Decisions about health and personal care:  
*What does it take to be legally capable?*

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October 23, 2013
Jenny Hatch (Virginia, US)
Jenny in her own words

My name is Jenny Hatch. I am 29 years old and I have Down Syndrome. Last year I was placed in a group home. I did not want to be there. I told everyone that I was not happy and did not like it. I just wanted to go home to my friends Jim and Kelly's.

Jewish Family Services was my guardian. She was my case worker. She was mean to me. She yelled at me and even hit me. I was not allowed to go to my job at the thrift store. I worked there for almost 5 years. I wasn't allowed to have my friends or co-workers visit or even call me. I wasn't allowed to have my cell phone or computer. I felt like a prisoner but I didn't do anything wrong.
in her own words

I was told I had rights at the group homes, but that wasn’t true. It was like they didn’t matter, like I didn’t exist. JFS took away my rights, my choices, my independence. A guardian is supposed to help me reach my goals.

Instead, I was kept away from my community, my church, and my friends. I kept telling everyone I was unhappy but no one listened to me.
in her own words

I lost a year of my life being forced to stay in group homes and forced to work at a job I did not want.

How is making sure that what happened to me doesn't happen to someone else?

Who is making sure that if it is doing the right thing?

Just because people have a disability does not mean the need a guardianship. Many times they may need just a little help.

Thank you.

Jenny Hatch
The Personal is the Political

“For anyone who has been told you can’t do something, you can’t make your own decisions, I give you Jenny Hatch — the rock that starts the avalanche”

The Washington Post (quoting Jonathan Martinis)

“The Jenny Hatch Justice Project
A project of Quality Trust
for individuals with disabilities


“Jenny.
Take a seat, on the bus, right next to Rosa. I think you’d have a lot to talk about.”

Doing Damns the Darkness Blog
What does it take to be legally capable? (health & personal care)

1. **Background principles & values**
   - A “paradigm shift” toward decision-making *supports*

2. **Legal capacity in NS: health & personal care**

3. **Substitute decision-making in NS: supportive, responsive, responsible**
Conditions / circumstances may impair decision-making . . .

- Dementia(s) / Alzheimer’s Disease
- Intellectual disability
- Brain injury
- Mental health problems / psychosocial disability
- Transient trauma / shock
These are not equivalent to incapacity at law

- “Legal capacity” is defined differently across jurisdictions and types of decision
- “Legal capacity” reflects political choices
- “Legal capacity” reflects our core values as a society, including the relationships we wish to build among family and community members
What's in a decision?
What’s in a decision?
Fundamental values (within limits)

- Autonomy / Respect for persons
- Equality / Non-discrimination / accommodation / equal concern & respect

Counterweights / Limits
- Protection of the vulnerable
- Efficient & principled use of scarce resources
Legal capacity – central principles

The constitutional guarantee of autonomy protects bodily integrity & the right to make decisions of fundamental personal importance... even where those decisions appear risky or foolish.

Legal capacity – central principles

Presumption of legal capacity (adults)

- Onus lies on the one challenging capacity
- Requires *evidence* to displace legal presumption
Legal capacity – central principles

- Definitions vary across jurisdictions and types of decision

- Those empowered to formally assess legal capacity also vary
  - Specialized tribunals, courts, physicians, social workers, other health professionals . . .
Legal capacity – central principles

- Often (& increasingly) recognized as:
  - **Decision-specific** (treatment, finances, testamentary, marriage . . .)
  - **Time-sensitive** (may fluctuate)
Legal capacity – central principles

- *Not equivalent* to diagnosis, age, I.Q., Mini-mental state score

- *Not dependent* on agreement with professional opinion / advice
U.N. Convention on the Rights of Persons with Disabilities [CRPD]

- Canada ratified March 2010
- Wide participatory base in drafting
- Speaks to social determinants of disability / marginalization (rights to education, health, work, adequate standard of living)
- Relevant to interpreting domestic laws & pressing for reforms
CRPD, Article 12

Equal recognition before the law

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

2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity...
**CRPD, Article 12: Canada’s interpretive declaration**

“To the extent Article 12 may be interpreted as requiring the elimination of all substitute decision-making arrangements, Canada reserves the right to continue their use in appropriate circumstances and subject to appropriate and effective safeguards.”
## Article 12: A “Paradigm Shift”

<table>
<thead>
<tr>
<th>Substitute Decision-making</th>
<th>Supported Decision-making</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of internal “capacity” to make one’s own decisions</td>
<td>All decision-making takes place in a framework of supports</td>
</tr>
<tr>
<td>Transfer of decision-making authority to another</td>
<td>Decision-making supports to be tailored to the individual’s needs</td>
</tr>
<tr>
<td>(Suspicion, Surveillance, Coercion)</td>
<td>(Respectful assistance within a range of meaningful options)</td>
</tr>
<tr>
<td>Individual as dependent, passive, absent</td>
<td>Individual as self-directing within a framework of supports</td>
</tr>
</tbody>
</table>
A “Paradigm Shift”

Instead of restricting autonomy of those who need extra support to comfortably participate in all aspects of life, the CRPD requires states to provide access to such support and to respect the autonomy of all persons with disabilities.

- World Network of Users and Survivors of Psychiatry, Statement on the implications of the CRPD on forced treatment (Mar 14, 2011)
Political not Metaphysical
(In)capacity in law: social / human rights model

- Ask how social environments and mental conditions interact to produce disability.

- Ask how conditions under which capacity is assessed may impair the ability to demonstrate capacity.

- Ask how conditions may be altered to support legal capacity.
Decision-making supports...

- Individual and context specific...
- Range of meaningful options
- Assistance understanding & exploring options
  - Familial OR peer OR state-provided assistance
- Assistance communicating a choice
  Also: crisis intervention, building of relationships of trust vs coercion...
Wider supports (Social determinants of legal capacity)

- Countering employment discrimination (Art 27), poverty (Art 28), homelessness (Art 28), violence (Art. 16)
- Accessible, voluntary community supports (Arts 14, 19)
- Best practices in crisis intervention, including supportive housing, peer-run shelters (Arts 14, 15, 17 & 19)
- Public education about mental health & human rights (Arts 4(1)(h), 8, 21, & 25)
- Public deliberation about what constitutes meaningful supports (Arts 4(3), 29) - in different cultural contexts
Legal Models: Works in Progress

B.C. – Representation Agreement Act

- Incapacity not to be based on one’s “way of communicating with others”
- May appoint trusted person to assist with decisions or to make decisions in specific areas
- Capacity to appoint based in expression of preferences & trust (except where authorizing actions vs. one’s will)
- Representative to respect “current wishes” if “reasonable” (unless agreement states otherwise)
Legal Models: Works in Progress

Personal ombudsperson - PO-Skåne (Sweden)

- State-funded service / alternative to family support
- Aimed at most isolated, marginalized
- Acts only at client’s request
- Meets with client in the community, works to establish relationships of trust / communication
- Advocates for client’s interests
2. Legal capacity in NS: health & personal care

- Multiple statutory regimes
  - Incompetent Persons Act
  - Adult Protection Act
  - Involuntary Psychiatric Treatment Act
  - Hospitals Act
  - Personal Directives Act
  - Powers of Attorney Act – FINANCES & PROPERTY ONLY

- Also, judge-made law (common law)
## Incapacity in NS (partial list)

<table>
<thead>
<tr>
<th>Statute</th>
<th>Nature of incapacity</th>
<th>Assessor</th>
<th>SDM</th>
<th>SDMs authority</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Incompetent Persons Act</strong></td>
<td>“incapable from infirmity of mind of managing own affairs.”</td>
<td>Court [2 physicians]</td>
<td>Court-appointed guardian</td>
<td>Estate and person</td>
</tr>
<tr>
<td><strong>Hospitals Act</strong></td>
<td>Treatment in hospital or property decisions</td>
<td>Physician; consult with other health pros</td>
<td>Statutory list</td>
<td>Treatment in hospital or property decisions</td>
</tr>
<tr>
<td><strong>Personal Directives Act</strong></td>
<td>Personal care, including health care, continuing care, home care</td>
<td>Physician does formal assessment</td>
<td>Per directive or, if no directive, statutory list</td>
<td>Per directive or, if no directive, statute states the determinative factors</td>
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<td><strong>Involuntary Psychiatric Treatment Act</strong></td>
<td>Treatment incapacity required for involuntary hosp or CTO</td>
<td>Psychiatrist; consulting w other health profs</td>
<td>Statutory list</td>
<td>Treatment in psychiatric facility / CTO</td>
</tr>
<tr>
<td><strong>Adult Protection Act</strong></td>
<td>Abuse / neglect; mental infirmity or physical disability; &amp; incapacity to decide re offer of services</td>
<td>Court (evidence from AP worker / physician / other health profs)</td>
<td>SDM under Personal Directives Act or court-ordered services</td>
<td>Per Personal Directives Act –if no SDM, court may place limits on Minister’s care plan</td>
</tr>
<tr>
<td><strong>Powers of Attorney Act</strong></td>
<td>“Legally incapacitated” from managing estate</td>
<td>Lawyer (poss assisted by health prof)</td>
<td>Person granted power of attorney</td>
<td>Property only</td>
</tr>
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</table>
Court-appointed Guardian (*Incompetent Persons Act*)

- S.2(b) “a person, not an infant, who is incapable from infirmity of mind of managing the person's own affairs”.

- S.3(4) Guardian has “care and custody of the incompetent person and the management of the incompetent person's estate”.

- Global / vague standard of capacity & powers
  - Contrary to guarantees of equality & autonomy (not to be deprived arbitrarily / disproportionate harm to right)
Incompetent Persons Act: Critiques of NS Law Reform Commission, 1995

- Act does not reflect current social needs or values
- Act should require court to consider
  - the specific kinds of decisions in issue,
  - the adult’s way of communicating,
  - available support and resources,
  - the wishes of the adult, including those expressed in an advance health care directive
- Should require least restrictive intervention
- Court “should not appoint a guardian unless alternatives, such as providing support and help, have been tried or carefully considered”
Adult Protection Act

- **S.3(b) Adult in need of protection**
  - Subject of abuse / neglect / self-neglect
  - **Incapable of protecting/caring for self** “by reason of permanent physical incapacity or permanent mental incapacity, and refuses or is unable to provide for” own protection / care

- If Minister satisfied 3(b) criteria met (and if adult or SDM under Personal Directives Act agrees), “shall assist in obtaining” services (s.7) . . .
9(3) Minister may apply to court for declaration that a person is an adult in need of protection and does not have the mental capacity to decide whether to accept the assistance of the Minister,

The court may, where it appears to be in the best interest of that person, issue one or more of the following orders . . .
Adult Protection Act

- Authorizing Minister to refer adult to services including placement in an approved facility
- Protective intervention order directed to a person who is a danger to the adult (prohibiting contact, requiring payment of maintenance)
- Appoint a temporary guardian for person or estate or both
- Issue a supervision order directed to the SDM or any person having care or control of the adult, which may include terms and conditions related to the adult’s residence or estate
Adult Protection Act: Critiques

- Incapacity or lack of adequate range of options?
- Social / human rights model: exhaust supports before declaring legal incapacity
- Least restrictive intervention?
- Attention to wishes / values of individual?
NS Involuntary Psychiatric Treatment Act [IPTA]

Criteria for involuntary hospitalization / treatment

- mental disorder;
- in need of psychiatric treatment in psychiatric facility;
- as a result of the mental disorder,
  - has caused or is threatening to cause serious harm to self or other OR
  - is likely to suffer serious physical impairment or serious mental deterioration, or both
- is not suitable for voluntary admission; and

(e) as a result of the mental disorder, the person does not have the capacity to make admission and treatment decisions
Treatment capacity: NS IPTA

**IPTA s.18 (1)** the psychiatrist shall consider whether the patient fully understands and appreciates

- (a) the **nature of the condition** for which the specific treatment is proposed;
- (b) the **nature and purpose of the specific treatment**;
- (c) the **risks and benefits involved in undergoing** the specific treatment; and
- (d) the **risks and benefits involved in not undergoing** the specific treatment;

**(2)** ... whether the patient's mental disorder affects the patient's **ability to fully appreciate the consequences** of making the treatment decision.
What is expected in order to demonstrate “full” understanding and appreciation?

Discriminatory standard (identical requirements for other persons in NS, except for qualifier “fully”)?

What would it mean to assess this capacity fairly? During 72-hour observation?
Consequences of incapacity under IPTA

- Involuntary psychiatric hospitalization (other terms & conditions apply)
- Possibly, Community Treatment Order
- Substitute Decision Maker assigned under the terms of the Act (close family member or, if none, Public Trustee)

*Have we provided adequate voluntary supports?*
NS *Hospitals Act*: treatment capacity

- Addresses capacity to make decisions about treatment in hospital (apart from involuntary psychiatric patients)
- Physician assesses
- If incapacity established, a substitute decision maker [SDM], selected according to a statutory list, decides
- SDM must decide in accordance with statute
S.52 (2A) Does the patient understand and appreciate . . .

(a) the condition for which the specific treatment is proposed;

(b) the nature and purpose of the specific treatment;

(c) the risks and benefits involved in undergoing the specific treatment; and

(d) the risks and benefits involved in not undergoing the specific treatment . . .
NS Hospitals Act – treatment capacity

(2B) ... whether the patient's mental disorder affects the patient's ability to appreciate the consequences of making the treatment decision.
**Understanding / appreciation?**

*Starson v. Swayze* (2003 SCC)

- **Ability to understand** = “the cognitive ability to process, retain and understand the relevant information”

- **Ability to appreciate** = ability “to apply the relevant information to [one’s] circumstances, and . . . to weigh the foreseeable risks and benefits of a decision or lack thereof”
Failure of understanding / appreciation not necessarily a failure of ability (vs sufficiency of information, transitory circumstances eg sedation)

Disagreement w/ professional about diagnosis or causes of condition is not necessarily incapacity (conflict of values or opinion?)

BUT inability to recognize symptoms / facts about one’s condition or circumstances is a sign of failure to “appreciate”
Re Crewe 2007 NSSC 322
Appeal of assessment under NS Hospitals Act

- Declared incapable of decision re proposed surgery
- Court invalidated this change in legal status

1) inadequate information imparted to Mr. Crewe
2) emotional impact of diagnosis & proposed surgery

Evidence did not establish inability to understand/appreciate; general testimony about delusional ideation not linked to this decision
Legal safeguards: Assessing Capacity
From Starson (SCC 2003); Re Koch (Ont. Sup.Ct 1997)

- **Inform** re nature / purpose of assessment, right to have trusted person present, right not to participate

- **Address circumstances** that may compromise capacity (emotional / environmental / medical)

- **Inform**: reinforce understanding

- **Probe**: encourage elaboration if response is not understood

- **Probe**: consult corollary sources, consider reassessing at another time
Hospitals Act – substitute decision-maker

- (a) a person who has been authorized to give consent under the Medical Consent Act or a delegate authorized under the Personal Directives Act;

- (b) the patient's guardian appointed by a court of competent jurisdiction;

- (c) the spouse of the patient;

- (d) an adult child of the patient;

- (e) a parent of the patient;

- (f) a person who stands in loco parentis to the patient;
Hospitals Act – substitute decision-maker

- (fa) an adult sibling of the patient;
- (fb) a grandparent of the patient;
- (fc) an adult grandchild of the patient;
- (fd) an adult aunt or uncle of the patient;
- (fe) an adult niece or nephew of the patient;
- (g) any other adult next of kin of the patient; or
- (h) the Public Trustee.
Hospitals Act – substitute decision-maker (additional criteria for those in clauses c to g)

- (a) **personal contact** with the person over the preceding twelve-month period (except for a spouse)
  - or granted a court order to waive the twelve-month period;

- (b) is **willing** to assume the responsibility for making the decision;

- (c) **knows of no person of a higher rank** in priority who is able and willing to make the decision; and

- (d) makes a statement in writing **certifying the relationship** to the person and the facts and beliefs set out in clauses (a) to (c).
Personal Directives Act (in force since April 2010)

Recognizes advance directives for health care and other personal care decisions in and beyond hospital

- may appoint “delegate” to make personal care decisions & / or
- may give specific instructions about personal care in the event of incapacity
- may state one’s “values, beliefs and wishes” about future personal-care decisions
s.2(l) “personal care” includes, but is not limited to, health care, nutrition, hydration, shelter, residence, clothing, hygiene, safety, comfort, recreation, social activities, support services . . .
Personal Directives Act: Capacity to make a directive

S.2(a) "capacity" means the ability to

- understand information that is relevant to the making of a personal care decision and

- appreciate the reasonably foreseeable consequences of a decision or lack of a decision
Where no advance directive:
   Statute authorizes “nearest relative” to make decisions regarding
   - health care
   - placement in a continuing care home
   - home care services

... or if no relative able / willing, Public Trustee
**Personal Directives Act**

Who assesses capacity under the PDA?

- **Formal assessment by physician (on request):**
  - “Physician”, not necessarily psychiatrist
  - Directive may name person w/ whom physician must consult
Understanding / appreciation – e.g., decisions about long term care

- Matters of relevance (partial list?)
  - Nature of identified problems at home
    - Difficulties with self-care?
    - Consistency of situation with values?
  - Nature of the proposed placement
  - Risks / benefits of placement
  - Risks / benefits of refusal
  - Alternatives (home care, other supports?)
    - *Decision to live with risk?*
Understanding / appreciation – e.g., decisions about long term care

- Probe responses that are confusing / partial – look for the reasons / values that may be guiding choice.

- Answer any questions the person may have about the decision.

Adapted from *Assessing Capacity for Admission to Long-Term Care Homes - A Training Manual for Evaluators*

- Jeffrey Cole, MSW, RSW; Noreen Dawe, MSW, RSW (2012, revised 2011)
Supported decision-making – (common sense?)

- Slow down?
- Repeat information in a different way?
- Meet at a different time of day?
- Ask permission to involve a trusted consultant / friend?

“Determining capacity is not a test of prior knowledge”: Duty to inform, confirm understanding, adapt information to meet individual’s needs

Ed Montigny, “Notes on Capacity to Instruct Counsel” (ARCH Disability Law Centre, ON).
Personal Directives Act: more information (including sample form)

- Capital District Health Authority: “Let’s Talk About Personal Directives”
Personal Directives Act

- DOES recognize legal capacity is decision-specific
- DOES recognize legal effect of prior statement of wishes / values
- DOES thereby encourage communication among families, and with care providers, about wishes and values relating to care
Personal Directives Act

- DOES NOT state a presumption of capacity
- DOES NOT mandate exhausting all means of supporting legal capacity
- DOES NOT supply an accessible process for contesting incapacity OR substitute decisions (these challenges require application to a court)
3. Substitute decisions: legally required considerations

**Hospitals Act**

- The substitute decision-maker shall make the decision in relation to specified medical treatment

- (a) in accordance with the patient's **prior capable informed expressed wishes unless**
  - (i) technological changes or medical advances make the prior expressed wishes **inappropriate** in a way that is contrary to the intentions of the patient, or
  - (ii) **circumstances exist that would have caused the patient to set out different instructions** had the circumstances been known based on what the substitute decision-maker knows of the values and beliefs of the patient and from any other written or oral instructions;
(b) in the absence of awareness of a prior capable informed expressed wish, in accordance with what the substitute decision-maker believes the wishes of the patient would be based on what the substitute decision-maker knows of the values and beliefs of the patient and from any other written or oral instructions; and

(c) if the substitute decision-maker does not know the wishes, values and beliefs of the patient, in accordance with what the substitute decision-maker believes to be in the best interest of the patient.
Hospitals Act

- Best interests to be determined in light of

- (a) whether the condition of the patient will be or is likely to be **improved by the specified medical treatment**;

- (b) whether the condition of the patient will improve or is likely to **improve without** the specified medical treatment;

- (c) whether the **anticipated benefit to the patient from the specified medical treatment outweighs the risk** of harm to the patient; and

- (d) whether the specified medical treatment is the **least restrictive and least intrusive treatment** that meets the requirements of clauses (a), (b) and (c).
Personal Directives Act (delegates)

- In making any decision, a delegate shall
  - (a) follow any instructions in a personal directive unless
  - (i) there were expressions of a contrary wish made subsequently by the maker who had capacity,
  - (ii) technological changes or medical advances make the instruction inappropriate in a way that is contrary to the intentions of the maker, or
  - (iii) circumstances exist that would have caused the maker to set out different instructions had the circumstances been known based on what the delegate knows of the values and beliefs of the maker and from any other written or oral instructions;
(b) in the absence of instructions, act according to what the delegate believes the wishes of the maker would be based on what the delegate knows of the values and beliefs of the maker and from any other written or oral instructions; and

(c) where the delegate does not know the wishes, values and beliefs of the maker, make the personal-care decision that the delegate believes would be in the best interests of the maker.
A statutory decision-maker shall

(a) act according to what the statutory decision-maker believes the wishes of the person represented would be based on what the statutory decision-maker knows of the values and beliefs of the person represented and from any other written or oral instructions; and

(b) where the statutory decision-maker does not know the wishes, values and beliefs of the person represented, make the personal-care decision that the statutory decision-maker believes would be in the best interests of the person represented.
Take-aways

- **ADVOCATE** for safeguards & supports to promote legal capacity – recognition in law & policy

- **PLAN** by identifying the emotional, social & material supports you and others require to maintain legal capacity; plan also for last-resort mechanisms for having one’s wishes respected despite incapacity

- **SUPPORT** the decision-making abilities of oneself and others

- **RESPECT** the wishes & values of others through responsible supportive & substitute decision-making
Reconstruction (with the requisite supports)
Principles of decisional capacity: further resources


Further resources
