Visit of UNCRPD Delegation from Japan

19th May 2015
Office of the Public Advocate
Outline

• UNCRPD Guiding legislation and strategy
• Supported Decision Making
• Capacity in legislation
Definition of Disability

(e) Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others,
Article 12 Equal recognition before the law

Persons with disabilities have the right to recognition as persons before the law.

Persons with disabilities enjoy legal capacity on equal basis with others in all aspects of their lives.

**Persons with disabilities access the support they may require in exercising their legal capacity**

All measures that relate to the exercise of legal capacity are safeguarded to prevent abuse; they respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest possible time and are subject to regular review by a competent, independent and impartial authority or judicial body.
1. States Parties shall **take all appropriate legislative, administrative, social, educational and other measures** to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.

2. States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of **information and education on how to avoid, recognize and report instances of exploitation, violence and abuse**. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.
3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.

4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.

5. States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.
Equality and non-discrimination

Article 5

1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.

2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.

3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.

4. Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.
Convention Against Torture

- torture means any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for such purposes as obtaining from him or a third person information or a confession, punishing him for an act he or a third person has committed or is suspected of having committed, or intimidating or coercing him or a third person, or for any reason based on discrimination of any kind, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity. It does not include pain or suffering arising only from, inherent in or incidental to lawful sanctions.
Principle 1: The equal right to make decisions
All adults have an equal right to make decisions that affect their lives and to have those decisions respected.

Principle 2: Support
Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.

Principle 3: Will, preferences and rights
The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.

Principle 4: Safeguards
Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.
ALRC Support Guidelines

(1) General

(a) Persons who require decision-making support should be supported to participate in and contribute to all aspects of life.

(b) Persons who require decision-making support should be supported in making decisions.

(c) The role of persons who provide decision-making support should be acknowledged and respected—including family members, carers or other significant people chosen to provide support.

(d) Persons who require decision-making support may choose not to be supported.
(1) Supported decision-making

(a) In assisting a person who requires decision-making support to make decisions, a person chosen by them as supporter must:

   (i) support the person to express their will and preferences; and

   (ii) assist the person to develop their own decision-making ability.

(b) In communicating will and preferences, a person is entitled to:

   (i) communicate by any means that enable them to be understood; and

   (ii) have their cultural and linguistic circumstances recognised and respected.
(2) Representative decision-making

Where a representative is appointed to make decisions for a person who requires decision-making support:

(a) The person’s will and preferences must be given effect.

(b) Where the person’s current will and preferences cannot be determined, the representative must give effect to what the person would likely want, based on all the information available, including by consulting with family members, carers and other significant people in their life.

(c) If it is not possible to determine what the person would likely want, the representative must act to promote and uphold the person’s human rights and act in the way least restrictive of those rights.

(d) A representative may override the person’s will and preferences only where necessary to prevent harm.
Where is the real incapacity?

<table>
<thead>
<tr>
<th>Incapacity</th>
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<tr>
<td>Family incapacity</td>
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Capacity

- Presumption of capacity
- Capacity is decision specific
  - Understand the facts involved in the decision
  - Know the main choices that exist
  - Weigh up the consequences of the choices
  - Understand how the consequences affect them
  - Communicate their decision
Stepped Model

- Autonomous Decision Making
- Assisted Decision Making
- Supported Decision Making
- Substitute Decision Making

Arrows indicate the progression from Autonomy to External intervention.
Supported Decision Making

Steps

- Supported Decision Making by agreement
- Supported Decision Making by tribunal appointment
- Representational agreement
- Co-decision maker

Autonomy

External intervention
Metapreferences

Quality of Intuition

Least precise / explicit

Definition of concepts specification of relationships measurement of magnitudes

Most precise / explicit

Quality of Analysis

INTUITION

ANALYSIS
Fig. 3. Activations associated with risk anticipation (risky decisions minus safe decisions) are shown onto the mean anatomically standardized T1 image of all subjects.
| **Table 2** Framework to Facilitate SDM among Adults with Lower Literacy: Examples of Good Practice from the Decision Support Literature and Suggestions for Further Research |
|---|---|---|---|
| **Staged Framework for SDM** | **Required Skills and Competencies** | **Research among Lower Literacy Groups** | **Potential Areas for Future Research among Lower Literacy Groups** |
| Stage 1: Understanding the condition and the management | Interpret written or spoken medical terminology and make sense of condition and suggested therapy. | Guidelines for creating written health care materials for lower literacy groups. 23–24 Using visual illustrations to enhance understanding and recall. 25–29 Involvement of lower literacy consumers in the development of health care materials. 30 | Reducing analytic burden of information by using ordered formats with salient visual cues, making options explicit. 30 Use of narratives/anecdotes to enhance understanding. 31–33 Interpretation of visual illustrations in health communication. Enhancing vividness and evaluability of health information. Involvement of lower literacy groups in the development of patient decision aids. |
| Stage 2: Understanding the consequences: risks, limitations, benefits and uncertainties | Understand the likelihood of different risks and benefits—carry out basic calculations and interpret probabilities. Compare options against each other. | Natural frequency format better among adults with high numeracy, no effect among adults with low numeracy. 34 Better among obstetricians, not midwives or patients. 35 Use of a statistics primer increased lower and high education participants understanding medical risk information. 36 Different presentation formats impact cognitive and effective responses to risk information particularly among adults with lower numeracy. 37 | Frequency format better than probability format for communicating quantitative outcomes. 38 Use a consistent denominator, and a variety of formats. 39 Systematic ovals and bar charts found to be most effective graphical formats for communicating risk outcomes. 41,42 Identify optimum methods for communicating quantitative information to lower literacy and lower numeracy patients. Using theory-based methods of numeric processing to guide provision of numeric information to patients. |
| Stage 3: Identifying salient preferences and combining utilities with probabilities | Anticipate future health states (affective forecasting). Identify preferences for different outcomes. Combine with probabilistic information on chance of occurring. | Computer-based values clarification exercise using imagery and entertainment-education found 1) acceptable among lower literacy. multiethnic women with breast cancer. 43 and 2) reduced decisional conflict and increased self-advocacy among lower literacy men considering PSA testing. 44 | Use of decision analysis principles to combine personal preferences and probabilistic information shown to support SDM. 45,46 Develop best methods for clarifying values within decision support tools. Identify methods to help patients combine preferences with probabilities. |

(continued)
# Decision Making Disability

## Disability

<table>
<thead>
<tr>
<th>Disability</th>
<th>Supported Decision Making Response</th>
<th>Focus of intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>A person’s impairment</td>
<td>Decision making skills training</td>
<td>Person with a disability</td>
</tr>
<tr>
<td>Attitudinal Barriers of others</td>
<td>Equal recognition before the law.</td>
<td>Person with a disability</td>
</tr>
<tr>
<td></td>
<td>That will, preferences can be expressed.</td>
<td>Person with a disability Potential supporters</td>
</tr>
<tr>
<td></td>
<td>That decisions can be made.</td>
<td>Family and Friends</td>
</tr>
<tr>
<td></td>
<td>Increased autonomy can enhance personal safety.</td>
<td>Wider Community</td>
</tr>
<tr>
<td>Environmental Barriers</td>
<td>Reasonable accommodation to decision making Assistance and Support.</td>
<td>Family and friends</td>
</tr>
<tr>
<td></td>
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<td>Wider Community</td>
</tr>
<tr>
<td>INTERVENTION LEVEL</td>
<td>DESCRIPTION OF INTERVENTION</td>
<td>TARGET POPULATION</td>
</tr>
<tr>
<td>--------------------------</td>
<td>---------------------------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------</td>
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<tr>
<td>Primary Universal Interventions</td>
<td>Education</td>
<td>Entire Community</td>
</tr>
<tr>
<td></td>
<td>Stigma Reduction</td>
<td></td>
</tr>
<tr>
<td>Secondary Interventions</td>
<td>Provision of assistance</td>
<td>Disability sector — individualised funding facilitators</td>
</tr>
<tr>
<td></td>
<td>Engaging of a supporter on an ad hoc basis when required</td>
<td>Health sector</td>
</tr>
<tr>
<td></td>
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<td>Justice sector</td>
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<td>Financial sector</td>
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<tr>
<td>Tertiary Interventions</td>
<td>Facilitation of Supported Decision Making Agreements.</td>
<td>Specialist non-government providers.</td>
</tr>
<tr>
<td></td>
<td>Education &amp; training of those involved in secondary-level interventions.</td>
<td>Some specialist individualised funding facilitators may develop these skills.</td>
</tr>
</tbody>
</table>

Figure A12: A Population-based Model of Assisted and Supported Decision Making.
Supported Decision Making - Distinguishing features

• Not counselling or therapy
• Not a drug and alcohol intervention
• Not formal cognitive rehabilitation
• Not mentorship
• Is distinct from advocacy, although advocacy may be a component of the supporters role
Supported Person (Decision Maker)

The person receiving support needs to be able to:

Express a wish to receive support

Form a trusting relationship with another person(s) (supporter or monitor)

Indicate what decisions they may need support for

Indicate who they wish to receive support from for which decision

Express a wish to end support if that time comes

Be aware that they are making the final decision and not their supporter (take responsibility)
Supporter

The decision supporter needs to:

Respect and value the supported person’s autonomy and dignity

Know the supported person’s goals, values and life experiences

Respect the individual decision-making style of the supported person and recognise when and how support may be offered

Form a trusting relationship with the supported person

Be willing in the role of supporter, to fulfil their duty to the supported person, and not use this role as a way of advancing their own interests or any other person’s interests

Be able to spend as much time as is required to support a person make each decision

Assist in the expression of that decision to others if required
Monitor

• To be aware of all decisions made and how support is provided.
• To provide assistance to the supported person and supporter in undertaking the supported decision making process.
• To act as a resource for the other parties when a matter is difficult to resolve.
• To take necessary action if the monitor believes that the supported decision making agreement has broken down.
SA Trial (26 people)
Relationship with supporter

![Bar chart showing the relationship with supporter at the start and completion of the trial.](chart.png)
SA Trial (26 people)
Health decisions

- Medical tests
- Treatments
- Hospital
- Medication
- Weight
- Communication Technology
- Toileting
SA Trial (26 people) Accommodation Decisions Made
SA Trial (26 people)
Lifestyle Decisions Made
7—Impaired decision-making capacity

(1) For the purposes of this Act, a person will be taken to have impaired decision-making capacity in respect of a particular decision if—

(a) the person is not capable of—

(i) understanding any information that may be relevant to the decision (including information relating to the consequences of making a particular decision); or

(ii) retaining such information; or

(iii) using such information in the course of making the decision; or

(iv) communicating his or her decision in any manner; or
Impaired Decision Making Capacity

(2) For the purposes of this Act—

(a) a person will not be taken to be incapable of understanding information merely because the person is not able to understand matters of a technical or trivial nature; and

(b) a person will not be taken to be incapable of retaining information merely because the person can only retain the information for a limited time; and

(c) a person may fluctuate between having impaired decision-making capacity and full decision-making capacity; and

(d) a person's decision-making capacity will not be taken to be impaired merely because a decision made by the person results, or may result, in an adverse outcome for the person.
(c) a person is, in the absence of evidence or a law of the State to the contrary, to be presumed to have full decision-making capacity in respect of decisions about his or her health care, residential and accommodation arrangements and personal affairs;

(d) a person must be allowed to make their own decisions about their health care, residential and accommodation arrangements and personal affairs to the extent that they are able, and be supported to enable them to make such decisions for as long as they can;
Advance Directives

• Advance Care Directive
  – former Enduring Power of Guardianship
  – former Medical Power of Attorney
  – former Anticipatory Direction.

• Enduring Power of Attorney
Consent

- Person
- Advance Care Directive - Substitute Decision Maker
- Guardian
- Prescribed relative who has a close and continuing relationship
- Adult friend who has a close and continuing relationship
- Adult who is charged with day to day supervision and care
- Guardianship Board
Parens patriae jurisdiction

• The state as parent
• Recognised in the Statute Prerogativa Regis of 1324.
• Functions delegated to the Chancellor and passed to the court of Chancery in 1696.
• Jurisdiction not affected by Statute Administered by the Supreme Court.
People affected by Legislative Powers

- CLCA
- Overlap
- G&A Act
- AIP Act
- MH Act
Means the inability to look after his or her own health, safety or welfare or to manage his or her own affairs 
as a result of

(a) any damage to, illness, disorder, imperfect or delayed development, impairment or deterioration, of brain or mind

(b) any physical illness or condition resulting in inability to communicate intentions or wishes in any manner whatsoever
## Where is the real incapacity?

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<td>Economic incapacity</td>
<td>Greater support to economically disadvantaged groups.</td>
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31—Powers of guardian

A person appointed as a guardian under this Part has and may exercise, subject to this Act and the terms of the Board's order, all the powers a guardian has at law or in equity.
S 32 (2)

(2) The Board cannot make an order under subsection (1) unless it is satisfied that, if such an order were not to be made and carried out, the health or safety of the protected person or the safety of others would be seriously at risk.
G & A Act Section 32

(1) The Board, on application made by an appropriate authority in respect of a person to whom this section applies—

(a) may, by order, direct that the person reside—
   (i) with a specified person or in a specified place; or
   (ii) with such person or in such place as the appropriate authority from time to time thinks fit,

according to the terms of the Board's order; and

(b) may, by order, authorise the detention of the person in the place in which he or she will so reside; and

(c) may, by order, authorise the persons from time to time involved in the care of the person to use such force as may be reasonably necessary for the purpose of ensuring the proper medical or dental treatment, day-to-day care and well-being of the person.
Aged and Infirm Persons' Property Act 1940

7—Circumstances under which protection order may be made

(1) Where it is made to appear to the satisfaction of the court that any person is, by reason of age, disease, illness, or physical or mental infirmity—

(a) unable, wholly or partially, to manage his affairs; or

(b) subject to, or liable to be subjected to, undue influence in respect of his estate, or the disposition thereof, or of any part thereof; or

(c) otherwise in a position which in the opinion of the court renders it necessary in the interest of that person or of those dependent upon him that his property should be protected as provided by this Act,

the court may make a protection order in respect of the estate or part of the estate of that person.
Mental Health Act 2009

- This clause provides that a medical practitioner or authorised health professional may make an order for the treatment of a person (a *level 1 inpatient treatment order*) if it appears to the medical practitioner or authorised health professional, after examining the person, that—

  the person has a mental illness; and

  because of the mental illness, the person requires treatment for the person's own protection from harm (including harm involved in the continuation or deterioration of the person's condition) or for the protection of others from harm; and

  there is no less restrictive means than an inpatient treatment order of ensuring appropriate treatment of the person's illness.
24—Treatment of patients to whom level 1 orders apply

(1) A patient to whom a level 1 inpatient treatment order applies may be given treatment for his or her mental illness or any other illness of a kind authorised by a medical practitioner who has examined the patient.

(2) The treatment may be given despite the absence or refusal of consent to the treatment.
269C—Mental competence

A person is mentally incompetent to commit an offence if, at the time of the conduct alleged to give rise to the offence, the person is suffering from a mental impairment and, in consequence of the mental impairment—

(a) does not know the nature and quality of the conduct; or
(b) does not know that the conduct is wrong; or
(c) is unable to control the conduct.
269H — Mental unfitness to stand trial

A person is mentally unfit to stand trial on a charge of an offence if the person's mental processes are so disordered or impaired that the person is—

(a) unable to understand, or to respond rationally to, the charge or the allegations on which the charge is based; or

(b) unable to exercise (or to give rational instructions about the exercise of) procedural rights (such as, for example, the right to challenge jurors); or

(c) unable to understand the nature of the proceedings, or to follow the evidence or the course of the proceedings.
## PRIORITY ACTIONS

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<tr>
<td>2.1.</td>
<td>Amend the <em>Evidence Act 1929</em> to give people with complex communication needs a general entitlement to have a specially trained Communication Assistant present for any contact with the criminal justice system.</td>
</tr>
<tr>
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<td>Lead Agencies: Attorney-General’s Department</td>
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<tr>
<td>2.2.</td>
<td>Establish a service in the non-government sector which provides a pool of trained independent Communication Assistants to facilitate communication between witnesses or defendants and an investigative interviewer. The Communication Assistants would be available throughout the criminal justice process.</td>
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<td>2.3.</td>
<td>Amend the <em>Evidence Act 1929</em> to clarify and increase access to appropriate support persons for vulnerable witnesses. The support person could be a friend or relative and would provide emotional support throughout the criminal justice process.</td>
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G&A Act 1993 Principles

- Paramount consideration given to the wishes of the person if he or she were not mentally incapacitated (only as far as can be ascertained)
- Present wishes
- Not to disturb adequate informal arrangements
- Least restrictive while consistent with proper care and protection.
31—Powers of guardian

A person appointed as a guardian under this Part has and may exercise, subject to this Act and the terms of the Board's order, all the powers a guardian has at law or in equity.
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(2) The Board cannot make an order under subsection (1) unless it is satisfied that, if such an order were not to be made and carried out, the health or safety of the protected person or the safety of others would be seriously at risk.
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according to the terms of the Board's order; and

(b) may, by order, authorise the detention of the person in the place in which he or she will so reside; and

(c) may, by order, authorise the persons from time to time involved in the care of the person to use such force as may be reasonably necessary for the purpose of ensuring the proper medical or dental treatment, day-to-day care and well-being of the person.
(3) Nothing in this section empowers the placement or detention of a protected person in —

(a) a correctional institution or any other place in which persons charged with or convicted of offences may be detained; or

(b) any part of an approved treatment centre under the Mental Health Act 1993 that is set aside for the treatment of persons with a mental illness.
Example (1): Enhancing decision making capacity: Brain Injury

- Impaired memory
  - Repeat discussions – consistency in response, when presented the same facts
  - Written advice
- Other cognitive symptoms
  - Risk of impulsiveness – reflect on decisions over time
  - Support executive functions: Recognise need to step through new situations, and support planning
  - Fatigue – limit duration of sessions
Example (2): Enhancing Decision Making Capacity: Schizophrenia

• Positive symptoms:
  • decision specific nature of capacity
  • Repeat discussions due to limitations in attention and learning when unwell

• Negative symptoms and cognitive symptoms
  • Incorporate into recovery approach of setting personal goals and establishing personal authority.
  • May need time, simple information, repeat explanations, engagement with the individual
CTO’s Evidence for intervention

Cochrane Collaboration – CTOs

• CTOs – no significant difference in
  – Service use
  – Social functioning
  – Quality of life
  – However less likely to be the victim of violence

• Numbers needed to treat
  – 85 orders to prevent one admission
  – 27 to prevent one episode of homelessness
  – 238 to prevent one arrest
It is not possible to state whether community treatments orders (CTOs) are beneficial or harmful to patients.
OCTET: Time to readmission
Burns et al, Lancet, May 2013

Figure 2: Time to readmission
SA Mental Health Act
“Supported Decision Making”

47—Patients' right to be supported by guardian etc
(1) A patient is entitled to have another person's support, wherever practicable, in—
(a) the exercise of a right under this Act; or
(b) any communications between the patient and a medical practitioner examining or treating the patient or between the patient and the director or staff of a treatment centre in which the patient is treated or detained.
(2) The support may be provided by—
(a) if the patient is a child—a parent or guardian of the patient; or
(b) a guardian, medical agent, relative, carer or friend of the patient who has been nominated by the patient for the purpose or who has or is assuming responsibility for the care of the patient; or
(c) a person who provides advocacy services whether on a professional or voluntary basis; or
(d) a community visitor.
Informal and formal pressures and coercion

Coercion and compulsion in community mental health care

Andrew Molodynski*, Jorun Rugkåsa, and Tom Burns
Oxford University Department of Psychiatry, Social Psychiatry Group, Oxford, UK

British Medical Bulletin 2010; 95: 105-119
Persuasion
- Clinician sets out benefits of a particular course of treatment
- Provides information and answers concerns and questions
- Patient is free to either accept or reject the advice about the treatment

Leverage
- Clinician can use personal relationship with patient to influence decision-making process
- Additional pressure can be placed on patient by expressing approval of one course of action and disapproval of another

Inducement
- Clinician may suggest that patient will receive additional support or services if they agree to participate in the suggested course of treatment

Threat
- Clinician may suggest that services and support will be withdrawn if patient does not comply with treatment
- Clinician may also mentioned that use of the MHA will be considered if the patient does not comply with treatment

Compulsion
- Clinician will compel the patient to take treatment against their will by legally requiring them to adhere to treatment, either in the community or hospital, by using provisions of the MHA
Conclusion

- Dignity
- Identification of environmental and attitudinal barriers
- Assisted and Supported Decision Making
- Leadership that is generative and enabling rather than limiting and controlling
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