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Robert Wood Johnson  
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**THE BOGGS CENTER ON DEVELOPMENTAL DISABILITIES**

*New Jersey's University Center for Excellence in Developmental Disabilities Education, Research, and Service*

*New Jersey's Leadership Education in Neurodevelopmental and Related Disabilities Program*

# Developmental Disabilities Lecture Series



**SPRING 2022 WEBINARS**



## Supported Decision Making



**Michael J. Kendrick, PhD**

Former Director, Supported Decision Making  
Center for Public Representation  
Northampton, MA

**April 8, 2022**

# Webinar Housekeeping

## Handouts

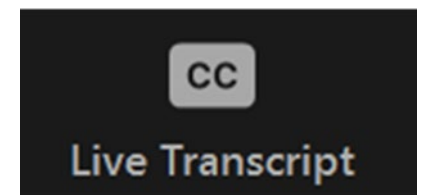
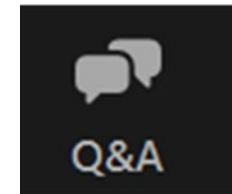
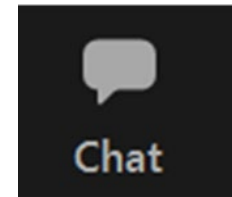
- **Handouts** may be downloaded from the link in the **Chat** box. The link will be posted multiple times throughout the presentation.
- The handouts will also be posted on The Boggs Center website:  
[http://rwjms.rutgers.edu/boggscenter/dd\\_lecture/audio.html](http://rwjms.rutgers.edu/boggscenter/dd_lecture/audio.html)
- Questions may be asked in the Q&A box. You will not be able to type in the Chat box.

## Q & A

- We are planning to have a brief Question & Answer session at the end of the lecture.
- In order to ask a question, you have to type it in the **Q&A** box.

## Closed Captions (CC)

- Closed captions are available. To view captions, click **CC** and select **Show Subtitle** from the menu.



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# Supported Decision Making

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# Definition of Supported Decision Making

“A series of relationships, practices, arrangements, and agreements, of more or less formality and intensity, designed to assist an individual with a disability or other limitations or impairments to make and communicate to others decisions about the individual’s life.” Robert Dinerstein

***Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision Making, 19 HUMAN RIGHTS BRIEF 8, 10 (Winter 2012).***



# Definition of Supported Decision Making

- A similar definition of supported decision making practice also applies to other groups in society whose autonomy and rights may lead to their losing the right to make their own decisions such as persons with mental health needs, elderly persons, persons with conduct disorders etc., though the practice of supported decision making is currently more extensive with persons with disabilities.
- It is notable that in the case of the state of Alaska, that their current supported decision making statute applies to all Alaskan citizens irrespective of whether they have notable functional impairments or other limitations.



# Key Elements of Supported Decision Making

- ▶ In reality, most people routinely seek support with at least some of their decisions and may blend informal “natural” supports with their personal decision making processes with formal supports with other aspects of their decision making such as the use of consultants, tax advisers, financial guidance more generally, psychological and behavioral counseling, fitness guides, travel agents, architects, contractors and so on.
- ▶ The preceding are varieties of targeted support from professional sources and in a given person’s life, formal supports to decision making may blend in with less formal supports including “natural” supports in their decision making.



# The Terms “Guardian” and “Conservator”

- A guardian is a court-appointed fiduciary who is responsible for ensuring that the personal, day-to-day needs of a child or incapacitated adult are taken care of. The person whose well-being the guardian is responsible for is called a “ward”.
- In the case of a child, often the guardian is the primary caregiver, living with the child and fulfilling a parental role.
- This is not always the case with an incapacitated adult. The guardian of an incapacitated adult is usually in charge of making sure that the ward gets adequate medical treatment and that the ward’s caregivers are doing an adequate job of meeting his or her personal needs.
- A conservator, or guardian of the property, on the other hand, is a court-appointed fiduciary who is responsible for managing the financial affairs of a child or an incapacitated adult. The conservator takes care of real estate, manages bank accounts, and handles investments. His or her duties can range from paying bills to buying and selling stocks and bonds to managing rental property on behalf of the ward. (The above taken from Robert Kulas 2010)
- In some state laws these terms are used interchangeably, so it is important to clarify their precise legal meaning and duties.



# Supported Decision Making Practice

- Supported Decision Making (often referred to as SDM) is an alternative to guardianship and conservatorship that allows an individual with a disability, impairment or other limitations to work with a personally selected mix of supporters to make his or her own choices in their life.
- In this approach, the individual designates people to be part of a support network to help him or her with those aspects of their decision making for which they feel a need for support.
- SDM promotes self-determination, control and autonomy. It can strengthen independence and autonomy over time
- Unlike *substituted* decision-making where guardians, family members or caregivers *make decisions for the individual*, supported decision making enables the person to make his or her own decisions with assistance from a trusted network of supporters when the person feels they may need it.



# Enlisting Supported Decision Making Supporters

- ▶ In essence, we all often informally seek our own sources of support when we feel we need it and thus engage in supported decision-making with many of our decisions that are challenging for us.
- ▶ Depending on the issue of concern to us, we reach out to families or friends, colleagues or classmates, mechanics or mentors before we decide to go on a blind date, buy a used car, change jobs, renew a lease, sign up for a hot yoga class or undergo cataract surgery. We confer and consult with others, and then we decide on our own.
- ▶ In most people's circumstances "natural support" with their decision making is both informal and variable in its value depending upon those offering and receiving such support.

# Role of Supported Decision Making Supporters

- ▶ People who may take advantage of supported decision making practice may, for example, need assistance making decisions about various matters such as living arrangements, health care, lifestyles, financial matters and other life concerns, but *they may not normally need a guardian to make those decisions for them*.
- ▶ What they might need instead is a trusted network of personally chosen supporters to engage their questions and review their options as they engage the specific content of specific decisions.
- ▶ With such assistance they can confer with and consult their supporters, and then in due course reach their own decisions.
- ▶ All of this means that the person may potentially be much better supported and strengthened in their personal decision making than would otherwise be the case because of the intentionality, commitment and quality of the support provided by the supporters.



# Role of Supported Decision Making Supporters

- Supporters can potentially be anyone that the person trusts such as family members, co-workers, friends, relatives, past or present service providers etc.
- It is critically important that the focus individual select supporters who they know well and can trust to respect his or her will and preferences and will honor the choices and decisions the individual makes.
- The mix of such persons may vary over time as the person discovers new supporters or existing supporters are not available.
- Where the person has a limited network of potential supporters such supporters can deliberately be recruited much as is the case with other intentional personal support networks.



# Different Supporters for Different Decisions

- Supported decision making practice essentially formalizes “natural supports” somewhat by first placing an explicit emphasis on supporting the focus person (sometimes called the “decision maker”) with a selected range of decisions that the person seeks assistance with.
- It also explicitly defines those providing decision making support as being “decision supporters” and links such individuals to specific areas of personal decision making.
- When supported decision making is performed optimally, it can potentially strengthen and further evolve both the capacities of the person and the quality of the decisions taken.



# Substituted Decision Making vs. Supported Decision Making

- Supported decision making as a practice has arisen in recent years due to the recognition that guardianship/conservatorship has the effect of depriving the person receiving it of their legal right to make their own decisions usually for the remainder of their lives.
- That right and responsibility is transferred to the designated substitute decision maker i.e. the (legal) guardian/conservator.
- Many people have referred to this as “civil death”, as the person essentially loses all normative rights and legal options in relation to decision making and the guardian/conservator essentially assumes ultimate legal control of the person’s life and the responsibilities that may ensue.



# Scale and Challenge of Increasing Adoption of Supported Decision Making

- ▶ Due partially to enhanced medical care, many people with I/DD will likely outlive their parents and family caregivers. Data suggest that by the year 2030, there will be several million individuals over 60 years old with intellectual disabilities in the U.S. who will be at risk of guardianship.
- ▶ At the same time guardianship numbers are increasing, there has been what disability experts call a “paradigm shift” from the overly protective, restrictive and often the oppressive construct of guardianship to the more rights-focused construct of supported decision making (SDM).





# Introduction of Supported Decision Making as an Alternative to Guardianship

- Though just gaining a foothold in the United States, where **Texas** became the first state to pass SDM legislation followed by **Delaware** and now being pursued in many other states in the US, supported decision making has been evolving.
- Supported decision making (SDM) has already been in place in other countries. In some instances, for more than several decades, such as in British Columbia in Canada where there have been “representation agreements” as a legislatively guaranteed supported decision making option since the late 1980’s. These have now spread to many other jurisdictions in Canada.
- Since the passage of the **UN Convention on the Rights of Persons With Disabilities** over a dozen years ago, some countries have passed their own state or provincial laws to recognize supported decision making



# Challenges and Inherent Limitations of Decision Making

- Supported decision making is not a panacea for persons who practice it, as decision making is inherently challenging
- It is possible, even with quite helpful support from others, to still make poor decisions on occasion.
- At the same time, by practicing supported decision making *on an ongoing basis*, the capacities of the person related to making decisions can realistically be deepened and strengthened
- At the same time, decision makers typically remain vulnerable in relation to their decision making, since it is always possible to make poor decisions even in matters that the person has already considerable mastery of.
- However, if supported decision making is not practiced as a regular habit, the optimal benefits and potentials from the practice will likely not be optimized



# Legal Capacity

re: UN Explanatory note on legal capacity and forced interventions

- Legal capacity is what a human being can do within the framework of the legal system.
- It is a construct which has no objective reality but is a relation every legal system creates between its subjects and itself.
- Legal capacity gives the right to access the civil and juridical system and the legal independence to speak on one's own behalf.



# “Support” and “Substitution” Regarding Decision Making

- Support helps people to exercise their legal capacity; whereas substitution takes over and displaces the legal capacity of some people.
- Supported decision making can be of various degrees and periods of time, depending on the person’s need as deemed by him or herself. Needs can also be ascertained through a supportive process. Substitution is all or nothing. Once put in place it continues till dismantled.



# What is Legal Capacity?

- Several countries have long held that everyone – including individuals with disabilities has “legal capacity”.
- “Legal capacity” refers to a person's authority under law to engage in a particular undertaking or maintain a particular status.
- It also is a presumption that is voided by the premise of guardianship i.e. that the person lacks legal capacity and others must be appointed to provide it
- See [www.un.org/esa/socdev/enable/rights/ahc8docs/ahc8idc1218ex.doc](http://www.un.org/esa/socdev/enable/rights/ahc8docs/ahc8idc1218ex.doc)



# Recognition of Legal Capacity

- The denial of legal capacity has often been a legal reinforcement of social prejudice.
- All persons with disability have the right to develop a full human life and such development cannot happen without the opportunity to exercise capacity.
- To deny this opportunity to any group of persons is to perpetuate exclusion and to legitimize discrimination.



# Addressing the Spectrum of Need

- ▶ The support model acknowledges that there are times when other people make decisions for us, such as when a person is unconscious. Support continues to be provided to encourage the person to begin exercising legal capacity, while urgent needs are taken care of.
- ▶ Support must adhere to the same principles irrespective of the degree of support provided, for example, respecting the will of the person receiving support and without attempting to unduly influence. For example, conflict of interest would taint any degree of support.



# Supported Decision Making Agreements

- A distinctive feature of supported decision making practice often is the establishment of a formal “**supported decision making agreement**” between the person being supported and their supporters
- Such agreements specify both who is a formal supported decision making supporter and around what decision subject areas the person being supported has requested support
- Unlike with “natural supports”, the support being asked for is specified by formal agreement that can be modified at any point by the person being supported





# Presumption of Decision Making Capacity

- The existence or presence of personal limits with decision making ought not to be automatically taken to be evidence that the person should be summarily excluded from autonomy in their decision making
- Rather, given the principle of starting with the **least restrictive alternative**, an argument for strengthening the supports that might enable a given person to make improved decisions is prudent. This is true notwithstanding their limitations and it also preserves their ongoing crucial status of being the key decision maker in their own life.



# Supported Decision Making as a Meaningful Support

- ▶ The presence of supported decision making supports (SDM) does not deny that a given person may nonetheless still have limitations that they struggle with in relation to any given decision, much as that fact applies to most people given the content of a given decision.
- ▶ However, it does indicate a recognition that the person's abilities and capacities to address the content of a given decision can and should be strengthened and enhanced, such that the person has a greater probability of managing a given decision more optimally, but still not without continuing constraints due to their personal limitations.



# Key Features of Supported Decision Making Agreements

- The SDM agreement is a negotiated document between the person being supported and the persons nominated as supporters
- The SDM agreement invites others to play the role of supporter on specific aspects of the person's decision making
- Supported decision making is possible without having an SDM agreement, as informal supported decision making is a widespread practice in society
- The SDM agreement is essentially a publically shareable document as to the person being supported intentions and wishes regarding their personal decision making practices relative to the role of designated supporters



# Key Features of Supported Decision Making Agreements (continued)

- ▶ The SDM agreement typically specifies the responsibilities of supporters that the person being supported and the supporters have agreed to
- ▶ In most instances the SDM agreement is quite straightforward and comparatively easy to produce and modify in line with the person's emerging life circumstances
- ▶ The SDM agreement creates a publically referable basis for supporter role specification and accountability and it preserves the person's role as the prime decision maker in their own life



# Key Features of Supported Decision Making Agreements (continued)

- The SDM agreement **does not** mean that the person is incompetent to make his or her own decisions on their own (from SDMNY, January 2018)
- The SDM agreement **does not** certify that the person satisfies the capacity requirements established in law to deal with others (from SDMNY, January 2018)
- The SDM agreement **does not** mean that the person needs guardianship or cannot make decisions without those people (from SDMNY, January 2018)



# Key Features of Supported Decision Making Agreements (continued)

- Given that the overall intent of supported decision making is to uphold the right of the person to make their own decisions, the SDM agreement should not include items against the person's wishes
- SDM agreements do not obligate third parties (unlike "power of attorney" in legal proceedings)
- The SDM agreement does not authorize others to make decisions for the person being supported (from SDMNY, January 2018)



# Key Features of Supported Decision Making Agreements (continued)

- The SDM agreement does not allow others to substitute their own ideas or preferences for those of the person being supported (from SDMNY, January 2018)
- The SDM agreement does not obligate the person to get support *only* from the listed supporters (from SDMNY, January 2018)
- The SDM agreement does not require the person to consult only with the people listed in the agreement (from SDMNY, January 2018)
- The SDM agreement does not require legislation in order to be put into effect though it is often referenced in such statutes



# Key Features of Supported Decision Making Agreements (continued)

- ▶ The SDM agreement does not, by itself, ensure that the support provided will *always* be *per se* qualitatively adequate or available
- ▶ The SDM agreement does not prohibit the supporter from being able to give counsel that may differ with wishes of the person being supported, since offering counsel contrary to the person's intentions and preferences at the time does not in any way diminish the authority of the person to make the final decision
- ▶ The SDM agreement does not prohibit the person being supported from excluding, on occasion, their supporters from the process of making a given decision






# Key Features of Supported Decision Making Agreements (continued)

- The SDM agreement does not, by itself, entirely ensure that supporters and the person being supported are always clear in their roles and the conduct expected of them, though it does provide the basis for clarifying and specifying roles
- The SDM agreement does not necessarily have legislative recognition in many jurisdictions at the present time, though there are increasingly jurisdictions that have legislatively provided for their use in the context of offering an alternative to guardianship




# Scale of the Need for Supported Decision Making in the United States

- This “civil death” can extend to whether the people made into “wards” of the guardian can make their own decisions about their personal health care, their finances, whether to marry and raise a family, with whom to associate, and other day-to-day decisions others take for granted.
- At least 1.5 million adults in the United States are under guardianship/conservatorship, but the number could be as high as 3 million, given the remarkable dearth of data. Among the community of individuals with intellectual or developmental disabilities (I/DD), the number of “wards” under guardianship is expected to increase over the next few decades.



# Some State, National, and International Resources on Supported Decision Making

- <https://supporteddecisions.org>
- <http://www.supporteddecisionmaking.org>
- <https://sdmnevada.org>
- <https://www.tndecisionmaking.org>
- <https://www.arcind.org/future-planning/supported-decision-making/>
- <https://www.aclu.org/issues/disability-rights/supported-decision-making>
- <http://autisticadvocacy.org/2016/02/the-right-to-make-choices-new-resource-on-supported-decision-making/>
- [https://docs.wixstatic.com/ugd/c0271d\\_1a191b7604334a609db2efd4c4ee5abc.pdf](https://docs.wixstatic.com/ugd/c0271d_1a191b7604334a609db2efd4c4ee5abc.pdf)



# Some State, National, and International Resources on Supported Decision Making

- <https://www.americanbar.org/groups/disabilityrights/resources/article12.html>
- <https://www.alberta.ca/supported-decision-making.aspx>
- <https://www.internationaldisabilityalliance.org/CRPD>
- <https://www.internationaldisabilityalliance.org/CRPD>
- <https://decisionsupportservice.ie>
- <https://www.tandfonline.com/doi/abs/10.1080/23297018.2015.1063447?journalCode=rpj20>
- <https://www.mhe-sme.org/what-we-do/human-rights/promising-practices/>
- <https://www.inclusion-europe.eu/tag/supported-decision-making/>



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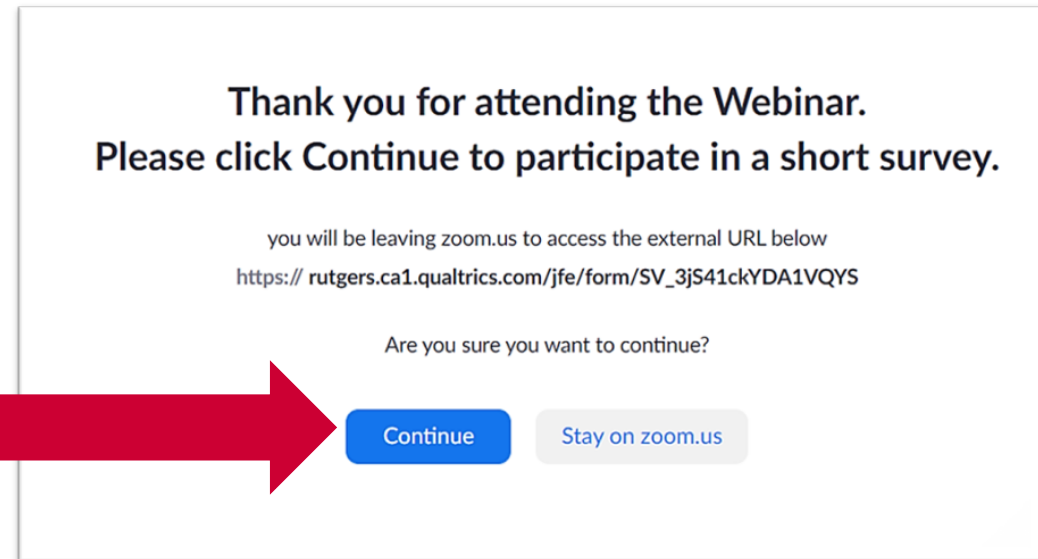


**Q & A**

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