

Supported Decision-Making: An Agenda for Action

February 2014

Introduction

Historically, people with cognitive disabilities have been placed under legal guardianship regimes, losing the right to make their own choices about life issues such as where to live and whether to work, marry, or receive health care. Supported Decision-Making (SDM), by contrast, offers an opportunity for many adults with disabilities to make their own decisions, consistent with fundamental human and legal rights, and an emerging international consensus.

SDM is a process in which adults who need assistance with decision-making – for instance, some people with intellectual or developmental disabilities (I/DD) – receive the help they need and want to understand the situations and choices they face, so they can make life decisions for themselves, without the need for undue or overbroad guardianship. Introduced as part of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), SDM can be a key element for improving experiences and opportunities for many people with different life conditions (Kohn, N., Blumenthal, J. & Campbell, A. 2012).

Since the Middle Ages, society has too often responded to people who need help making some decisions by taking away their right to make any decisions through the use of plenary or “full” guardianship (O’Sullivan, J., 2002; Salzman, L., 2010). In the United States, adult guardianship is a legal process governed by state law with different rules and systems in each state. In general, guardianship is ordered when a court determines that a person cannot make some or all decisions and is in need of “protection”; and that there are no less restrictive options for decision-making than guardianship.¹ This is considered a “substituted” decision-making approach because the court appoints a third party to make some or all decisions for the person. In the majority of cases, courts order full or “plenary” guardianship, where the guardian makes all decisions for the person with a disability. (Teaster, P., Wood, E., Lawrence, S., & Schmidt, W., 2007).

Article 12 of the CRPD challenges the existing system of substituted decision-making, including guardianship. It pushes us to move toward a new framework where people are supported to be their own decision-makers. Article 12 recognizes that all people have legal capacity and that governments must take appropriate action to provide people with access to the supports they

¹ “Less restrictive” options mean other ways of making decisions that protect the person’s rights and self-determination better than guardianship.

need and want to make their own decisions and order their own lives to the maximum of their capabilities (Dinerstein, R., 2012).

While there is no "one-size-fits-all" model of SDM, it generally occurs when people receive assistance from one or more trusted friends, family members, professionals or advocates - to help them understand the situations they face and choices and options they have, so they can make their own decisions. This process mirrors what happens for most adults when they make decisions such as whether to get car repairs, sign legal documents and consent to medical procedures: they seek advice, input and information from friends, family or professionals who are knowledgeable about those issues, so they can make their own well-informed choices.

This paper outlines actions taken and being taken to advance SDM as an alternative to guardianship, culminating in the findings and recommendations of the First Annual Symposium on Supported Decision-Making, held at the American University Washington College of Law on October 24, 2013.

Building the Agenda

The first step toward an Action Agenda was a one-day conversation (Roundtable) held in New York City in October 2012, where stakeholders met to discuss the rights of people with intellectual disabilities to make their own decisions, including the impact of the CPRD. Organized and supported by the American Bar Association and the Administration on Intellectual and Developmental Disabilities, the goal of the meeting was to explore concrete ways to move from a model of substituted decision-making, like guardianship, to one of SDM, consistent with an assumption of capacity for all adults. Roundtable participants included experts and stakeholders from a variety of disciplines and organizations, including lawyers; physicians; educators; services providers; siblings; parents; advocates; members of the judiciary; representatives from national and state organizations and participants from several government agencies.

In the summer of 2013, a 29 year old woman named Margaret "Jenny" Hatch won a landmark legal battle protecting her right to make her own life decisions using SDM, instead of being subjected to guardianship. Like many people with disabilities, Jenny faced a guardianship petition challenging her right to make decisions -- choices she had always made for herself, like where to live, what to do and who to see. At the request of her parents, the court put Jenny under a temporary guardianship and placed her in a group home, where they took away her cell phone and laptop and wouldn't let her see her friends. However, after a year of litigation, Jenny won the right to make her own decisions and now lives and works where she wants, has the friends she chooses, and encourages others to do the same.

The trial Court in Jenny's case was the first to order the use of SDM instead of a guardianship for a person with a disability, and received national and international attention for highlighting "an individual's right to choose how to live and the government's progress in providing the help needed to integrate even those with the most profound needs into the community."²

On October 24, 2013, a group sixty five participants was convened for an Invitational Symposium on Supported Decision-Making.³ The meeting was planned and coordinated by Quality Trust for Individuals with Disabilities, The Council on Quality and Leadership (CQL) and the Burton Blatt Institute (BBI), and hosted by the American University Washington College of Law. This event was also supported, in part, by funding from the Administration on Intellectual and Developmental Disabilities, Administration for Community Living, U.S. Department of Health and Human Services.⁴ National and international stakeholders and opinion leaders were invited to come together and outline an action agenda for moving forward to advance and implement SDM. Ms. Hatch and her supporters were invited to frame the issues from the perspective of the person needing assistance. Stakeholder representatives included advocates with disabilities, families, guardians, lawyers, researchers, government policy makers, providers and other professionals. This document reflects the conclusions and recommendations from the participants.

Challenges and Opportunities

It's an important time to have this conversation. This generation of people with disabilities is the first to grow up with the rights and opportunities protected and promoted by the Americans with Disabilities Act (ADA). There is growing recognition that over-reliance on formal systems of substituted decision-making can hinder or prevent inclusion, self-determination and community integration, in violation of the ADA and other federal laws (Salzman, L., 2010).

The 2012 Roundtable included conversation about needed legal and other reforms and changes that may lead to the end of guardianship as we know it. Roundtable participants brought many

² http://articles.washingtonpost.com/2013-07-20/local/40695386_1_group-home-guardianship-jim-talbert

See, also, http://articles.washingtonpost.com/2013-08-02/local/41002259_1_morris-and-talbert-jim-talbert-jenny-hatch ; <http://www.wavy.com/news/local/newport-news/jenny-hatch-in-her-new-life>

³ Symposium participants included the Administration on Intellectual and Developmental Disabilities, Open Society, Collaboration to Promote Self-Determination, Elizabeth Boggs Center, and the Autistic Self Advocacy Network.

⁴ Organizations receiving funding that undertake projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Intellectual and Developmental Disabilities policy.

backgrounds and experiences and raised a number of important and difficult questions, including:

- Should we build a bridge between the existing guardianship laws and full SDM?
- Can we revise current standards for guardianship to stress independent decision-making and the supports needed?
- Should implementation take place somewhere other than the judicial system?
- How would decision-making supporters be appointed?
 - What process would be needed to have them legally recognized?
- Where and how do we find the resources needed to create networks of support and trust for individuals?
- How do we prevent abuse and undue influence without denying legal capacity?
- How can we protect the integrity of the decision-making process?
 - Do we need standards and expectations for supporters? Should there be a reporting system?
 - Should supporters be required to keep records?
 - What kind of monitoring would be required?
 - Should monitoring differ for different kinds of decisions?
 - How should disputes between supporters and the person with a disability be resolved?
- How would SDM work for other populations? For example, what differences would we find in applying the idea to older individuals with dementia or to those with episodic mental health conditions?

An Agenda for Future Action

At the October 2013 Invitational Symposium, participants were divided into four workgroups: (1) People with disabilities, families and support networks; (2) Legal; (3) Policy and practice; and (4) Research. People from all stakeholder groups were represented in each working group to ensure that all perspectives were represented. Each group was provided with a standard framework, a facilitator and some general questions to start. The groups were challenged to come up with action steps and strategies to ensure SDM is used as a primary approach for assisting people with multiple types of challenges to make choices in various circumstances. The results of the group work are as follows:

GROUP 1 - People with Disabilities, Families, Support Network Issues

Woven through all of this group's discussion, was the idea that we need to re-evaluate everything we do (research/legal/policy/practice) from the perspective of the person with a disability. There are many good ideas (e.g., person-centered planning and self-determination) that have yet to be fully brought to life and translated to practice in a way that results in achieving the outcomes desired. Therefore, an effort to move SDM from theory to practice could help us to define and operationalize many of these ideas.

GROUP 1 Action Steps

1. Start with a focus on education. There should be an expectation that all children with disabilities will develop as decision-makers. SDM should be a basic expectation for everyone – not a “thing” or a “technology”.
 - Create a public awareness campaign about SDM options.
 - Track who is getting, understanding and implementing the message.
2. Frame decision-making as a basic human right and natural part of the human experience. From an early age, the expressed interests of children with disabilities should be heard, respected and considered in every activity that involves decisions about their life.
 - Create a “toolbox” that will help people explore the options for support.
 - Create a one stop resource center for information on SDM.
3. Focus on rights and expectations to set basic standards.
 - Identify and promote one uniform standard of good and ethical practice that would cut across all professions and job titles.
 - Identify ways to support and spread high expectations – perhaps using peer to peer support strategies and parent to parent support groups.
 - Identify and implement ways to help people explore different issues and circumstances – so that everyone can understand how people with very different abilities can take charge of their lives.
 - Recruit professionals (psychology/speech/OT/PT/Social work/lawyers and others) to embrace the expectation that people with disabilities should and will develop into their own decision-makers – so that people not directing their own lives becomes the exception instead of the norm.

4. Address the elephant in the room – SAFETY.

- Need a process for attacking the “myth” that safety in life can be achieved for anyone.
- Define what it means to be “safe”.
- Answer the burning questions that too often steer the conversation and action away from how to support the person:
 - Can we really keep people safe?
 - When does trying to keep people safe become abusive or coercive?
 - When does the cost of safety (loss of freedom and access to life) outweigh the benefits?
- Create a way for people to tell their stories of how they balance safety, autonomy, and dignity and risk in real life situations.
- Use real-life examples of people taking different paths and using different decision-making methods so the discussion moves away from being “hypothetical.”
- Share stories that illustrate what worked and did not work in different situations.

5. Create a way for people working on this issue throughout the country (and world) to link to and communicate with one another for the purpose of building momentum and advancing practice:

- Sharing resources;
- Telling stories;
- Networking with other professionals doing similar work;
- Getting technical assistance;
- Accessing sample tools and documents; and
- Forming strategic partnerships to address and advocate for specific issues, infuse SDM into everyday life, across the ADA, CRPD, Individuals with Disabilities Education Act (IDEA), Vocational Rehabilitation and other policy statements and laws.

GROUP 2 - Legal Issues

The legal group identified action steps necessary to advance SDM in the courts and the practice of law. There was consensus that SDM, with adequate resources, must be put in place before guardianship and that guardianship should only be considered if SDM has not succeeded. It

was acknowledged that SDM is generally not known to the general public, policymakers, the judiciary and many lawyers. Part of the legal challenge is to make this strategy known and understood. One of the best ways that we can do that, whether we are in court or talking to policymakers or parents and friends is to associate the right to make decisions, through SDM or otherwise, through known rights. **A person's right to make his or her own decisions is inherent in the U.S. and state Constitutions and other laws, and therefore should be legally enforceable. That right should not be dependent on the quality of any decision made.**

GROUP 2 Action Steps

1. Ensure that there is a bedrock human, legal and enforceable right to make your own decisions.
2. Ensure that this right is not contingent upon the quality of decisions you make, the process by which you make those decisions or the ways in which you communicate them.
3. If a person chooses to use accommodation or support to make decisions, this request for assistance should be recognized as a fundamental human right. The use of assistance should not be used as a pretext to take away any person's right to make decisions.
4. These rights should be communicated in policy, practice and law, and utilized throughout the lifespan (and be recognized and respected by third parties).
5. Communicate and advocate for these rights whenever possible. Whenever possible, preferably always, associate them with known rights. This will take the "mystery" out of SDM and allow it to be applied across the lifespan and life experiences – in courts, employment situations, educational settings and other areas.
6. Focus outreach and advocacy on third parties who have traditionally steered people toward guardianship. Stress that third parties have an affirmative duty to accommodate people's need or desire for SDM.
7. Pursue administrative and legal remedies against third parties that do not support a person's right to make his or her own decisions.
8. Outreach should also be targeted to the general public—strategic communication illustrating people's right, ability and legal capacity to make their own decisions.
9. Define this right, and disability in general, as a diversity issue, to make people with disabilities more visible and included in their communities.

GROUP 3 - Policy and Practice Issues (International, Federal, State, Local)

The policy and practice group began with a focus on critical principles and strategies to guide best practice. They generated a list of principles that are known, but not always reflected, in policy or day-to-day practice such as:

- Everyone has a right to make their own decision(s).
- People with disabilities have a right to be their primary decision maker.
- Good decision making is a skill that can be learned.
- SDM should be available to all who choose to use it.
- Everyone has a right to fail without serious injury or loss of rights.
- With good SDM, guardianship should be a last resort. With effective use of SDM, guardianship should not be needed. Relationships need to be valued, created, mentored and supported.
- All people need help making decisions. We are all diverse, we all make decisions individually and with support, at different times in life.

GROUP 3 Action Steps

1. Finalize a set of guiding principles that everyone will support.
2. Redefine disabled to differently abled.
3. People should have the right to maintain relationships with supporters while maximizing inclusion and rights.
4. Policies should facilitate community and personal relationship(s) with a focus on rights and choice.
5. Add SDM and the right to make one's own decisions to any statement of rights associated with programs or services.
6. Develop policies and strategies to support people to exercise their legal rights
7. Develop better guidance about what constitutes informed decision making.
8. Identify promising practices from CRPD implementation globally.

What specific policy changes are needed in Supported Decision-Making?

- All people should have the right to make their own decisions, as consistent with the integration mandate set out in the Olmstead decision.

- Require information on alternatives to guardianship to be provided as part of federal regulations (e.g., Medicaid, Older Americans Act, IDEA).
- Require IDEA regulations on transition planning to specifically address procedures for implementing SDM.
- Strengthen Preadmission Screening and Resident Review (PASRR) regulations to specifically address and implement SDM.

How can Supported Decision-Making be advanced in practice?

Training:

- Waiver and community providers must be trained to respect and implement SDM.
- Special education providers must be trained to respect and implement SDM.

Education:

- State and Federal Departments of Education must provide interpretive guidance on alternatives to guardianship and information on SDM.
- Inform judges, hearing officers and administrative law judges about SDM.

Structure and Process:

- Incentivize supporters to utilize SDM.
- Implement Employment First policies to get people integrated into their communities where they can make decisions and build relationships.
- Ensure that Medicaid decision processes for services are in accessible formats.
- Review state guardianship laws and suggested appropriate changes to recognize less-restrictive alternatives including SDM.
- Create and implement a campaign by people with disabilities advocating for SDM.
- Ensure that SDM becomes a cornerstone in all service provision.
- Monitor systems specific to SDM and government supports to identify best practices.
- Strive for total system change in thinking and implementation.

GROUP 4 - Research Issues

The research group addressed critical questions regarding ways research can assist with advancing knowledge about SDM. The list of research questions generated reflects that much work is needed to better define both the current status and the scope of current practice.

While some initial research has been done in this area, more is needed to create a body of evidence that will support new practices. This basic research will inform what quality indicators can be used to measure progress and impacts over time.

GROUP 4 Action Steps

What are the priority questions related to policy and practice evaluation?

- What is the problem? Examine size, cause, scope, impact of guardianship. Identify who are the typical guardians, what funding mechanisms are perpetuating guardianship, and what legal provisions are perpetuating it.
- Do we know how many people live in segregated settings and who are under guardianship? How many people live with their parents / family and are under guardianship?
- How many service agencies have a policy (unwritten or otherwise) that “requires” guardianship before service provision / coordination? Why are such policies and practices utilized?
- What are public schools / VR systems advising parents during the transition process? How can students and their parents/supporters be better prepared for the transition process?

What interventions should be tested to enhance Supported Decision-Making?

- Teaching self-advocacy and SDM to students in special education, at least by the time of transition planning.
- What, exactly, constitutes SDM in particular circumstances? What are the best practices for implementing SDM?
- Identify the elements of responsibility, including duty, freedom, rationality and, accountability.
- What constitutes “consent capacity”?

Conclusions

There is significant agreement on what should and needs to be done. Because the traditions around protection and support are strong, creating significant change will require consistent and coordinated effort. The challenge for leaders is to identify the steps they can take within their scope of influence AND work collaboratively with others to create new policies, systems and practices.

These fundamental principles reflect the clear consensus on what is needed to guide future action:

- ❖ Uniform standards and guiding principles that can be universally adopted.
- ❖ The need to compile existing information in one place, and track new information and efforts as they emerge in the U.S.
- ❖ The need for research, including studies into how SDM is working in the U.S. and abroad.
- ❖ The need to identify barriers to needed reform in guardianship and other support practices.
- ❖ The need to develop alternatives for people under guardianship now as well as those who are or may be facing guardianship.
- ❖ The importance of sharing stories – both success and real life challenges.

Additionally, the following three principles should also be reflected in all actions:

1. Recognize and respect that everyone has an equal right to make their own decisions, regardless of their diagnosis or functional challenges
2. Be respectful of the various opinions and deeply held beliefs that have led parents and advocates to choose different options for decision-making support, including SDM.
3. Promote the use and development of practices that will provide people in need of support with individualized decision-making assistance in a way that imposes the absolute minimum restriction of rights.

This report is the beginning of a long-term effort to promote the use of SDM. The Jenny Hatch Justice Project⁵, formed by Quality Trust for Individuals with Disabilities is committed to serving as a link to connect people and projects working on these issues throughout the country and abroad. We will reconvene stakeholders annually to take stock of progress and continue to advance SDM policy and practice, now and in the future.

⁵ You can contact the Jenny Hatch Justice Project (JHJP) by phone at 202-448-1448, through email at JHJP@dcqualitytrust.org, or on the web at <http://jennyhatchproject.info/>.

The First Annual Symposium on Best Practices in Supported Decision Making was organized by:

