Mental capacity assesses people's ability to make decisions based on their ability to understand and retain information, and to use it in reaching a decision. If a person is deemed to lack 'mental capacity' others are allowed to make decisions for them ('substitute decision-making').
- Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD) says that people with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. Legal capacity is the law's recognition of the validity of a person's choices.
- So the CRPD makes a clear distinction, separating this idea of 'mental capacity' and instead focuses on the fact that everyone has 'legal capacity'; that is, an ability to exercise their rights.
- Article 12 in particular focuses on the idea of respecting a person's choices and the need to restore decision-making autonomy to them. It affirms that no one ever loses their legal capacity even if their mental capacity is impaired. It ensures people can access the right supports to allow them to make their own decisions.
- This approach recognises decision-making deficits do, at times, exist. However, the typical response of the law in the past to these deficits – all around the world and not just in Ireland – is to focus on substitute decision-making. The Convention requires a shift beyond looking at 'mental capacity' to 'legal capacity'. It is a new approach that supports people in making decisions, based on their will and preferences. States must ensure there are appropriate and effective safeguards that ensure respect for the rights and will and preferences of the person.

The current law governing capacity in Ireland is 140 years old. It uses the Wards of Court System, based on the Regulation of Lunacy [Ireland] Act 1871. The Irish Government has committed to introducing capacity legislation in line with the CRPD. The Department of Justice published a Heads of Bill in 2008 in relation to capacity and is currently preparing a bill to replace the outdated Wards of Court System.

There is concern however, that the new capacity legislation may not be fully compatible with human rights standards, in particular with Article 12 of the CRPD, which champions legal capacity. If the new legislation is to be in line with the CRPD it must adhere to the requirements, values and spirit of the Convention.

The issue of legal capacity has specific importance in relation to mental health, as some people may find themselves unable to make decisions themselves for a period of time. Although the Mental Health Act is a separate piece of legislation, because it sets out the circumstances in which a person may be admitted to, detained and treated in a hospital against their will for mental health issues, there are clear implications in relation to ascertaining a person's capacity to make decisions. sThe Department of Health is currently reviewing the Mental Health Act 2001 and recently published its interim review of the Act. It is essential this review recognises the interplay between the new capacity legislation and incorporates the same rigorous human rights standards as set out in the CRPD in relation to decision-making capacity.

The report of the citizens' jury will provide legislators with an opportunity to consider the voices of experts by experience. The recommendations aim to give practical advice on what the new capacity law should include.

> “
>
> **An equal and dignified law for all people. Taking all human rights into consideration [and] empowering people to feel whole and integrated at every level of society. Respecting individual choice and always remembering that personal choice brings freedom and peace of mind.**
>
> ”

There was rich and in-depth discussion over the course of the four days that covered a wide range of opinions and topics concerning legal capacity and mental health. The discussion was based on people's own personal experiences and opinions, prior knowledge and information received during the citizens' jury, including the perspectives of the expert witnesses. To cover the full spectrum of opinions and matters discussed is not possible in this report. However, a brief outline of the key areas of discussion and views is given below.

Legislation

The law governs treatment and detention issues and has a huge impact on people's lives, experiences and choices. The legal default position is also one of deference to the concept of benign paternalism in psychiatry (e.g., the PL judgement).[3] Psychiatry is unique in the area of medicine in having powers to curtail people's liberty and to forcibly treat them against their expressed wishes. These practices are exempt from the normal due process that applies to the only other area where people can be deprived of their liberty, i.e., within the criminal justice system. Detail on legislation past, present and future, provided the grounding for a wealth of discussion over the course of the citizens' jury. The importance of having progressive and human rights based legislation in order to change practices and attitudes was emphasised repeatedly over the four days.

The content of the new capacity legislation has not as yet been published and therefore the discussion focused mainly on the text of the 2008 Heads of Bill and the CRPD.

There was discussion around the interaction between the Mental Health Act and upcoming proposed capacity legislation. Some members of the jury felt that the two laws should be merged. Others felt they were not in a position to comment on the interaction as they did not know enough about the legislation. However, the importance of having clarity on the interaction of both pieces of legislation and on which would take precedence in various situations was emphasised.

---

[3] The PL case is outlined in Case Study 3: Sunday 10 June in appendix c.

Presumption of capability to make decisions [4]

The jury discussed the importance of the principle that everyone should be presumed to have the capability to make decisions. There was consensus that it was essential that the new legislation reflected this. Some members of the group felt that the same standard of proof should be applied to decision-making capability as is applicable in the criminal justice system, namely that it should be proved beyond a reasonable doubt that the person lacks the capability to make a decision.

The jurors feel it is essential that the term ‘capacity’ is clearly defined in the legislation as they too found the discussion at times difficult because of the lack of a clear definition.

There was much discussion around what happens when a person is deemed to lack decision-making capability. It was clear there was much concern that once someone is labelled as not having decision-making capability this label can stick for a long time. One juror commented on the fact legislation should recognise that a person’s decision-making capability can fluctuate and that people could make their own decisions in moments of lucidity.

Use of language and communication

The group discussed the use of language as both a barrier to and a means of communication. The importance of simple and clear language was emphasised both in respect of the language contained in the legislation and language used by health professionals. The group expressed concern that these barriers may not be addressed in the legislation. The discussion emphasised the need for the type of communication to be tailored to the needs of the individual, so they can understand the important information being given. This could include plain English, sign language, and interpreters. One of the jurors in particular highlighted the fact that sign language needed to be promoted as a language and a means of communication. The juror stressed that it was an important means of communication

[4] Please note this report uses the term ‘decision-making capability’ rather than ‘decision-making capacity’ so as not to confuse the distinctions made above in relation to mental versus legal capacity.

for much of the population including many people with mental health problems and, in particular, children with autism.

The need for the use of clear and simple language by mental health professionals was highlighted on many occasions over the four days. It was emphasised that such language must be used at all stages of interaction. The use of plain and clearly explained language in particular, at the time of assessment and in relation to treatments including medication, was emphasised.

Best interests versus will and preferences

There was much discussion around the concept of best interests. Discussion included – What are best interests? Whose best interests are being considered? How are such best interests being considered? What factors are taken into account in determining best interests and who determines such best interests? During the discussion, a number of jurors stressed the point that what constitutes best interests is a matter of perception. The majority of jurors were opposed to the idea of another person deciding someone's best interests.

The general consensus was that the best interests approach was overly paternalistic and subjective and should be replaced by a consideration of the will and preferences of the person. The jury felt that it was imperative the will and preferences approach should be enshrined in the new legislation. In establishing a person's will and preferences, there was discussion around the importance of advance directives.[5] The jurors thought that advance directives could play an important role in deciding how people are treated when they are deemed to lack decision-making capacity. A recurring idea was the need for an independent advocate. One of the jurors raised the point that a person may be coerced into having different wishes in different circumstances and that this vulnerability should be taken into account.

[5] An advance directive is a statement about the type and extent of medical or surgical treatment you want in the future, in the event that you are not able to make that decision at the relevant time. In some countries, there is legislation which provides for the recognition and enforcement of such directives and in some cases provides for the way in which they should be made. There is currently no such legislation in Ireland.

Decision-making

Decision-making in relation to mental health was a common theme throughout the four days. The discussion centred on when and how decisions are made and what happens when a person is deemed to lack the ability to make decisions. The participants agreed that decision-making should be supported and not substituted. Some felt that adequate supports were not in place and that it was important that various supports should be named and provided in law. Some of the group said there is a need for an independent support or advocate that is separate from family and from health professionals.

There was a divergence of opinion in respect of the fundamental concept of decisions being made, in any form, on behalf of someone else. Some jurors felt that any decision they made, including the decision to self-harm or to attempt suicide, should be respected. Others felt that this was not the case and that where there was a risk or danger to themselves or others it was reasonable that decisions were made on their behalf. To this end some members of the jury felt that they could depend on family to make decisions on their behalf while others felt that it was preferable to have an independent advocate to represent them.

Assessments

The issue of assessments was explored and debated in depth over the four days. How, when and by whom assessments should be conducted was discussed among the participants.

All participants were of the opinion that a major weakness of the current system lies in the fact that the power of assessing decision-making capability lies with a psychiatrist. There was common consensus that a full multi-disciplinary team was needed to make an assessment and that assessments must be conducted on a case by case basis, and should be time, place and issue specific. Furthermore, the need to have standardised assessments, with clear criteria in respect to admission, treatment and the administration of electro-convulsive shock therapy [ECT], was emphasised.

The role of psychiatrists in assessments was discussed at length. Some jurors felt they should have no role whatsoever in the assessments, others felt that a psychiatrist that was truly independent from the treating psychiatrist should have an input [but not a lead role] while others felt that it was acceptable to have the leading psychiatrist involved as part of a multi-disciplinary team.

The jurors discussed the lack of support given to them when it came to assessments and the importance of having an independent advocate was emphasised by some participants. It was felt that advocates should be well resourced, independent and accountable.

Some participants thought that an independent support team, comprised of parties chosen by the individual, should be put in place prior to the assessment. There was agreement that assessments should be subject to regular independent review with one member of the jury suggesting a time frame of 48-72 hours for each re-assessment, while another suggested a two-week period.

The importance of conducting an assessment in language and a format the individual could understand was emphasised. The ability to challenge and dispute an assessment was raised during this discussion as an important issue.

Risk and dangerousness

Another element discussed was the assessment of the ‘risk and dangerousness’ of the treatments that may be administered. One of the jurors thought that treatment risk should be outlined and any possible harm or potential damage to the personhood of the individual caused by the treatment decision of the treating psychiatrist should be included.

The risk of mis-diagnosis was also mentioned as something that should be considered when carrying out assessments of risk and dangerousness.

Some of the jurors felt that a legal mechanism should be in place with regard to assessments. Participants felt that risk assessments must be based on a strong body of evidence and be subject to legal safeguards.

A more focused discussion took place on whether there should be legislation providing for the detention or treatment of people against their will if they pose a risk to themselves or others. There was some confusion about how involuntary detention is currently governed by the Mental Health Act. However some jurors felt there should never be treatment or detention without the consent of the person. Others felt it was appropriate to detain or treat someone against their will where such a real threat existed, and that capacity legislation should provide for such situations. Some members of the jury felt risk and danger are issues that concern the general population and should not be covered by the capacity legislation or mental health law, but by criminal law, as they are no more prevalent in mental health patients than in the population at large.

Medication and treatment

The issue of medication and alternative treatments was broached at various stages throughout the citizens' jury. Where it was deemed necessary to prescribe medication the jurors felt the nature, reason and side effects should be fully explained to the person and that they should then be allowed to make fully informed choices about whether or not to take medication. The importance of being given 'time and room' to consider the option of treatments and medication was mentioned by some of the jury.

When discussing the issue of medication the role of the pharmaceutical industry was mentioned on a number of occasions. One member of the jury recommended there should be a legal safeguard in place banning pharmaceutical companies from offering incentives based on the amount of prescriptions. The administration of certain treatments can impair or even worsen an individual's capacity and because of this it is essential the person is given full and impartial information regarding possible side-effects of any treatment by the treating psychiatrist. The group also discussed the importance of mental health practitioners being aware that telling patients they will be on a specific treatment or have a particular diagnosis for life can be devastating for people. Hope is crucial to recovery.

The over-reliance on the bio-medical model approach to mental health was discussed. One juror argued that psychiatry is an inexact science.

The jury spoke about the difficulty around making a mental health diagnosis. Participants made the point that a diagnosis may be inaccurate and medication may not always be the most appropriate course of treatment. Jurors felt it was essential that alternatives to medication should be offered to the individual and fully explained in language that a person understands.

The importance of having adequate individual care plans in place including a plan for after care and a plan for the event of relapse was also discussed. It was suggested that these care plans should be formulated by multi-disciplinary teams under the lead of the individual [the patient] concerned. In addition it is very important to include strengths-based assessments, rather than the present deficit only approach.

The more general discussion of treatment concerned the right to refuse treatment, with the right to refuse ECT being specifically raised on a number of occasions. There was a divergence of opinion on whether isolated incidents should consign patients to certain treatment. Some participants felt that ECT should never be forcibly administered.

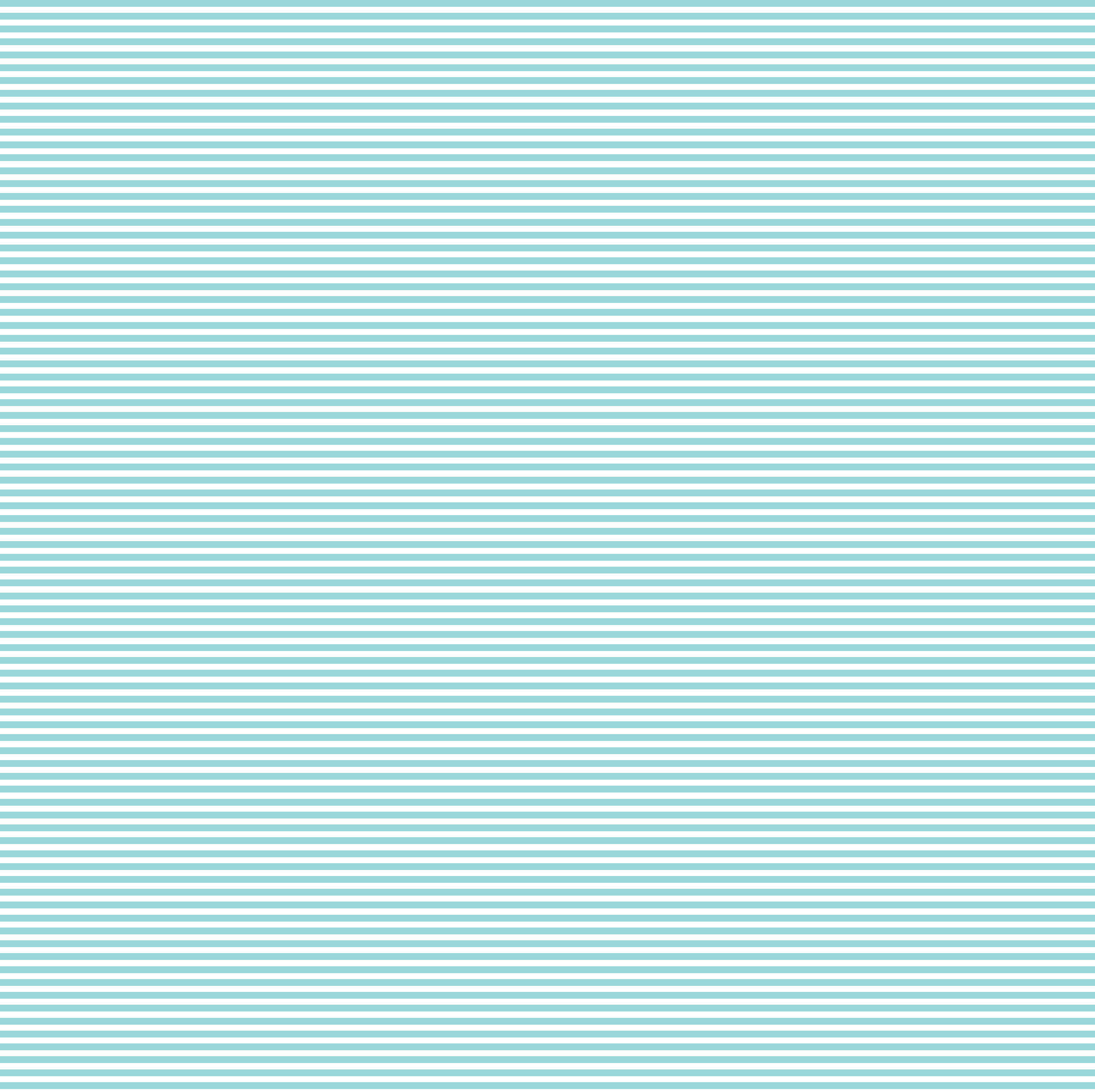
The importance of being offered alternatives to medication arose again and again over the course of the four days. The importance of communication and the use of clear language when it came to explaining the different types of treatments and their side effects were also stressed throughout the citizens' jury.

Power imbalance

The existence of a power imbalance between a person with a mental health problem and a mental health professional was discussed at length over the four days. Some members of the jury felt that power relations are entirely weighted in favour of psychiatrists. One juror commented that the power ultimately rested with pharmaceutical companies who could influence psychiatrists.

The importance of treating each individual as an equal and with dignity and respect at all times was emphasised. It was felt legislation could and should address this power imbalance and take into account the disparity between the individual and the medical professional in relation to education, expertise and communication skills and abilities.

Safeguards such as advance directives, independent advocacy, supported decision-making and other best practice supports should be used to ensure that the rights of the person have precedence over the opinions of health professionals.



> **“**
>
> **Above all, a person centred and recovery based practice needs to be brought centre stage.**
>
> **”**

The charge is at the heart of a citizens' jury and defines the scope and outcome of the project. It consists of the questions relating to the key issue of the jury (capacity law) and requires jurors to use the discussions and testimonies of the expert witnesses to make recommendations for the final report. The charge questions were developed after the first three days of discussion in order to best capture the key themes that had emerged. The charge presented to the citizens' jury by the AI team on legal capacity consisted of three questions that covered the issues that had been explored over the course of the jury process.

The method chosen to discuss the charge questions and to make recommendations based on the charge was to divide the participants into three subgroups. Different subgroups were chosen for each charge question. The subgroups were asked to prepare an opening statement, to make recommendations and to explain how they arrived at the recommendations.

All the recommendations from the three groups were then pooled together and grouped under common headings. All participants were requested to vote for the recommendations they felt were the most important around each question.

Although there was sometimes a divergence of opinions and ideas within and between groups, these recommendations were agreed upon within the groups.

All the jurors have agreed that these are the most important recommendations to come from their discussions and must be taken into account by those writing the new capacity legislation.

1 Charge question

How should assessments be conducted when there is an issue with decision-making in relation to mental health?

Opening statement[6]

Everybody must be presumed to have the capacity to make his or her own decisions at all times until clearly proven otherwise. Assessments should be a collective decision, involving a range of expert opinions including, for example, an advocate, legal representative, professional health person chosen by the individual, all on equal terms. They should be time and issue-specific, and subject to independent, regular review. If a decision is made that a person lacks decision-making capability, any subsequent treatment decisions must take into account the will and preferences (including, for example, advance directives) of the individual concerned, recognising people experience fluctuations in their decision-making capability.

- There should be a comprehensive, standardised, multi-disciplinary team approach to assessments. There was a divergence of opinion as to who should take the lead in carrying out assessments. Some felt that it was appropriate for a psychiatrist to take the lead, others thought that a lawyer or legal advocate or representative would be more appropriate. Some recommended there should be a mandatory independent advocate and the option of legal, family/friends, or other supports to facilitate communication with the person. One group stated there needed to be an independent support team in place prior to the initial assessment, chosen by the individual

---

[6] The opening statements are an amalgamation of the three individual subgroup statements.

(comprising a psychologist, legal support and advocate) and that the initial assessment should not be completed by the treating psychiatrist.

- The assessment must be person-centred. The communication tools used must be clearly understood by the individual. Advance directives, made when a person has full decision-making capacity, must be taken into account, so that the person's will and preferences are adhered to. The individual must have an opportunity to question assessments.
- The individual must be able to access decision-making support. Necessary supports must be offered and made available and clear language must be used.
- Assessment must be time, place and issue specific, it should apply for the shortest time possible (i.e., only cover a particular decision at a particular point in time) and subject to independent review.
- Safeguards and regular checks need to be in place in relation to assessments. The approach to assessments must be standardised and the criteria for assessments in relation to admission, treatment (e.g. ECT) and medication, must be clear.

2 Charge question

How should the law deal with the issue of risk and dangerousness?

Opening statement

The assessment of ‘risk and dangerousness’ must be formally set out, be multi-disciplinary, be regularly reviewed and include an assessment of any treatment risk (e.g. harm caused by the treatment itself and damaged personhood of the individual). Currently the default position is that if you have a mental health problem it is assumed you will be more likely to be a ‘risk’ and ‘dangerous’. In fact, people with mental health difficulties are no more dangerous or at risk than the general population. Those assessing should also consider the risks of mis-diagnosis. The law should be used only when a criminal offence takes place.

- Risk management must be based on proper assessment; clear definitions are required. There must be clearly articulated reasons for the risk and evidence based assessment of ‘risk and dangerousness’. Legally binding safeguards and formalised risk assessment tools are needed. It is recommended that such assessments should be subject to regular review (every 48-72 hours was suggested).
- There should be a right to challenge an assessment. The person should have access to an independent route to appeal the decision related to their assessment that they are a risk or dangerous. Some participants felt the same burden of proof as applies in a legal context should be used. There should be due process when proving risk of dangerousness to others. There was, however, a divergence of opinion on this point.
- Decisions about risk should take into consideration a range of opinions. The decision as to whether the person poses a risk to him or herself or to others should be group-based i.e., include a range of opinions including the individual, the multi-disciplinary

team, peer support and, where appropriate, family/friends. It should be made with the person involved in the process [for example the open dialogue approach in Finland which involves all stakeholders] and approached on a case-by-case basis with as much background information as possible. It is important that it is not just a psychiatrist that has the authority.

- Some jurors felt risk and danger are issues that concern the general population and should not be covered by the capacity legislation at all but by criminal law, as they are no more prevalent in mental health patients. There was a divergence of opinion as to whether isolated incidents of harm to yourself or others should consign the patient to certain treatment.

3 Charge question[7]

In relation to decision-making and mental health, how should the law consider the issues of:

- The power imbalance between the person with a mental health problem and the medical professional
- The issue of medication

Opening statement

The individual should be treated as equal and afforded dignity and respect at all times. The law needs to take into consideration the present power relations which are entirely weighted in favour of psychiatrists. The majority of the jury believed that alternatives to medication should always be offered. If medication is prescribed, the nature, reason and side effects should be explained so the person may make a choice. The law must use safeguards such as advance directives, independent advocacy, supported decision-making and any other best practice supports available to ensure that the rights of the person have precedence.

The power imbalance

- Treatment must be person centred. Plain language should be used in discussion with the person. The person should have the support of an advocate if needed. Individual care plans should be developed by a multi-disciplinary team and with the full involvement of the person concerned.
- The individual should be allowed time and space to make decisions. There should be a plan devised for aftercare and for the possibility of relapse. Some members of the jury felt that the ultimate decision should not be made by a clinician but by the individuals themselves.
- There should be a formal reporting system in place that includes details of how and why a particular diagnosis has been arrived at and treatment recommendations/options.

---

[7] Although not directly related to capacity law, the issues of power imbalance and medication are inextricably linked by the actual practice of making capacity decisions and administering treatment. These issues were extremely important for the jurors and must be taken into account by lawmakers.

- The decision to detain and the decision to treat are two separate decisions. They should be dealt with separately.
- There should be awareness raising about medication, the risks and side-effects, before the psychiatrist prescribes the medication.

Medication

- Individuals should be offered alternatives to medication.[8] There has to be choice for treatment and a right to refuse treatment. It was recommended that all alternative therapies and treatments should be explored and fully explained prior to medication. Medication use should be based on personal choice following the provision of balanced up-to-date information concerning the potential risks and side effects to health and well-being. The administration of medication needs to be 'as needed' with review of the length of treatment and efficiency.
- There should be supports in place for coming off medication.
- There should be a ban on pharmaceutical companies offering incentives to prescribing doctors. The jury expressed concern regarding the influence of pharmaceutical companies.
- There must be safeguards in relation to how medication is administered. Suggestions in relation to such safeguards included that the reporting of harm caused by the treatment should be placed on a statutory footing, an independent complaints mechanism should be in place and chemical restraint should be distinguished from treatment and respected accordingly.

The group was divided on the issue of ECT with some participants feeling that it should never be administered. There was consensus on the right to say no to ECT.

8
The majority (14 of the 17 jurors) considered this to be the highest priority recommendation

“

My hope is that recommendations made by the jury are taken on board by the legislators.

”

A key part of the citizens' jury process was to collect personal statements that sum up the individual experiences of the process and what they hope it will achieve. Below is an abridged selection of personal responses from the jurors.

- We have the opportunity to create a future where rights, equality and justice are realised. Mental health law and capacity legislation must reflect such a vision for a fairer future and uphold our commitment to progressing human rights for all people, irrespective of difference in Ireland and internationally. I hope we get it right.
- My hope is that the capacity legislation will incorporate the principle that people with mental health problems or intellectual disabilities enjoy legal capacity on an equal basis. Existing legislation, even with the reforms proposed to date, do not protect my human rights and this is very frightening. Safeguards to ensure the principle is translated into practice need to be put in place and the notion of "in his or her best interests" removed from proposed law, and respect given to the rights, will and preferences of the person in accordance with the UN Convention on the Rights of Persons with Disabilities.
- It was nice to be asked to come to Amnesty International and to consider my personal views on the law and mental health. Being asked was an opportunity not always afforded to the ordinary "man or woman in the streets", that was not just nice and good, but was also a privilege.
- This was a great opportunity to affect change in the law and also to affect change in the lives of a vulnerable group in our society. It is not often we can do this, maybe once in a lifetime. Under the auspices of Amnesty International that community came together, expressed themselves and took control of their lives.
- The citizens' jury was brilliant. Hard focused work. Good fellowship. Addressing vital issues on a collaborative basis.

- Psychiatry is not an exact science. How it is practised is not even scientific. Its power to do good is counterbalanced by its power to do harm. It makes mistakes and when these occur it is practically impossible to have these mistakes reversed. Judicial oversight must change from a position of deference to assumed benign paternalism, to one of subjecting it to the full rigour of the law. Transparency and accountability levels in this profession must be improved on many levels – from diagnostic standards, to risk assessments, to including treatment risks in weighing up treatment decisions. And, of course, to providing choices and alternatives to the unproven biomedical model. Above all, person centred and recovery based practice needs to be brought centre stage. Anything that reduces the power imbalances that currently exist should be supported. Capacity legislation should assist in this regard.
- I enjoyed the experience of participating in the citizens' jury on mental health and capacity. I feel that it is an important, topical area of discussion at present and coincides well with the legislative review, which is ongoing. Each of the sessions allowed for reflection, discussion and deliberation on areas such as assessment and risk. These are intrinsic and important factors in the psychiatric process and require our full attention in any review of capacity legislation. This group is the voice, often unheard, within our mental health services! The emphasis needs to be redirected back to the service user incorporating the recommendations of the group.
- Thank you Amnesty for giving a voice to service users on the issues that directly affect us. I think that any positive changes in the Mental Health Act would be welcome and I feel as though I had a part to play.
  A positive, empowering four days of action research; engaging with others, ideals and wish lists to formulate recommendations for positive, empowering change.

- I thought the last four days were very useful. I learned a lot about capacity legislation that I did not know about. I think it was very good to have people from a wide variety of backgrounds to give their opinions and the one theme I got from the last few days was that everybody on the jury had the best interest of the service user being the most important core of the new capacity bill.
- An equal and dignified law for all people. Taking all human rights into consideration, empowering people to feel whole and integrated at every level of society. Respecting individual choice and always remembering that personal choice brings freedom and peace of mind.
- "Nothing about us without us!" is the motto of people with 'disabilities' who empower themselves to advocate for fair, adequate and appropriate services that are supporting each individual on their journey of recovery in a beneficial manner. Adopting such an active role requires awareness and actions: people educating themselves, taking responsibility for promoting wellness and speaking up and out on their own behalf. A further step is exchanging experiences with other people in similar situations and advocating for those who are not (yet) in a position to walk this road, and supporting them when they set out on their own journey, thereby replicating the process and confounding their own position and maintenance of wellness. Taking part in the citizens' jury reflects my own personal development.
- The process of being involved in a citizens' jury charged with making recommendations on the new capacity legislation has been an empowering process. My hope is that recommendations made by the jury are taken on board by the legislators. I need protection from the State to make decisions, I may need supports such as my will and preference taken into account and having legal standing. I should be treated as an equal before the law. I should have the choice of alternatives to medication and hospitalisation. I should have a nurturing place in which I can recover.

- Participating in this citizens' jury has proven to be a fantastic opportunity for me to empathise with and gain knowledge of the lived experiences of people who use mental health services. My aim as a health professional is to provide people with a high quality, person centred and holistic service. I feel that this is what is lacking in our mental health services; the ability to empathise and place oneself in another's shoes. Being a part of this jury has allowed me to understand issues I would have previously lacked insight in. I will carry all I have learned from this inspiring, knowledgeable and positive group of people forward both into my professional and personal life, with the aim of having a positive impact on others.

Appendices

a Citizens' jury background 52
b The process of a citizens' jury 54
c How the citizens' jury worked 54
d The case studies summary 56
e Outline of article 12 CRPD 61
f Outline of Scheme of the Mental Capacity Bill 2008 62

a Citizens’ jury background

A citizens’ jury consists of a small panel of non-specialists, modelled on the structure of a criminal jury. In an independent setting, the ‘jury’ examines an issue of public significance and on the final day delivers a ‘verdict’ based on a charge.

The concept of a citizens’ jury was developed in the 1970s simultaneously by Ned Crosby, founder of the Jefferson Centre, a non-profit organisation in the United States and by Peter Dienel who came up with a similar concept of “Planning Cells” in Germany.

Two examples of a citizens’ jury in action

1 In spring 2000, the Scottish Executive commissioned pilot citizens’ (or people’s) juries and ‘stakeholder’ juries in two area-based social inclusion partnerships in Scotland. This was part of a programme attempting to ‘encourage community capacity-building and a further shift in culture among public sector bodies to more effective community involvement in decision making’.

2 The former Secretary of State for Trade and Industry and Minister for Women in the UK, Patricia Hewitt, wanted to commission a citizens’ jury to help to develop policies that will support people juggling family and work commitments. Sixteen jurors, broadly representative of the wider population, were recruited. Jurors had some scepticism about whether the jury would influence Government policy. However, its influence was evident in elements of the Chancellor’s pre-budget speech at the end of 2004 – the proposed increase in maternity pay was in keeping with the thrust of the jurors’ recommendations

A citizens' jury provides people with an opportunity to learn about an issue, deliberate together and develop common ground solutions to the issue. It assists decision-makers and legislators in acquiring both a comprehensive understanding of what public opinion might be on an issue, and realistic solutions to the issue and to any problems it poses, based on the recommendations made by informed members of the public. Furthermore the results and recommendations of the jurors can be used to generate wider public debate about the issues.

It is a deliberative and participatory process and the jury is given information from a number of different sources about the issue for discussion. The jurors work in a variety of formats, including plenary sessions, group discussions, and paired and individual work to ensure that everyone has the opportunity to contribute to the process in a meaningful way. The facilitators can provide general information on the issue and information is also presented by 'witnesses', who are often experts in the field, offering the jury a variety of opinions on the issue. Question and answer sessions and group discussions with the witnesses and jurors are used to develop and deepen discussion.

It is a four-day process, with day one spent bringing jurors up to speed on the issue at hand; days two and three exploring the issue in more detail, with a focus on the participation of witnesses; and most of the fourth day dedicated to deliberating the charge and developing recommendations.

Juries do not necessarily have to work towards agreement, but there is usually a movement towards some sort of shared opinion. The aim is not to achieve unanimous agreement but to discuss the issue and arrive at recommendations.

There are of course shortcomings with such a project, most notably in relation to representation and time. There are a limited number of participants and therefore the process may not address all opinions and perspectives of the wider public. Another drawback is that there is a limited amount of time to discuss and explore the depth and complexity of the issue.

b The process of the citizens' jury

This citizens' jury focused on the issue of mental health and legal capacity.

Information about the citizens' jury was circulated to a selection of mental health support services[9] and potential jurors were invited to put their names forward. The jury comprised 12 women and seven men. Of the participants, 16 were or still are using mental health services, while three work in the area of mental health.

AI staff acted as facilitators. The recommendations arrived at were solely the result of the opinions and work of the jurors.

Over the four days, the citizens' jury examined the themes of decision-making, assessments, and risk and dangerousness in relation to legal capacity and mental health.

c How the citizens' jury worked

On the first day the participants were given an overview of the workings and process of a citizens' jury. The participants outlined their hopes, expectations and fears of the project and drafted a group contract. Information concerning legislation, including Article 12 of the CRPD, the 2008 Heads of Bill on 'mental capacity' and the 1871 Lunacy Act, was presented to and discussed by the jury. This information gave context and understanding to some of the issues that the legal capacity legalisation may cover. The issue of decision-making in relation to mental health was also examined.

On the second day the issue of assessments in relation to mental health was explored through group discussion, the examination of case studies and the input of expert witnesses. The case studies were based on real examples. Questions concerning when assessments are made, who makes assessments and how the process of assessment should be altered were explored. The expert witnesses who participated were Dr Siobhán McHale, a consultant in liaison psychiatrist in Beaumont Hospital, who examined case study one, Kara Madden, the mother of

---

[9] These organisations included the Irish Advocacy Network, Shine, Mental Health Ireland, Grow, EVE Ltd, Gateway Project, Áras Folláin, Suicide or Survive and through AI's EEAG.

an expert by experience, who offered her view on case study two and Jim Walsh, a member of the Irish Advocacy Network and a mental health academic, who spoke about the third case study. The expert witnesses provided their opinions on the case studies and took part in a question and answer session with the jurors.

The third day focused on when risk and dangerousness become issues in the context of mental health. The morning session involved an examination of case studies by the jurors who were initially divided into three discussion groups and then regrouped to provide feedback to the whole jury. In the afternoon expert witnesses provided their comments on the case studies. Dr Mary Keys, a mental health and human rights academic from NUI Galway and current member of the Mental Health Commission examined case study one; Dr Pat Devitt, the Inspector of Mental Health Services looked at the second case study and Áine Hynes, who is a partner of St. Johns Solicitors and Chair of the Irish Mental Health Lawyers Association, gave her opinion on the third case study.

The jury then debated the motion "There should always be mental health law to detain or treat people against their will if people pose a risk to themselves or other people." This concluded in a plenary session and input from the expert witnesses who participated in the group discussion.

The fourth day consisted of a brief overview and recap of the previous three days. Participants were given time for individual reflection and asked to reflect on the themes of decision-making in relation to mental health, assessments and risk and dangerousness and to provide one recommendation relating to each of the three areas. Jurors were asked to identify strengths, weaknesses, opportunities and threats in relation to the 2008 Heads of Bill and recent political statements from the Government on what the law will cover.

Each day ended with a brief wrap-up session and evaluation of the day.

d The case studies summary

Case Study 1
Saturday 9 June

Charlie is an involuntary patient in a mental health hospital in Dublin. He has been diagnosed as a “chronic paranoid schizophrenic”. In May 2012 he was found to be suffering from an ulcerated foot, which had become gangrenous (severely infected) and was transferred to a general hospital. A surgeon advised Charlie that if his leg was not amputated from below the knee his chance of survival was small.

But Charlie would only agree to limited treatment and not full amputation. However, the hospital considers that Charlie does not have capacity to refuse treatment. Therefore, the hospital will not promise Charlie that they would not amputate his leg some time in the future, even if he doesn’t agree.

Charlie instructs his solicitor to get an injunction (a court order) preventing the amputation of his leg without his written consent. In his evidence to the court Charlie said that he refused his consent to amputation because he would “rather die with two feet than live with one”. He expressed delusions of having an international career in medicine during the course of which he had never lost a patient. He also expressed his complete confidence in his ability to survive his present trials aided by God, the good doctors and the good nurses.

Case Study 2
Saturday 9 June

Joan is a 36-year-old woman who on a number of occasions during the last 18 years has been admitted to her local mental health hospital for treatment for a diagnosis of schizophrenia. Some of her admissions have been voluntary and in recent years she has been detained as an involuntary patient under the Mental Health Act 2001. Joan is rarely willing to accept treatment or advice from mental health professionals. She responds quickly to anti-psychotic medication when involuntarily administered and her psychiatrist reports that she becomes “calm, cheerful and friendly to others on medication, with minimal residual delusions and hallucinations”.

Occupational therapy assessment shows enduring impairments of her ability to organise her routines and activities of daily living and she cannot consistently budget. Psychiatric assessments have said “even at her best she never gains insight and does not believe that she has a mental illness or benefits from medication”.

Joan has been recently discharged from detention under the Mental Health Act 2001. She has been offered accommodation in a high support hostel but refuses to live there. She discontinues medication after her discharge and chooses to live rough to avoid secret agents and tormenters. Joan has alienated friends, family and neighbours.

Joan’s sister, Mary, is worried about her as she is very undernourished and living in an unhygienic state due to self-neglect, with tormenting delusions and hallucinations. Mary feels Joan lacks the capacity to make decisions about her welfare, medical treatment including psychiatric treatment and her financial affairs. She wants to make decisions for Joan in her best interests and hopes that the new legal capacity legislation will allow her to do this. Joan wants to make her own decisions and does not like Mary interfering in her life.

Case Study 3
Saturday 9 June

Larry is a 49-year-old man with a diagnosis of autism who subsequently developed mental health problems. He is considered incapable of consenting to medical treatment. He lived as an inpatient at a hospital for more than 30 years. In 2009 he went to live with social care paid carers, although the hospital remained responsible for his care and treatment. In March 2012 after becoming agitated at a day centre [banging his head off a wall and punching himself] he was taken back to hospital where a consultant psychiatrist decided he required inpatient treatment for a “mood disorder”.

Larry was compliant so his doctor decided that he should be admitted as a voluntary patient. He is not formally detained as an involuntary patient under the Mental Health Act 2001 meaning that a tribunal does not have to review his detention. If Larry resisted his detention or tried to leave the hospital it is likely he would be involuntarily detained under the 2001 Act.

Larry's carers are advised to stay away for a few days so that Larry can improve and benefit from the treatment of his mood disorder. Larry's doctors then consider that it is in his best interest to stay in the hospital long-term and not to live with his carers any more.

His carers want Larry to come back to live with them and they feel he would prefer this than living in the hospital. They began legal proceedings against the hospital as they feel as they feel he is being detained and treated without any oversight of his detention and his wishes are not being considered by the hospital.

Case Study 1
Sunday 10 June

Melanie was born in 1981. In 2000, she was diagnosed as "suffering from depression" and received treatment. She subsequently experienced "intermittent episodes of anxiety" and had contact with mental health services. On 4 March 2005, she tried to end her life by tying a pillowcase round her neck. Her general practitioner admitted her to hospital following an emergency referral. On 7 March 2005, she was diagnosed by a consultant psychiatrist, as suffering from a severe episode of a recurrent depressive disorder. On 18 March, she was assessed as having made a sufficient recovery to be discharged and she went on holiday for a week with her family to Egypt.

On 31 March, she cut both of her wrists with broken glass and her consultant psychiatrist advised that she should be readmitted to the hospital. On 11 April, she tied lamp flex round her neck and was assessed by the doctor who considered that she was experiencing psychosis and was at a high risk of deliberate self-harm and suicide. Melanie agreed to a voluntary admission to the hospital and the doctor noted that, if she attempted or demanded to leave, she should be assessed for detention under the Mental Health Act.

She was prescribed a course of drugs and kept under 15 minute observations. A ward nurse assessed that Melanie posed a moderate to high risk of ending her life. On 18 April Melanie's father expressed concern that Melanie's health was not improving and reported that she continued to have momentary suicidal thoughts since her admission and had asked her parents to "get her out" of the hospital. On 19 April Melanie met with her consultant psychiatrist and requested that she leave. Her parents expressed concern at her discharge to come home. The consultant psychiatrist agreed that Melanie could return home for two days and two nights.

Melanie left the ward that day and she spent most of the following day with her mother. In the late afternoon of 19 April Melanie said she was going to see a friend. Some time after 5pm she hanged herself from a tree in a park near her home.

Case Study 2
Sunday 10 June

Mary was born in 1962. She is an involuntary patient in a forensic mental health hospital and is detained under the Mental Health Act 2001. She was transferred to the hospital four years ago "suffering from serious psychiatric complaints which caused her to be a source of danger and risk, not only to herself, but also to others". Mary's primary diagnosis is that she "suffers from paranoid schizophrenia and a borderline personality disorder". Her doctors describe her condition as being "particularly severe". It is associated with the risk of extreme violence to others, including children.

Mary has "homicidal preoccupations arising from persecutory delusions and hallucinations. Unfortunately, these focus particularly on children in general, and sometimes, in particular, on the children of those who come into contact with her." Her psychiatrist states that she loses insight and lacks the capacity to give or withhold consent to treatment. In order to treat her schizophrenia with anti-psychotic medication it is necessary for her doctors to continuously monitor her. This involves obtaining a full blood count at regular intervals to prevent against a fatal risk of a sudden drop in white blood cell count. Mary refuses the treatment and refuses to allow blood samples to be taken to monitor her white blood cell count.

Mary is treated involuntarily and the anti-psychotic drug is administered even when she protests and resists. When Mary resists giving a blood sample she is restrained by nursing staff and her arm is secured in a form of physical restraint and the blood samples are taken. When she struggles the doctor attempting to collect the blood from a single vein may not be able to obtain the sample and she may require sedation. The risks associated with drawing a blood sample from Mary include potential bruising and laceration, along with a low level of pain. There is also the risk of third party injury to medical or nursing staff by her violent reaction that could result from needle stick injuries.

Case Study 3
Sunday 10 June

On 26 August 2011 Peter became a voluntary patient at a mental health hospital following a “psychotic episode at home”. His father and a family friend accompanied him to the hospital. He was seen to display “aggressive, violent and at times inappropriate behaviour”. His admission notes from 26 August indicated that he was confused and expressed a desire to leave. Peter accepted medication once admitted to the hospital. The following day he was examined by a consultant psychiatrist, and a care plan was developed that involved close observation and a continuation of medication, and he consented also to histories being taken from family members and his general practitioner.

He remained a voluntary patient and continued to be treated as such until the 13 September 2011, when he expressed a desire to leave the hospital at which point his doctor who used powers under the Mental Health Act 2001 that prevents voluntary patients leaving the hospital. Peter was subsequently detained involuntarily under the

Mental Health Act. When Peter came before the tribunal for a second time on 11 October he indicated that he did not want to be in hospital, but then indicated that he would stay on a voluntary basis for a couple of days, and indicated that he would not take his medication if he left the hospital. He denied that he had a mental illness and denied any difficulties with his family. The tribunal gave an order renewing his involuntary detention.

The consultant psychiatrist having expressed his opinions to the tribunal on 11 October that Peter required involuntary detention revoked the renewal order the following day deciding that he no longer suffered from a 'mental disorder' as defined in the Act. The applicant was not invited or allowed to leave the hospital and remained in a locked ward and even though then a 'voluntary patient' was not free to leave. He subsequently expressed on a number of occasions an intention to leave, but was not permitted to do so, and no order to detain him under the Mental Health Act was made and his detention was not reviewed by a tribunal as he was considered a voluntary patient.

e Outline of article 12 of the CRPD

Background

In 2008 the United Nations adopted a new Convention on the Rights of Persons with Disabilities. People with mental health problems were involved in negotiating this treaty and it says that it is not the person who has a disability but society that disables people through barriers and denial of rights. Countries are asked to sign up to and ratify (agree to respect) human rights Conventions. The Fine Gael/ Labour Government has said they want the law to be in line with what the Convention says, specifically Article 12 on equal recognition before the law (legal capacity).

The law
Article 12 says

1 States reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

2 States shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

3 States shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

4 States shall provide appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards should ensure respect for the rights, will and preferences of the person. The safeguards should be free of conflict of interest and undue influence. They should be proportional and tailored to the person's circumstances. They should apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body.

5 States shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

f Outline of Scheme of the Mental Capacity Bill 2008

Background

In September 2008 the last Government published an outline, or scheme, of new law to repeal the 1871 Lunacy Act. The Government said the aim of the law is to "modernise the approach to capacity". It aimed to deal with situations when people could not make decisions themselves.

The law

The Bill had a number of different aspects

- Everyone should be presumed to have capacity unless it is proven otherwise.
- It defined capacity as the ability to understand the information relevant to the decision, to retain that information and to use or weigh that information.

  It said that a person’s past and present wishes should be considered but it also said a decision could be taken in someone’s ‘best interests’. It did not set out how a person would be supported. The Scheme was not clear on how it would work with the 2001 Mental Health Act. The bill proposed a new system from the Wards of Court. It said that:

  - The courts would decide if you can make decisions.
  - A psychiatrist would help to assess capacity.
  - The court can appoint a guardian to make a decision for someone. It proposed establishing an Office of Public Guardianship to “promote public confidence in the process of dealing with persons who lack capacity”. It said people could appoint a third party to make decisions for them if they are unable to make decisions for themselves - this is called an Enduring Power of Attorney.

AMNESTY
INTERNATIONAL