

The Paradigm of Supported Decision Making

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This presentation draws on work done in the Working Group on legal capacity and related issues of the International Disability Caucus, with many thanks to all participants

What is the support paradigm?

- Alternative to guardianship and substituted decision making
- No single model but an approach to legal capacity based on inclusion rather than exclusion of people with disabilities
- Every person has a will and is capable of making choices [FN1]
- Autonomy can coexist with interdependence [FN1]
 - “Supported decision-making gives legal recognition to a process for self-determination that is communal and interdependent”

Support and legal capacity

- “The social model of disability says that the problem is not within the individual, but in the society which does not meet this person in such a way that he can function. This applies also to problems with legal capacity. It's not a problem inside the individual - which should be met by forced intervention or guardianship - but society must relate in another way to this person, so that his [or her] disability regarding legal capacity diminishes. [FN 2]

Support and legal capacity continued

- “Supported decision-making is an example of this. If some persons have [difficulty] to express and communicate their wishes, the solution is not to put in a guardian, but to develop a relation and ways, which make it possible for this person to express and communicate what he [or she] wants.”
[FN 2]

How does support work?

- Support is based on a relationship of trust
 - Even if a person cannot use language, she or he can still establish trusting relationships
- Can be simple or complex, transactional or more comprehensive
 - Assistance with information and communication in signing contracts or making health care decisions is a kind of support
- Requires patience and respect for the person's own style and process of making decisions

Support for people with high level of need

- “When a person does not speak [or sign], there are many other ways to express feelings and desires.
- “Those providing support need to be very attentive to cues that indicate likes and dislikes.
- “There must be safeguards to ensure that providers of support do not overrule the will of the individual with a disability.” [FN 3]

Equal legal capacity

- Disability Convention guarantees to people with disabilities equal legal capacity in all aspects of life (Article 12.2)
- Emancipates people with disabilities from guardianship and prepares the way for full implementation of support paradigm
- Support paradigm is a way to implement the norm of equal legal capacity

Equal legal capacity continued

- People with disabilities have the same rights to exercise legal capacity as others - e.g. to assert rights in court, to make contracts, to marry, to give or refuse consent to medical treatment or other services, to vote
 - Any laws purporting to disqualify people from such acts based on disability would be invalid
 - For example, mental health laws that violate the right to free and informed consent

Equal legal capacity continued

- Where exercise of legal capacity is required, relevant systems have duty to ensure accessibility to people with disabilities, and to accommodate supported decision-making
- Competence recognized in law has broad effects in individual lives and for people with disabilities collectively
 - Fosters equality in all aspects of life, including personal relationships and work
 - Enables individual development by affirming the power of choice

Equal legal capacity continued

- Support ensures that recognition of equal legal capacity does not entail abandonment of social solidarity
 - Legal capacity de-coupled from illusion of self-sufficiency
 - Dialogue about interdependence opened up for society as a whole
 - Need for more logical and humanistic approach to prevent exploitation
 - Guardianship has never successfully served this purpose, and amounts to blaming the victim

Equal legal capacity continued

- Sliding scale of support instead of binary model capacity/incapacity
 - Fluctuating needs can be met without risk of losing rights and freedoms
 - Support systems will not function perfectly, but can be safeguarded against abuse
 - Failures are not institutionalized by creating a separate category of people who are legally incapacitated

Construction of legal capacity

- Legal capacity is a social and legal construct - not an attribute of a person [FN 4]
- Legal capacity refers to recognition of an individual as a person with legal rights and responsibilities, who is entitled to exercise those rights and responsibilities for him or herself (capacity for rights plus capacity to act)
- The construction of legal capacity as being dependent on any cognitive, perceptual, physical, communication and relational capabilities discriminates based on disability
- Support paradigm constructs legal capacity without reference to evaluation of capabilities - as a marker of self-determination in a given legal system

Legal capacity in human rights law

- CEDAW Article 15 first explicit mention of legal capacity
 - Guaranteed equality between women and men
 - Applies to women with disabilities
 - Under Article 15, CEDAW Committee addresses both restrictive laws and economic and social factors that are obstacles to women's exercise of legal capacity
 - This suggests that similar concerns should be taken up under Disability Convention
 - e.g. third party reluctance to accept people with disabilities as decision-makers

Legal capacity in human rights law continued

- Recognition everywhere as a person before the law (UDHR Article 6 and ICCPR Article 16)
- CRC Article 12 suggests evolving legal capacity of children
 - Applies to children with disabilities and reaffirmed in CRPD Articles 7.3 and 3(h)

Related rights and values

- Independent living movement
 - “Autonomy doesn’t mean being able to get there myself, but I decide where to go”
- Complementarities in human rights framework
 - Inter-relatedness of all human rights
 - Realization of economic, social and cultural rights necessary to free development of the personality (UDHR Article 22)
- Feminism and women’s human rights
 - Equality in relationships depends on autonomy and mutual consent

Self-determination

- *“I was respected as an individual and allowed to decide what I needed instead of it being assumed that I had lost all powers of decision.” [FN 5]*
- *“My understanding of support is that the person supporting me will listen to what I say. They will take time to understand my issue and help me to understand my choices. They will then help me to achieve the things I want for myself.” [FN 5]*

Self-expression

- *“Even with all the tools available, Charlie still can’t express his choices independently. We don’t always know what he wants, decisions aren’t always perfect, but together we can support him to make decisions about where he wants to live or what he wants to do.”*
[FN 5]

Responsibility

- *“It can be easier to not have any responsibility for yourself. However, I believe that each of us yearns for freedom, independence and self-determination. Our spirit yearns to be proud and free.” [FN 5]*

Liberation

- *“For years, even people who knew them well believed they were not able to make any decisions for themselves. We started to talk to them as real people in a safe environment and the results have been amazing. People who were in the institution with me and I know have never made their own decisions are now talking about the things they like. They are also talking about the things that they don’t like. They have found their voice even though many do not use the spoken word to communicate.” [FN 5]*

Examples of support

- Support networks of family and friends
- Personal ombudsperson (PO-Skåne)
- Community responsibility
- Personal assistance
- Peer support
- Advance planning
- Support to individuals complements accessibility measures in information and communication, government and legal system, and services of all kinds

Family-based networks

- Family can create support network around one of its members [FN 6]
- Relies predominantly on volunteers rather than paid workers
- Can draw on larger community, such as religious community
- Developed for people with high support needs
- Advantages of a network: involvement of different caring individuals minimizes dependence on any one person to interpret wishes

Family-based networks continued

- Network is for specific purpose of supported decision-making, person may have other supporters for other purposes
- Network is based on close, trusting relationships in which a person can safely and effectively express his or her wishes

Family-based networks continued

- Example: The support network of a young man who does not speak and uses a wheelchair noticed that he moved close to the door every time he arrived home. His support network understood that he wanted his own apartment, and began helping him to get one.
 - They introduced him to a potential roommate since it was not feasible financially for him to live alone; this did not work out since one loved to watch opera on TV and the other hated it. At the time I learned about it, the process was ongoing.

Personal Ombudsperson (PO-Skåne)

- Service implemented by group of users and survivors of psychiatry [FN 2]
- Funded by Swedish government
- PO takes “commissions” from the person who wants his or her services and is accountable only to that person
 - No records are kept and all papers belong to the client
 - No office and no bureaucratic forms to sign

Personal Ombudsperson (PO-Skåne) continued

- Developed to meet high support needs of people with psychosocial disabilities
 - People “who are living entirely in a symbolic world of their own, living barricaded in their apartments or living homeless in the streets”
- Cannot act until the person makes a request
- Works on relational model to make contact, develop communication, establish relation, initiate dialogue and take commissions

Personal Ombudsperson (PO-Skåne) continued

- PO must both have advocacy skills and be available to talk about all kinds of concerns
 - Often the most pressing concerns are not practical but relational or existential
 - “Why should I live? Why has my life become the life of a mental patient? Is there any hope for a change?”

Personal Ombudsperson (PO-Skåne) continued

- Service operating successfully for 10 years
- Initially costs increase because people assert their rights and systems must respond
- Ultimately costs decrease as people no longer need a PO

Personal Ombudsperson (PO-Skåne) continued

- “Supported self-decision”: independent from authorities, psychiatry, family members and service systems, PO establishes relation counter to disablement and allows person to express needs and receive support without having others take over or impose burdensome conditions

Community responsibility

- Appropriate where community ties are strong
- Community should take responsibility for well being of all its members and extend solidarity to support people with disabilities
 - Need to ensure that people with disabilities are equal partners and lived expertise is respected
- Such work of the community should be funded by the central government

Personal assistance

- Personal assistance can be used for supported decision-making
 - For example, assistance with reading and filling out forms for people who have language or script disability
 - Giving information about environment if people have a perceptual disability
 - Talking through options with trusted individuals

Peer support

- Peer support develops collective knowledge about living with a disability
- Respect for lived experience and personal choices
- Non-hierarchical; promotes self-empowerment in communal setting
- Used by independent living movement, self-advocacy, user/survivor of psychiatry movement, landmine survivors, networks of women with disabilities

Advance planning

- Can be used in health care or other contexts, such as to deal with guardianship of children
- Allows person to anticipate difficulty and prepare for it
 - Designate advocate to help communicate wishes
 - Decide on specific measures to be taken and those to be avoided

Advance planning continued

- Users and survivors of psychiatry have used advance planning to exercise control over what happens in a crisis
 - Individualized
 - Trauma-informed
- Developed in context where crisis resulted in legal incapacitation
- Now that equal legal capacity is required, can be used with greater freedom and safety as a form of supported decision-making

Accessibility measures

- Systemic accessibility measures are complementary to individualized support
- For example, a health care provider should have sign language interpreters available, rather than make individuals bring, and pay for, their own interpreter (CRPD Articles 25, 9, 21)
- Access to justice requires accessibility measures in the law enforcement, courts and prison systems (CRPD Articles 13, 14, 9, 21)

Accessibility measures continued

- Accessibility requires training of service providers and officials interacting with general public to effectively serve people with disabilities (CRPD Article 4g)
- Systemic accessibility measures may be sufficient in some cases, but many people will need personalized support systems

Common factors in support

- Grass roots initiatives and small scale; community or family level
- Driven by, and accountable to, choices of person being served
- Often grounded in close relationships that are not limited to assistance with discrete tasks

Divergent factors

- Factors that may be accommodated differently in different types of support
 - Need to respect family-based support systems and also ensure that unwanted family involvement is prevented
 - Need to ensure reliability of supporters and also avoid intrusion on personal privacy and confidentiality of support relationships
- Freedom and safety to make decisions with chosen support are underlying values in all circumstances

Other factors

- Gender and disability - intersecting discrimination with regard to legal capacity
 - Overcoming expectations of incompetence and passivity
 - Autonomy includes sexual and reproductive rights
 - Provide for single-gender support systems as an option
- Cultural competence - need for availability of supporters who reflect ethnic, religious, language and sexual orientation diversity

Other factors continued

- Develop different models of support based on existing resources, strengths and values of a given society, and to accommodate diverse needs of people with disabilities
- Indigenous people with disabilities
 - Indigenous decision-making processes may be communal and already reflect values of supported decision-making
 - Ensure that people with disabilities are treated equally with others in such processes

Other factors continued

- Existing types of support have been developed in particular countries to serve particular sectors of people with disabilities
- It may be possible to generalize and abstract some common factors, but not necessary to identify a single “best practice”
- Cross-disability and interregional dialogue would be desirable to explore relevance of models in different contexts

How to implement

- Need for comprehensive law reform, since incapacity may be embedded in more than one section of laws (CRPD Article 4.1)
- Positive measures to establish support framework (CRPD Article 12.3 and 12.4)
 - Maintain flexibility so as not to narrow support to one model

How to implement continued

- Close consultation with disabled people's organizations requires for all aspects of implementation and monitoring (CRPD Articles 4.3 and 33)
 - Importance of DPO leadership and involvement in identifying disabling laws, creating legislative and policy frameworks, and developing and evaluating different kinds of support
- International cooperation among DPOs, governments, other NGOs and communities to share information, ideas and experiences (CRPD Article 32)

Positive measures

- The obligations in relation to positive measures (CRPD Articles 12.3 and 12.4) have to be read in light of the norm of equal legal capacity
 - Article 12.4 requirement to respect the rights, will and preferences of the person refers back to equal legal capacity
 - Measures related to the exercise of legal capacity can only function under the support paradigm, not substitution

Safeguards to prevent abuse

- Safeguards should not over-protect people with disabilities
- Support is fiduciary relationship with inherent obligations of accountability and loyalty

Safeguards to prevent abuse continued

- In some situations desirable to have closer scrutiny
 - CACL identifies the following situations as needing formal accountability of supporters:
 - Communicating or interpreting a person's will and preferences
 - Administration of financial resources

Safeguards to prevent abuse continued

- PO-Skåne prioritizes privacy and confidentiality to meet needs of a population for whom bureaucracy and involvement of authorities would be an obstacle

Safeguards to prevent abuse continued

- CACL calls for availability of external review to ensure that support respects the person's will and preferences and is free from conflict of interest and undue influence
 - While this sounds unobjectionable, it would place people at risk of having to defend their support relationships, counter to the need for confidentiality and avoidance of intrusion in personal matters
 - Such review should be limited to support involving interpretation of a person's will and preferences, where opportunity to express dissatisfaction is otherwise not available

Safeguards to prevent abuse continued

- Measures to prevent exploitation and abuse in fiduciary relationships would apply to supported decision-making
- People with disabilities are guaranteed access to justice in CRPD Article 13, including accommodations to facilitate effective participation in legal proceedings

Safeguards to prevent abuse continued

- Obligations related to prevention of all forms of violence, exploitation and abuse against people with disabilities are comprehensively addressed in CRPD Article 16
 - Includes preventive education, law enforcement, protective services, recovery and reintegration services for victims, and monitoring of programs designed to serve people with disabilities
 - All such measures should respect individual dignity and autonomy in keeping with CRPD Article 3 (Principles)

Providing access to support

- Support will mostly take place informally, and will be developed by people with disabilities, their families, friends and communities, peer support networks and collaborating groups and organizations
- Government can play a role in encouraging the development of different kinds of support systems, and in facilitating access to support by those who may want it
 - Measures could include active promotion through seminars and community forums, funding and policy support of DPO initiatives

Providing access to support continued

- “Support to seek support”
 - Relationship can be initiated by a person seeking support or by a person offering support
 - Outreach should be an overall component in a policy framework
- Coordination with systemic accessibility measures
- Coordination with legal reforms

Providing access to support continued

- Interim support
 - CACL proposes office of Public Facilitator to provide interim support to individuals while helping them to develop networks within the community

Existing laws

- No government has fully implemented the support paradigm as required by the Disability Convention.
- Existing models should be compared with the CRPD obligations.

Existing laws continued

- Sweden has abolished plenary guardianship and instituted a system of support services for people with disabilities and a “last resort” option of partial guardianship [FN 7]
 - Mentor or “god man”
 - Appointed by court
 - Drawn from family members or recruitment of professionals and community members
 - Acts only with consent of person receiving support
 - Paid for services

Existing laws continued

- Sweden continued
 - Trustee or “forvaltare”
 - Guardian-like powers but person retains the right to vote
 - Person is restricted from acting in matters under authority of the trustee
 - Other services, such as personal assistant, escort and contact person also available

Existing laws continued

- Discussion of Swedish system
 - System retains the distinction between legal capacity and incapacity, rather than equalizing legal capacity of people with disabilities and others
 - Existence of the trustee option means that the mentor's obligation to act only with a person's consent is a question of mandate rather than respect for individual rights and freedoms
 - Seems onerous to have appointment of mentors by a court, and not clear whether a person can refuse support

Individual representation agreements

- Several countries or units of federal states allow individuals to designate others to represent them in lieu of having a substitute decision maker appointed by a court [FN 7]
 - While this gives people somewhat more control, it is still within the incapacity paradigm and coercive in nature

Assistance regime

- In some Latin American countries, there are two regimes for incapacity: plenary guardianship and assistance [FN 8]
 - Assistance means that the person's approval plus that of the assistant are required to take actions
 - This is similar to a support paradigm but it is coerced interdependence, rather than agreed

Children and legal capacity

- In all legal systems, legal capacity is limited by age
- Children have an evolving legal capacity
 - Right to freely express views, given due weight in accordance with age and maturity (CRC Article 12)
 - Disability Convention applies support paradigm to children - equal right to express views which are given due weight, and entitled to disability- and age-appropriate assistance to realize this right (CRPD Article 7.3)

Conclusions

- Collaborative study will be needed, both within each country and internationally, to fully explore the support paradigm and what it means for society and for people with disabilities
- Support paradigm is a necessary and logical step in creating an inclusive society that guarantees equal human rights of people with disabilities

Conclusions continued

- As individuals have the need to take risks in order to develop themselves, world society must abandon protectionism in favor of self-determination and solidarity for all people, including people with disabilities

Footnotes

- FN 1 Report of CACL Task Force on Alternatives to Guardianship
- FN 2 PO-Skåne and Supported Self-Decision
- FN 3 IDC Flyer on Legal Capacity
- FN 4 Advocacy Note on Legal Capacity
- FN 5 Expert Paper produced for the Special Rapporteur on Disability
- FN 6 Speakers at program on “Self Advocacy and Inclusion,” 3 August 2005

Footnotes continued

- FN 7 Herr, “Self-Determination, Autonomy and Alternatives for Guardianship” in The Human Rights of Persons with Intellectual Disabilities
- FN 8 Discussion of legal capacity in Venezuelan law, <http://www.monografias.com/trabajos17/personas-juridicas/personas-juridicas.shtml>;
Discussion of legal capacity in Argentinian law, <http://html.rincondelvago.com/capacidad-juridica.html>