



Supported Decision-Making



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2018

The logo for the 2018 TASH Conference. The word "TASH" is rendered in large, bold, 3D-style letters. Each letter is filled with a different texture and color: 'T' is a rainbow gradient, 'A' is a wood grain, 'S' is a blue and red map, and 'H' is a yellow and black geometric pattern. Below "TASH" is the word "CONFERENCE" in a blue, sans-serif font. To the right of the letters is a glowing blue hexagonal icon containing a white geometric design of three interlocking triangles.

TASH

CONFERENCE

Portland, OR | November 28 - 30

SAVE THE DATE

Each year, the TASH Conference brings together a diverse community of stakeholders who gain information, learn about resources, and connect with others across the country to strengthen the disability field. This year's conference theme, "Be Creative - Innovative Solutions for an Inclusive Life," reminds us to think outside the box during times of uncertainty. Creativity, innovation, and determination can pave the way for meaningful and inclusive lives for people with disabilities.

Call for Proposals Deadline: Tuesday, June 5, 2018
Early-Bird Registration Deadline: Tuesday, September 4, 2018



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Letter from the President of the Board of Directors

It is a surprise to find an edition of *Connections* about my grandmother, Eliza Rachel Edwards. Born of enslaved Africans, she espoused the value of education although hers ended in the third grade. All of her children graduated from high school; two completed college. In my childhood, she supported “my” decision to say bedtime prayer and attend church services several times a week. Later, in my maturity, she did provide guidance and perspective as I made both life and commonplace decisions. And, these were my decisions to abide and to bear the consequences. She supported my decision-making, and sometimes the decision.

As frequently asserted in this edition, we all seek autonomy and sovereignty in our decision-making. Individuals with disabilities are part of “we all”. TASH advocacy of Equity, Opportunity, and Inclusion illuminates the intersection with decision-making. Conversely, the epitome of dehumanization is to eliminate choice and self-determination. In this edition, you are provided a history and legal basis of Supported Decision-Making (SDM) and you are encouraged to understand and advocate SDM.

This is TASH. We light the path to the next plateau; from guardianship, to limited guardianship to SDM. And, like the curb-cut, one day this approach, SDM, will be

universal and utilized by all. Let’s raise a cup to acknowledge our progress.

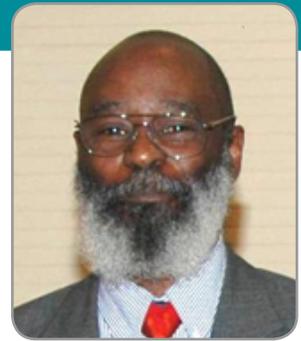
Wait! To help TASH increase its advocacy for SDM and to effectively respond to current threats to the Medicaid waiver, special education, ADA, etc., give a cup of coffee to TASH, two cups! That’s about \$10 a month. Go to the website and make a recurrent contribution.

We are TASH. This edition, as previous editions on self-advocacy, post-secondary education and other topics, is a helpful addition to our advocacy / social justice toolkit.

Share the article. Share the wealth.



Ralph W. Edwards, President
TASH Board of Directors



Ralph Edwards, President

Letter from the Executive Director

Dear Members,

I am excited to share with you our last edition of *Connections*! Its focus on Supported Decision Making and Informed Consent is timely in light of the community living and employment policies all of us have been working to promote. The gains we have made through both litigation and legislation since the U.S. Supreme Court decision in *Olmstead v. L.C.* in 1999 and the passage of the Workforce and Opportunity Act nearly a decade and a half later are significant achievements in the struggle for the civil and human rights of individuals with disabilities. However, these achievements can only be fully embraced when individuals with disabilities are able to fully express their needs, desires, and wishes.

Throughout history, individuals with disabilities were routinely viewed as incapable of making even the most basic decisions about their lives. Court appointed guardians or conservators became the sole deciders in where a person lived, what they did during the day, what health care they would (or would not) be provided, and how their finances would be handled. In some cases, the rights to marry, vote, and enter into contracts were made the purview of another family member or total stranger. The vast majority of these court appointed guardians can be said to carry out their duties to the individual who becomes their “ward” with all due diligence. Nonetheless, once a guardianship or conservator decree is entered, the very presumption of competence rarely comes up and opportunities to gain

experience in making life choices are rarely offered.

This edition of *Connections* offers viewpoints that challenge the status quo with regard to the need for court appointed decision makers. Using a variety of approaches and alternatives, supported decision making has been shown to be a highly effective alternative to legal constructs that frequently end up limiting the ability of individuals with disabilities to live “enviable lives”. As Tia Nelis, our Director of Public Policy and Advocacy stated at a recent meeting with the Department of Justice,

People with disabilities want to make informed choices about what is really important to them. They want to be informed. If your talking about choice, give us all the information we need in ways that we can understand it. Then all of the good work you are doing in *Olmstead* will help make our dreams come true.

Many thanks for your membership and support of TASH.



Ruthie-Marie Beckwith, PhD, Executive Director



Ruthie-Marie Beckwith,
Ph.D., Executive Director

Introduction

By Guest Editors Ruby Moore and Mark Friedman

We all make decisions—big and small—every day. We may take for granted that we have the right to exercise such autonomy over our lives and that we often have a network of trusted friends and allies with whom we consult to make the important decisions that affect our lives. This is not always the case for people with disabilities, especially if the person is under guardianship.

This issue of the TASH newsletter provides a collection of articles on groundbreaking work on being done around the country and internationally to implement Supported Decision-Making. Supported Decision-Making represents a fundamental shift in thinking about the best ways to support the independence, autonomy, dignity and self-determination of people with disabilities, consistent with the foundational values of TASH and its members.

Using Supported Decision-Making, a person with a disability clarifies the areas of decision-making where he or she might need some assistance. This could be anything from employment to healthcare decisions. Then the person chooses people to give that help. This could be a few people or a larger group of trusted supporters to assist in different areas of decision-making. This

sometimes involves creating a Supported Decision-Making agreement and going to court to make the agreement legal and binding. Supported Decision-Making can serve as an alternative to guardianship and a means to promote self-determination, control and autonomy. It can involve a change in the role and legal status of the guardian when one is currently in place.

Cathy Costanzo, the Executive Director of the Center For Public Representation explained in a recent presentation at the Kennedy Library in Boston, Massachusetts how “People under guardianship experience a kind of “civil death” because they have no rights to 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.

Supported Decision Making was introduced internationally through the ratification of the Convention on the Rights of Persons with Disabilities (CRPD), to foster independence, and to create a framework within which a person with a disability can make her own decisions with assistance from a network of supporters in trust relationships with the person with a disability.

TASH is pleased to present this collection of original articles that includes the experience and reflections of leaders in public policy, legal and civil rights for people with disabilities, parent and family advocacy, science and research. We hope you will enjoy reading it as much as we have assembling the authors and articles.

Ruby Moore and Mark Friedman

Introduction

About the Guest Editors



Ruby Moore

Ruby Moore

Ruby Moore is the Executive Director of the Georgia Advocacy Office, the designated Protection and Advocacy System for People with Disabilities in Georgia and is the President-Elect of TASH. Ruby is nationally known for her work in the disability field over the past 41 years, particularly in the areas of the ADA, employment, rehabilitation,

augmentative communication, and the design and implementation of settlement agreements.

Ruby has decades of experience in individual and systemic advocacy and has worked as an expert in dozens of class actions lawsuits, including landmark cases in the disability field. Her work has taken her throughout the U.S. and several other countries to bring people out of exile and to develop policies, practices, relationships, and services to support people with disabilities to have good lives. She has given testimony before U.S. Senate committees, Congressional hearings on employment of people of disabilities, the U.S. EEOC, federal court judges, and was an invited speaker at a United Nations conference in Iceland.

Ruby continues to work at the local, national and international level, to improve disability policy and the opportunities available to people with significant impact of their disability, to live and work in the community.



Mark Friedman

Mark Friedman

Dr. Mark Friedman teaches Disability Studies at the City University of New York and research design to doctoral students at Rosalind-Franklin University of Medicine and Science in Chicago.

He is the CEO of Blue Fire Consulting providing training and technical assistance to non-profit and governmental agencies. He has worked for

multiple self-advocacy organizations in Pennsylvania and nationally. He is the former Chairperson of the Pennsylvania Developmental Disabilities Council and the author of several seminal research publications.

Dr. Friedman received his Ph.D. degree in Organizational Leadership from the Union Institute and University and his MA in Organizational Development from Antioch University.

Articles from Our Contributors

Supported Decision Making and Deinstitutionalization: Lessons Learned from the Autistic Self Advocacy Network's Invitational Summit

By Kelly Israel

The Autistic Self Advocacy Network (ASAN) held an international summit, with funding from the Open Society Foundation, on supported decision making on October 18th and 19th of 2016, titled “Invitational Summit on Supported Decision Making and the Transition to the Community.” We held the summit because we wanted to answer the following questions:

Does access to supported decision making help people with disabilities move from institutional settings to a life in the community?

When a person with a disability is transitioning from an institution into the community, are there specific things that person will need to successfully live within that community, i.e. affordable housing, relationships with the community, etc.? Does supported decision making help people with disabilities gain access to these things?

Can supported decision making be used effectively with people who previously had very little choice or control over their lives?

Are supported decision making principles equally useful for reducing institutionalization in every country and context? Are there supported decision making principles that can be applied not just in the United States, but internationally, to support the broader goal of autonomy for all people with disabilities?

About the Summit

The summit was held in Washington, D.C., at American University, Washington College of Law. The summit was invitation-only, because our intention was to foster rich discussions between people with significant experience in supported decision making, deinstitutionalization, and disability rights. 45-47 people attended our summit. The attendees were self-advocates with disabilities, parents, lawyers, policymakers, human rights advocates, former judges and present-day court staff, the leaders of multiple disability rights nonprofits, providers of disability support services, and other stakeholders with substantial experience grappling with these issues.

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10 of the attendees came from countries other than the United States. There were attendees from Mexico, Serbia, Turkey, the Czech Republic, Bulgaria, Columbia, people who had worked on supported decision making pilot projects abroad, and several international disability rights organizations.

Summit Structure

Our summit focused on how supported decision making related to four things many people with disabilities need to live lives in the community, which we called “Elements of Community Integration.” People with disabilities who are transitioning from an institution into the community may find community living difficult if not impossible without access to most of these elements. The elements we identified were Housing, Relationships and Natural Supports, Access to Healthcare, and Long Term Services and Supports.

First, affordable, disability-accessible housing integrated within the community is crucial to ensuring that persons with disabilities have places to live other than in institutional settings.

Second, any person in the community requires a network of personal relationships and natural supports within that community. These networks allow any person to rely upon their fellow community members when they need help.

Third, any person in the community must receive healthcare services within their community. Without proper healthcare from sources within a community, a person cannot maintain an independent life there.

Fourth, many people with disabilities need certain services and supports in the community in order to perform activities of daily living. Some may need personal care attendant services to perform activities of daily living and live and work in the community. Others may need daily health care or vocational rehabilitation services.

The summit was divided into four segments, during each of which the summit attendees discussed how supported decision making related to one of the four elements of community integration. Each segment was divided into a panel, where a 4-5-person panel of experts discussed their work as it related to the topic; breakout discussion groups, during which the summit attendees split into groups of 6-7 people and discussed the topic

among themselves; and finally breakout presentations where the summit reconvened and each breakout group presented what their discussion group talked about to all other attendees.

The discussions attendees held at the summit were wide-ranging and complex, and we did not always come to concrete conclusions about what are some of the most contentious issues in the supported decision making movement. Nonetheless, there were a number of key themes present in each of the topics we discussed. After the summit was over, ASAN pulled together¹ all of what we heard from the presentations, handouts, PowerPoints, and group discussions at the summit. We conducted numerous follow up interviews with the summit attendees, particularly our international invitees. From this information, ASAN created its own recommendations on how supported decision making can be used to help transition people with disabilities from segregated settings into community-based settings. Most of this material will be covered in ASAN's upcoming White Paper on the summit, which will be available at <http://www.autisticadvocacy.org> once it is released. This article discusses what we learned and all that we still have left to discuss.

Housing

Slow, Methodical Use of Supported Decision Making Greatly Aids the Move from an Institution to Housing in the Community

One of the key questions raised at the summit was this: how could a person who has never made a decision before, who might have lived in an institution for decades, learn to make decisions? Nowhere is this more important than when an institutionalized person with a disability is trying to choose where in the community they want to live. The key to successful supported decision making in this context is tailoring the process to the person's individualized needs, introducing one decision at a time, and presuming competence.

Hana Solařová of Lumos, an international organization working to end institutionalization of children around the world, demonstrated at the summit and in follow-up interviews how this process should work. She described how Lumos involves the child in their own deinstitutionalization using “interactive

¹ The quotes used in this article are compiled from notes written by ASAN staff members on what the attendees said at the summit, and may be approximate.

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case conferences.” According to Hana Solařová: “During the conference process it’s not just people sitting at a table — people walk around the room, write on flip charts, take votes...this format helps even children who have serious communication challenges.” Before and after the case conferences, Lumos teaches the child about life outside the institution. They use colorful pamphlets and worksheets that introduce new concepts to the child gradually.² The interactive case conference is just a start to the complex process of preparing these children for community living.

Using supported decision making to help a person choose where and how they want to live involves a greater amount of care and effort than putting someone under guardianship. The supporters involved must determine both how to communicate with the person with a disability (when the person has communication difficulties), what their preferences are, and how they can help that person find an apartment or home that matches the person’s goals and preferences. Ruthie Marie Beckwith of TASH says it is “...very time consuming. ...it really is a ‘one person at a time’ approach.”

Nonetheless, the approach can help people who have significant limitations live in the community. Gail Godwin of the support broker organization Shared Support Maryland relayed a story about a 25-year-old man who had been in an institution since he was a teenager. She said that they spent “a lot of time getting to know him, understanding his preferences for things like temperature and favorite color.” By presuming the man’s competence and taking the time to understand him, Shared Support Maryland helped him find a home that he would be comfortable in.

Landlords Are Either Our Greatest Allies or Fiercest Enemies

Landlords are often the gatekeepers who determine whether people gain access to affordable housing. One issue raised at the summit concerned how landlords would interpret prospective tenants who had supported decision making agreements rather than guardianships. There was a concern that the landlord would question whether the person with a disability was competent to sign the lease agreement themselves. Alison Barkoff, an attorney

² Lumos’ pamphlets help children who have been in institutions for years learn everything from emotional regulation to the basic structure of the family in their country. For instance “Moving to my New Home at: <https://wearelumos.org/content/moving-my-new-home-ii>.

at the Center for Public Representation, said: “If someone shows up with a supported decision making agreement, most likely the landlord will impose requirements -- like a guarantee that they can pay -- that they do not impose on other people. Landlords may not be as focused on legal capacity per se as doctors or banks may be, but disabled tenants will likely still run into unnecessary housing barriers.”

We also discussed conflicts between lease terms and the manifestations of disability. Summit attendees described everything from apartment cleanliness to excessive noise as disability-related behavior that could create a lease violation. We asked questions on how supporters could help a person make the choices they want about their living space while keeping them aware of the negative consequences of those choices.

Landlords willing to work with people with disabilities who are using supported decision making can aid in the resolution of disability-related disputes. Leslie Salzman, the Director of Clinical Legal Education at Cardozo Law School, described a Section 8 housing case where an older woman forgot to renew her application for Section 8 housing benefits. When the woman attempted to re-apply for a Section 8 housing voucher, with the help of her daughter, the government agency administering the vouchers refused to accept the application because the daughter signed it and was not the woman’s guardian. The landlord in the case was supportive, willing to accept the tenant’s portion of the rent payment even without Section 8 benefits. The landlord’s support contributed to the resolution of the case in the woman’s favor.

ASAN recommends, based on these discussions, that disability rights advocates conduct outreach to the landlord community on supported decision making. ASAN will include this recommendation in its upcoming White Paper on the summit.

Accessible, Affordable Housing

Good supported decision making laws will not produce successful outcomes unless we improve the low-income housing market. Attendees repeatedly mentioned the critical shortage in affordable housing. Lauren Onkeles Klein, former Practitioner in Residence at American University Washington College of Law, said: “We’ve all really acknowledged this – there are problems with affordable housing for everybody. They stifle what can be done with supported decision-making in the realm of housing. In some ways, we just need to join with the people who are fighting for affordable housing generally –that allows room

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for supported decision-making to breathe.” Lack of affordable housing was a cross-cultural issue. Dana Kořínková, attorney at QUIP in the Czech Republic, described the housing shortages and complications in her country, and how they influence deinstitutionalization. Lack of affordable housing, as well as lack of community based services and supports, are major obstacles for people attempting to leave institutions.

Supported decision making can be an important tool for opening up non-segregated housing options. “While some families believe that segregated settings are safe and attractive,” Robin Shaffert of The Arc noted: “...creating the culture change that gives parents [an understanding of] the dignity of risk, the [drive to] work with their son or daughter to develop independent living skills, natural supports...this is what will build safety for people with IDD.” Affordable housing must coexist with the services and supports many people with disabilities need. Several attendees at the summit mentioned that many people with disabilities continue to live with their families because there are no services and supports that would help them achieve independence.

Although affordable housing must coexist with long-term services and supports, this does not mean that housing and long-term services and supports should be delivered by the same people. For truly independent living, we must advocate for services and supports that are delivered separately from housing. Dohn Hoyle of the Arc of Michigan said: “autonomy, not supported decision making, should be the goal,” and that “if people have their own place, they should be able to bring in whoever they want, hire and fire. How do we give people the most control possible?”

On Relationships and Natural Supports³

Peer Support is Critical

By providing institutionalized people with disabled role models who are successfully living in the community with supports, the former can see that they, too, are capable of community living. People with disabilities can be introduced to supported decision making by peers with disabilities. Several attendees described peer support related projects at the summit. Max Barrows of Green Mountain Self Advocates (GMSA) said that GMSA used games and peer-to-peer training to introduce the ideas of decision-making to young self-advocates. He said: “Peer to peer

³ For the purposes of this newsletter, we define “relationships and natural supports” as the ordinary relationships in one’s life. Supporters are often drawn from this group of people.

connections help people with disabilities get over the barrier of being afraid to speak up for themselves.”

Peers can also be advocates for community integration. Kapka Panayotova, one of the founders of the independent living movement in Bulgaria, once helped ten young men transition from institutions into the community. She said at the summit that peer support is “one of the most powerful tools for change.” She said that helping a person with a disability transition from a segregated setting into the community successfully means “showing in a very authentic way that you care about the person’s needs, wants, aspirations, and desires.” In many ways, peers with disabilities have a head start in this process. They faced many of the same problems once and can act as a “bridge” between an institutionalized person and people without disabilities.

ASAN therefore, on the basis of these discussions, supports robust funding for similar peer support programs and approaches in its upcoming White Paper.

The Role of Paid Staff in Supported Decision Making

Supporters, who help explain the pros and cons of decisions to a person with a significant disability, are a necessary component of supported decision making. Building a network of supporters can be a difficult process for people who lack relationships outside an institution.

There were a number of conversations around how involved a person’s disability service providers and staff should be in supported decision making. Specifically, we had conversations about: (1) whether paid staff should help people with disabilities make decisions, as supporters in a supported decision making agreement; (2) whether there should be people who are paid to help people with disabilities make decisions, in other words “paid supporters.”

Several attendees were concerned, in general, that treating ordinary human relationships into another paid “service” available to people with disabilities would turn these relationships into obligations. The concern was voiced best by Sharon Lewis, principal of the consulting firm Health Management Associates, who referenced a situation in which a state required its case managers to document the free actions performed by friends and family as if they were things these individuals were required to do: “[W]ith the intent of acknowledging natural supports,

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[one] state has issued policy that requires case managers who are incorporating natural supports into [person-centered planning], to document and track those commitments the same as paid services...This takes “natural” out of “supports!”

Multiple Supporters Are Best

ASAN found that the most effective supported decision making arrangements used multiple supporters with differing levels of expertise, rather than one supporter. For example Lynne O'Hara, President of the board of the WITH Foundation (formerly the Special Hope Foundation), showed us a video in which a woman with a significant disability successfully weighed the pros and cons of eye surgery, using a circle of support consisting of her mother, her primary care provider, and a health advocate from The Arc.⁴ Judge Kristen Booth Glen said: “I think it also may be a way to keep someone from pivoting back into the role of ‘decider’ rather than supporter.”

Supported Decision Making Cannot Happen Without Relationships and Support from Others in the Community

Relationships with the broader community are crucial for successful community living, particularly when the government does not provide support. Kapka Panayotova, from Bulgaria, described the ultimate outcome of the famous human rights case *Stanev v. Bulgaria* in a way that illustrates this point. Rusi Stanev, the plaintiff, was able to establish that his inability to challenge his placement in a cruel and unsanitary psychiatric home, due to his partial guardianship, violated his rights under Article 3 (right to be free of cruel and inhumane treatment) and Article 5 (deprivation of liberty without a fair hearing) of the European Convention on Human Rights.⁵ However, according to Kapka Panayotova at the summit, Mr. Stanev was nonetheless placed in another institutional setting upon winning his case, and he

⁴ To watch the video, you can view the WITH Foundation (formerly the Special Hope Foundation)'s video “Gabby’s Story” at: <https://withfoundation.org/healthcare-access-for-people-with-disabilities-special-hopes-video-shorts-tell-the-story/>. The version of the video ASAN had access to at the summit was five minutes long, half the length of the version on the WITH Foundation's website.

⁵ “The International Network for Economic, Social and Cultural Rights (ESCR-Net). (n.d.). *Stanev v. Bulgaria*, App. No. 36760/06, European Court of Human Rights. Retrieved from: <https://www.escr-net.org/caselaw/2016/stanev-v-bulgaria-app-no-3676006-european-court-human-rights>

received no services or supports that would help him integrate into the community or manage the money that he earned from his lawsuit. According to the Mental Disability Advocacy Centre (MDAC), his lawyers, he remained under Bulgarian guardianship for the rest of his life.⁶ However, according to the article, the relationships that he built between MDAC and himself, and the many others who became invested in his right to autonomy, allowed him to finally live in the community rather than in an institution.

Sharon Lewis suggested that schools have a role to play in ensuring that people with disabilities can build relationships and natural supports, by “making sure kids are being introduced to other kids at school...making sure they do things outside of home and school.” Her final point is vital: “Even if someone doesn't have a guardian appointed, [supported decision making] can't happen without relationships.”

On Healthcare

Informed Consent and Supported Decision Making

The summit debated every aspect of healthcare extensively, including: costs, delivery, context, and significant differences in the health care system from country to country. Facilitating access to affordable health care in the community took precedence over the use of supported decision making for many attendees. Some attendees expressed the opinion that in the healthcare context, especially in emergency situations, patient health can become more important than patient autonomy.

While the summit came to few concrete conclusions on the best approach for using supported decision making in healthcare, we concluded that healthcare supported decision making must include a way to establish informed consent. Supporters need a way to explain the benefits and risks of medical procedures to people with disabilities, particularly people with cognitive, intellectual, and/or developmental disabilities. People with disabilities do not need to know more about the risks and benefits of medical procedures than people without disabilities. Any method of establishing informed consent for a person with a disability must be useful in both complex and high-pressure situations, and must be comprehensible to the people of the

⁶ Mental Disability Advocacy Centre (MDAC). (9 Mar. 2017). A tribute to Rusi Stanev. Retrieved from: <http://www.mdac.info/en/news/tribute-rusi-stanev>.

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culture and socioeconomic background it is being used in.

ASAN discusses several ways that supporters might be able to establish informed consent, based on these discussions, in our White Paper on the summit.

Networking Disability-Competent Health Care Providers and General Practitioners Together

Acquiring disability-competent health care in the community can be difficult. Summit attendees discussed the lack of health care providers competent in treating people with complex medical conditions. Without accessible providers in the community, moving out of an institution may be difficult if not impossible.

Several breakout groups raised the possibility of networking disability-competent health care providers with general practitioners. We discussed linking rural doctors, some of whom may have years of experience treating people with developmental disabilities, with urban general practitioners. We also discussed various ways that supported decision making, when used in conjunction with person-centered planning style approaches, can be used to further involve a person with disability in their health care.

On Long Term Services and Supports⁷

Documenting a Person's Decision-Making Ability and Transferring This Information Between Disability Service Providers

Julia Bascom said that we have an “ethical obligation” to document the ways that people with disabilities (particularly nonspeaking people and people with communication-related disabilities) communicate their decisions, preferences, and choices. This documentation is necessary because of the high turnover of long term services and supports staff in many countries. When there is no record of the specific communication method used by the person, incoming service providers may assume, if the person communicates their decisions in a nonstandard way, that they cannot make decisions. These assumptions could lead to the person's placement under guardianship or in unnecessarily restrictive, segregated residential settings.

⁷ Long term services and supports refer to services that are delivered over a long period of time. Examples include nursing care, personal assistants, medical devices, employment supports, and others.

Some members of the group proposed the creation of a system which would document the way each specific person communicated their decisions and preferences. The system described must be: (a) centralized and accessible to anyone who provides services to that person; (b) cognitively accessible to the person with a disability; and (c) be supported by a robust infrastructure. There would also have to be rules that require the person's service providers to read the information present in the system and to use the communication methods described. Preferably, such a future system of documentation would coexist with countries in which robust legal alternatives to guardianship exist (such as supported decision making) and are in use.

Advocate for Money Follows the Person Style Approaches Globally

Many of our international attendees described long term services and supports as being limited, nonexistent, or only provided in institutions in their countries. Dragana Ciric Milovanovic, of Disability Rights International's regional office in Serbia, said that the only long term services and supports in her country are provided in institutions. While several supported living programs exist, these services are not provided using supported decision making principles. At the time of this writing, Dragana Ciric Milovanovic and her team have helped four organizations in Serbia develop supported decision making models.

Many attendees discussed whether it made more sense cross-culturally to promote supported decision making first or services and supports that allowed people to have choices of where and how to live in the first place. We found that the most globally applicable strategy would be to advocate for “Money Follows the Person” style approaches, where disability services funding and benefits are connected to the person with a disability rather than their location. For instance, if a person with a disability left an institution the services and supports funding would follow them outside the institution.

Fund Support Coordinators as Well as Supports

Support coordinators are organizations or people that help people with disabilities choose the services and supports that they want, rather than primarily providing supports. Support coordinators ideally have few conflicts of interest and are interested in facilitating the authentic wishes and choices of people with significant disabilities. Dohn Hoyle reports that the organization he is on the board of, Community Living Services Inc., functions

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as more of a support broker than a provider. He says that is because “97% of people with developmental disabilities in Michigan have a primary care physician. Medicaid funds them.” Gail Godwin of Shared Support Maryland also described her organization as a “support broker” organization.

This concept may help bring supported decision making to scale, as it demonstrates that it is possible to fund supporting someone to make their own choices through a long term services and supports system. While funding for support coordinators should not “replace” funding for providers, it can act as a way to provide the resources necessary to help bring supported decision making to scale.

Conclusion

We were in consensus that supported decision making was an important tool for increasing the autonomy and choices available to people with disabilities. We agreed that: (1) supported decision making that is tailored to a person's individual needs, careful and methodical, and introduces one decision at a time is always more effective than generic, one-size-fits-all approaches; (2) there should be more than one supporter, and more than one way to obtain a supporter; (3) peer support and community outreach and engagement are necessary for both supported decision making and successfully transitioning someone from an institution into the community; (4) cultural context, country, and situation are important considerations when using supported decision making.

We also discussed many other issues relevant to both successful lives in the community and supported decision making. No one summit will cover or address all that we must consider to make supported decision making real and effective for institutionalized people with disabilities. For now, we can say that we have added to the conversation.

About the Author

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accommodations issues. She has also worked for other public interest organizations on the death penalty and on guardianship in the United States. Her chief interests are the education of children with disabilities, supported decision-making as a viable alternative to guardianship, and the over-criminalization of people with developmental disabilities.

Supported Decision-Making for People with Disabilities: International Origins and Influences

By Robert D. Dinerstein, Professor of Law, Associate Dean for Experiential Education, and Director, Disability Rights Law Clinic, American University, Washington College of Law.

“**N**o man is an island,” poet John Donne wrote in the famous poem of the same name. All of us live in society enmeshed in a web of relationships with friends, family members, acquaintances, and others with whom we come into contact. We rely on many of these relationships to help us navigate the complexities of modern life. By interacting with others, we are able to make better decisions about our lives, from the trivial—what clothes should I wear this morning?—to the more profound—should I buy this house? Should I accept this job offer? Should I move in with my significant other?

Friends and family members can offer us advice about these decisions that we find helpful, or that we choose to reject. Getting assistance (or support) from others need not call into question our ability, in the end, to decide which advice, if any, to follow. As adults, we are entitled to autonomy and self-determination, to make our own decisions in our own way, and to live with the consequences when our choices do not turn out well. We are entitled to make mistakes, and, indeed, may learn more about ourselves and our situations by learning from those mistakes than we do when things go as planned.

The above description of adult decision-making is quite uncontroversial, and may even seem obvious. But until recently this description has not been seen as applicable to certain groups of people in society—people with intellectual disabilities; people with psychosocial disabilities; people with traumatic brain injuries; and older persons with conditions causing cognitive decline, such as dementia.¹ Society traditionally has assumed

¹ For ease of reference, I will use the umbrella term “people with disabilities” to describe all of these groups of people.

that people in these groups lack capacity to make their own decisions, with or without the assistance and guidance of others. Rather, people in these groups are thought to need protection rather than autonomy. They are thought to need someone to make decisions for them instead of deciding matters for themselves.

Since ancient Roman times, plenary guardianship (and, for financial matters, its close cousin, conservatorship) has been the vehicle through which people or institutions were appointed to make decisions for others.² The guardian might or might not consult with the person under guardianship—called the ward, allegedly incapacitated person, or similar term—and might seek to make the decision the person would have made if he or she had the capacity to do so (the so-called substitute judgment standard) or alternatively (and, in practice, more commonly) make the decision that the guardian thought was in the ward’s best interest. Ironically, although guardianship was premised on the need to protect the person supposedly lacking decision-making capacity, numerous cases came to light of guardian misconduct, involving, among other things, financial, emotional and physical abuse; financial self-dealing; and forcing people into nursing homes and other institutions.³

Many guardians have carried out their role in an appropriate and even admirable fashion. But even if guardianship appropriately served its protective purpose, many came to see it as problematic because of its displacement of the individual as decision-maker. That is, to deny an individual the right to make decisions about

² As scholars have noted, guardianships in medieval England and later were designed to protect property (often for the benefit of the Crown) from being dissipated because of the mental incapacity of the owner. See Kristin Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond*, 44 Colum. Human Rights L. Rev.93, 102-03 (Fall 2002).

³ For criticisms of guardianship, including those from congressional committees and the American Bar Association, see Robert D. Dinerstein, *Guardianship and Its Alternatives*, 235-236, Ch. 23 in *Adults with Down Syndrome* (Siegfried M. Pueschel, ed. 2006).

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his or her life is to consign him or her to a form of civil death.⁴

People with disabilities and their advocates thus sought an alternative to plenary guardianship. In an earlier era, the primary reforms were two-fold: creating limited guardianships, in which a court granted the guardian decision-making authority in only some areas of a person's life, and requiring that guardianship, whether limited or plenary, only be authorized if it was the least restrictive means of intervention. Unfortunately, neither of these reforms has been as robust as might have been hoped or expected. And even if guardianship were limited, it would still remove the person under guardianship's decision-making authority in those areas the guardianship covered.

Enter a true alternative to guardianship: supported decision-making. With origins in statutes in British Columbia, Canada, some states in Germany, and Sweden,⁵ supported decision-making became a key component of Article 12, Equal recognition before the law, of the United Nations Convention on the Rights of Persons with Disabilities (CRPD).⁶ The General Assembly adopted the CRPD in December 2006, and the treaty entered into force on May 3, 2008. Since that time, the Committee on the Rights of Persons with Disabilities (CRPD Committee), through its review of the over 60 State Parties that have appeared before it,⁷ and its issuance of General Comment No. 1 on Article 12,⁸ has forcefully advocated for the replacement of all forms of guardianship with supported decision-making.⁹

⁴ Id.

⁵ See sources cited in Robert D. 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 Hum. Rts. Brief 10 and endnotes 30-32 (2011-2012).

⁶ G.A. Res. 61/106, U.N. Doc. A/61/611, Convention on the Rights of Persons with Disabilities (Dec. 13, 2006).

⁷ United Nations Office of the High Commissioner of Human Rights, http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5 (listing of Concluding Observations of States Parties that have appeared before the CRPD Committee). As of November 16, 2017, the CRPD Committee has issued Concluding Observations for 62 countries.

⁸ Committee on the Rights of Persons with Disabilities, General Comment No. 1 (2014), Article 12: Equal recognition before the law. UN Doc. CRPD/C/GC/1 (adopted April 11, 2014), <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement>

⁹ As Amita Dhanda has noted, although Article 12 does not literally

Article 12 provides the basis for the growing international recognition of supported decision-making, which is a critical component of legal capacity. Article 12 (1) provides that "States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law." Article 12 (2) states that "States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life." Crucially, Article 12 (3) provides that "States Parties shall take appropriate measures to provide access to persons with disabilities to the *support they may require in exercising legal capacity*."¹⁰ Interestingly, Article 12 (3) never specifically mentions supported decision-making as such. But the CRPD Committee, policy-makers, and legal scholars have identified supported decision-making as the most significant form of support for legal capacity.¹¹

What then is supported decision-making? In a prior article, I defined it as follows:

*Supported decision-making can be defined as a series of relationships, practices, arrangements, and agreements, of more or less formality and intensity, designed to assist an individual with a disability to make and communicate to others decisions about the individual's life.*¹²

Relatedly, the CRPD Committee has defined support, as used in Article 12 (3), in the following terms:

'Support' is a broad term that encompasses both informal and formal support arrangements, of varying types and intensity. For example, persons with disabilities may choose one or more

prohibit guardianship and all other forms of substituted decision-making, a full contextual understanding of the Article implies that such restrictive forms of intervention in a person's decision-making are inconsistent with its view of legal capacity. See Amita Dhanda, *Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar of the Future*, 34 Syracuse J. Int'l L. & Com. 429, 460-61, cited in Dinerstein, supra note 6, at 9 & endnote 23.

¹⁰ CRPD, Article 12, Paras. 1-3 (emphasis added). Paragraph 12 (4) requires States Parties to ensure that safeguards are in place to protect persons' legal capacity. Paragraph 12 (5) seeks to protect the right of people with disabilities to engage in financial and property transactions.

¹¹ The CRPD refers to support in other provisions besides Article 12, including Articles 19 (Living independently and being included in the community), 20 (Personal mobility), 24(2) (d), (e) (Education). See. Dinerstein, supra note 6, at 9.

¹² Id. at 10.

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*trusted support persons to assist them in exercising their legal capacity for certain types of decisions, or may call on other forms of support, such as peer support, advocacy (including self-advocacy support), or assistance with communication. . . . Support can also constitute the development and recognition of diverse, non-conventional methods of communication, especially for those who use non-verbal forms of communication to express their will and preferences.*¹³

In Paragraph 29 of the General Comment, the CRPD Committee identifies a number of critical components of a supported decision-making regime:

- ◆ Supported decision-making must be “available to all” (and not be limited regarding people who need a high degree of support)
- ◆ All forms of support should be based on the “will and preferences of the person” (and not on his/her presumed best interests)
- ◆ A person’s mode of communication, even if limited or non-conventional, should not be a barrier to obtaining support
- ◆ Legal recognition of the support person(s) chosen by the person must be available and accessible, and “the state has an obligation to facilitate the creation of support,” especially for those who are isolated or do not have access to natural supports. Third parties must have the ability to verify the identity of the supporter and challenge the action of the support person if they believe that the support person is not following the will and preferences of the person.
- ◆ “Lack of resources cannot be a barrier” to using support, and the State must make sure supports are available at no or nominal cost to the person
- ◆ “Support in decision-making (or the need for it) cannot be used to deny other fundamental rights,” such as voting, reproductive rights, parental rights, etc.
- ◆ The person must have the “right to terminate or change the support relationship at any time”
- ◆ Safeguards designed to respect the will and preferences of the person must be available in all processes related to legal capacity and its exercise.

¹³ CRPD Committee, General Comment No. 1, *supra* note 9, at ¶ 17, at 4. My co-authors discuss General Comment No. 1 in Robert Dinerstein, Esmé Grant Grewal, & Jonathan Martinis, Emerging International Trends and Practices in Guardianship Law for People with Disabilities, 22 ILSA J. Int’l & Comp. L. 435, 446-48 (Winter 2016).

- ◆ The provision of support should “not be based on assessments of mental capacity,” but on “new, non-discriminatory indicators of support needs. . . .”¹⁴

As noted above, the CRPD Committee has conducted a complete review (that is, it has issued Concluding Observations) of 62 States in the 18 semi-annual sessions it has held to date. In every instance, the Committee has expressed varying levels of concern regarding the States’ commitment to supported decision-making. It has criticized practices in countries ranging from those that have made the most significant commitment to supported decision-making, such as Canada¹⁵ and Sweden,¹⁶ to those that seem either not to understand supported decision-making or continue to make substantial use of guardianship, such as Tunisia,¹⁷ Ecuador¹⁸ or Morocco.¹⁹

¹⁴ CRPD General Comment No. 1, *supra* note 9, at ¶ 29 at 6-7.

¹⁵ UN Convention on the Rights of Persons with Disabilities, Comm. on the Rights of Persons with Disabilities, Concluding observations on the initial report of Canada, ¶s 27-28 at 6, U.N. Doc. CRPD/C/CAN/CO/1 (8 May 2017), http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5

¹⁶ UN Convention on the Rights of Persons with Disabilities, Comm. on the Rights of Persons with Disabilities, Concluding observations on the initial report of Sweden, ¶s 33-34 at 5, U.N. Doc. CRPD/C/SWE/CO/1 (12 May 2014), http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5

¹⁷ UN Convention on the Rights of Persons with Disabilities, Comm. on the Rights of Persons with Disabilities, Concluding observations on the initial report of Tunisia, ¶s 22-23, at 4, U.N. Doc. CRPD/C/TUN/CO/1 (13 May 2011), http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5

¹⁸ UN Convention on the Rights of Persons with Disabilities, Comm. on the Rights of Persons with Disabilities, Concluding observations on the initial report of Ecuador, ¶s 24-25, at 4, U.N. Doc. CRPD/C/ECU/CO/1 (27 (October 2014), http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5

¹⁹ UN Convention on the Rights of Persons with Disabilities, Comm. on the Rights of Persons with Disabilities, Concluding observations on the initial report of Morocco, ¶s 26-27, at 5, U.N. Doc. CRPD/C/MAR/CO/1 (25 September 2017), http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5

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Notwithstanding the Committee's consistent rejection of all forms of guardianship, no country has completely eliminated it. But there is no question that the CRPD has played a critical role in spurring adoption of supported decision-making in a number of countries. As I have written previously, "States (or provinces or pilot projects within) such as Israel, Ireland, parts of Australia and New Zealand, the Czech Republic, Norway, and Bulgaria, among others, have either adopted or have indicated an intention to explore adoption of, SDM [supported decision-making]." ²⁰ Argentina, China, Colombia, India, Ireland, Lithuania, and Peru also have adopted supported decision-making to varying degrees, in legislation or in pilot projects. ²¹ Courts in other countries also have entered the fray. For example, on October 8, 2014, the Constitutional Court of [the Republic of] Georgia held unconstitutional that country's legal framework for decision-making by people with mental illness, leading the Parliament to promulgate a draft law that would comply with the CRPD. ²²

Although President Barack Obama signed the CRPD for the United States in 2009, the United States has not ratified the CRPD (ratification failed by five votes in 2012) ²³ and so is not formally bound by its provisions, including Article 12. But as Robert Fleischner's article in this issue observes, the CRPD has been influential in providing "soft law" support for domestic court decisions, ²⁴ as well as serving as an inspiration for state statutes, government agency reports, the American Bar Association, and uniform laws, to name only some of the arenas in which supported decision-making has been considered. ²⁵

²⁰ See Dinerstein, Grewal, and Martinis, *supra* note 14, at 443 & note 38.

²¹ See American Bar Association, Resolution 113, on supported decision-making, accompanying Report at 6, note 34, Adopted by the House of Delegates August 14-15, 2017 (discussing Convening on Article 12 sponsored by Open Society Foundations and held at American University, Washington College of Law, April 11-14, 2016).

²² See "Reforming the concept of legal capacity in Georgia," May 1, 2015 (unofficial translation by non-governmental organization Partnership for Human Rights, November 24, 2015).

²³ See United States International Council on Disabilities, The CRPD, available at <http://www.usicd.org/index.cfm/crpd>

²⁴ See *In re Dameris L.*, 956 N.Y.S.2d 848, 856 (Sur. Ct. 2012)

²⁵ The author has been involved in a number of these efforts, including participating in the ad hoc group that drafted the American Bar Association Resolution 113 advocating supported decision-making,

Supported decision-making is not a panacea. As more states consider legislation in this area, and as probate courts increasingly are asked to consider supported decision-making as a less restrictive alternative to guardianship, there will undoubtedly be challenges in both conceptualization and implementation. But in its embrace of the decision-making capacity of all people, whether or not they have disabilities, supported decision-making is on the cutting edge of recognizing the autonomy and self-determination of all people. And for that reason alone, it is a modality well worth our support and advocacy.

About the Author

Robert D. Dinerstein is director of the Disability Rights Law Clinic at American University, Washington College of Law, associate dean for experiential education, and professor of law since 1983. He served as an attorney for five years at the Department of Justice, Civil Rights Division, Special Litigation Section. He has a J.D. degree from Yale Law School and an A.B. degree from Cornell University. Among his many publications are: *Tales from a Supportive Guardianship*, *Court Review: The Journal of the American Judges Association* (2017); *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*, *Human Rights Brief* 8 (2012); "Guardianship and Its Alternatives," in *Adults with Down Syndrome* (Siegfried, 2006); and *A Guide To Consent* (AAMR, 1999).



Robert D. Dinerstein

see note 22, *supra*, and serving as an observer to the Uniform Law Commission's revision of the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act, approved by the National Conference of Commissioners of Uniform State Laws, Annual Conference, July 14-20, 2017 (available at <http://uniformlaws.org/Act.aspx?title=Guardianship,%20Conservatorship,%20and%20Other%20Protective%20Arrangements%20Act>). The National Council on Disability is about to issue a comprehensive report on guardianship, including an extensive discussion of supported decision-making. The author has served on an advisory committee to the Quality Trust for Individuals with Disabilities, a sub-contractor for the report.

Supported Decision-Making: Legal Basis and Practical Application

Robert D. Fleischner, Center for Public Representation

I. Introduction

Supported decision-making (SDM) is the future and the future is now. SDM can ensure dignity and self-determination regardless of the extent of a person's disability. Interest in SDM in the United States, perhaps a bit of an SDM late-starter compared to some other countries, is growing. Fortunately, there is already a robust body of scholarly literature providing a strong theoretical structure to SDM.

The federal government, some state agencies, and several foundations are providing needed funding to promote SDM and to help put it to use. Two states have enacted SDM legislation; others are sure to follow. Many peer, family, and professional groups urge adoption of SDM as an alternative to guardianship. Prestigious legal groups like the the American Bar Association support SDM. Numerous small – and a few big – mostly grass-roots projects are springing up around the country to implement SDM and to use it to prevent or to discharge people from guardianship. Some of the projects are being independently evaluated, beginning to provide empirical data to support the scholars' theories and families' and practitioners' experience. Significantly, judges have begun to recognize SDM and, at least in a few jurisdictions, the number of court opinions ending or refusing to start guardianship in favor of SDM is increasing.

Nevertheless, SDM is not without its skeptics. Some think it may be no more than a fad. Others suggest that it is just another, perhaps more subtle, way for third parties to control an individual with a disability. Still others worry that without court oversight there is a likelihood of coercion, manipulation and abuse. Some skeptics argue that even if SDM can work well for people with disabilities who are “high functioning,” it is inappropriate

(and impossible to implement) for people with more serious disabilities.¹

SDM proponents are prepared to respond to these concerns and to design SDM arrangements that are inclusive, free of coercion, and that safeguard against abuse. The fact is that experiences here and elsewhere (and the still nascent but expanding body of research) are demonstrating that SDM can and does work, and is safe, no matter the extent of a person's disability.

This article will survey the American statutory and regulatory legal basis for SDM, will describe some of the projects that have begun or will soon be in operation in the United States, and will summarize court cases adopting SDM as a guardianship alternative.

II. The theoretical support for SDM.

The overuse, misuse, and abuse of guardianships and conservatorships have been matters of grave concern for three decades.² Advocates have long urged guardianship reform and some real progress has been made. Nevertheless, many feel that despite increased due process protections, statutory preferences for limited guardianships, and efforts to encourage guardians to comply with meaningful codes of conduct,³ too many people with disabilities lose their rights needlessly.

¹ For a discussion of some of the concerns, see, Thomas Coleman, *Supported Decision-Making: A Critical Analysis*, (“Supported decision-making has great potential but also poses great risks”) available at <http://spectruminstitute.org/sdm/sdm-http://supportmydecision.org/news/2017/check-out-our-2015-2016-grant-report-1report.pdf>.

² This year, 2017, is the 30th anniversary of the ground breaking Associated Press series that first exposed the widespread abuses of guardianship and ushered in an era of gradual reform. http://articles.latimes.com/1987-09-27/news/mn-10389_1_guardianship-petitions.

³ The National Guardianship Association has standards of practice and conduct for guardians. http://www.guardianship.org/documents/Standards_of_Practice.pdf.

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Encouraged by positive experiences elsewhere in the world and stimulated by the international support for the empowering principals in Article 12 of the United Nations Convention on the Rights of People with Disabilities (CRPD),⁴ American scholars, families and advocates have urged the adoption here of SDM as an alternative to guardianship. Leslie Salzman,⁵ Robert Dinerstein,⁶ Nina Kohn,⁷ Arlene Kanter,⁸ and Kristin Booth Glen⁹ were among the early proponents of SDM. Their law journal articles provide the jurisprudential basis for using supported forms of decision making.

Michael Bach and Laura Kerzner,¹⁰ Eilionóir Flynn¹¹ and others writing from an international perspective, have discussed the

⁴ See Robert Dinerstein's article in this issue for more information about the CRPD.

⁵ E.g., Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 Univ. of Colorado L. Rev. 157 (2010) available at http://lawreview.colorado.edu/wp-content/uploads/2013/11/10Salzman-FINAL_s.pdf.

⁶ E.g., 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 1 (2012) available at <http://digitalcommons.wcl.american.edu/cgi/viewcontent.cgi?article=1816&context=hrbrief>.

⁷ Nina A. Kohn, et al., *Supported Decision-Making: A Viable Alternative to Guardianship?* 117 Penn. St. L. Rev. 1111 (2013) available at [http://www.pennstatelawreview.org/117/4%20Final/4-Kohn%20et%20al.%20\(final\)%20\(rev2\).pdf](http://www.pennstatelawreview.org/117/4%20Final/4-Kohn%20et%20al.%20(final)%20(rev2).pdf).

⁸ Arlene S. Kanter, *The Promise and Challenge of the United Nations Convention on the Right of Persons with Disabilities* (2007). 34 Syracuse J. Int'l L. & Com. 287 2006-2007.

⁹ E.g., Kristin Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship & Beyond*, 44 Colum. Hum. Rts. L. Rev. 93 (2012)

¹⁰ Michael Bach & Laura Kerzner, *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity* (2010) available at <http://www.lco-cdo.org/en/our-current-projects/the-law-and-persons-with-disabilities/disabilities-call-for-papers-january-2010/commissioned-papers-the-law-and-persons-with-disabilities/a-new-paradigm-for-protecting-autonomy-and-the-right-to-legal-capacity/>.

¹¹ E.g., Eilionóir Flynn & Anna Arstein-Kerslake, *The Support Model of Legal Capacity: Fact, Fiction, or Fantasy?* 32 Berkeley J. Int'l Law 124 (2014) available at <http://scholarship.law.berkeley.edu/cgi/viewcontent.cgi?article=1450&context=bjil>.

critical necessity of autonomy and explained the concept of “legal capacity,” the foundational underpinning of Article 12 of the CRPD. People with disabilities, family members, providers and their advocates have spread the word by publishing articles and presenting at conferences to explain the practical application of SDM.

Foundations, including the Open Societies Foundations (OSF), have provided funding to support SDM projects around the globe. Just as important, they have brought together their networks of NGOs, advocates, and visionaries to share ideas and to promote international dialogue. In the United States, some smaller foundations and a handful of state DD Councils have also assisted significantly in the development of SDM projects.

Although guardianship and its alternatives are matters of state law, there has been increasing interest in a national perspective from the federal government. Guardianship, after all, impacts federal programs as varied as Social Security payments and enforcement of the Olmstead integration mandates. The most important federal government guardianship related initiative has been the Administration for Community Living's (ACL) grants to support a National Resource Center on Supported Decision Making (National Resource Center), a valuable resource for anyone interested in SDM.¹²

III. The legal basis for SDM

A. International law – the CRPD

Most advocates look to the United Nations Convention on the Rights of Persons with Disabilities (CRPD) as the foundational basis and a jurisprudential justification for SDM.¹³ Even though the U.S. has not ratified the CRPD, it may have some influence on the law here and, indeed, has been cited by at least a few courts in guardianship cases and is almost always a central focus of analysis in law journal articles.

B. The Americans with Disabilities Act

Some believe that federal law, particularly the Americans with Disabilities Act (ADA), forbids or limits a state's ability to impose a guardian. Leslie Salzman, for instance, argues “that by limiting an individual's right to make his or her own

¹² ACL describes the grant at <https://www.acl.gov/programs/consumer-control/supported-decision-making-program>.

¹³ For a more in-depth discussion of the CRPD see Robert Dinerstein's article in this issue.

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decisions, guardianship marginalizes the individual and often imposes a form of segregation that ...violates the [ADA's] mandate to provide services in the most integrated and least restrictive manner.”¹⁴

C. State laws

However, even if some federal laws may be helpful, as noted, guardianship is mostly a matter of state law. States may, and a few have, incorporated SDM into state statutes and policies. As of autumn 2018, two states — Texas¹⁵ and Delaware¹⁶ — have enacted SDM laws. The District of Columbia has a regulation that recognized SDM as a way for students who are receiving special education services to make their own decisions about their education after they are 18.¹⁷

The Texas and Delaware SDM laws have become models for other jurisdictions. The laws share some important components, including definitions of SDM, mandates that it should be considered as an alternative to guardianship, delineation of the roles and responsibilities of supporters, and prohibitions on use of undue influence and coercion. Both statutes provide a significant degree of immunity to third parties (e.g., landlords, doctors, bankers) who rely in good faith on an SDM agreement in a transaction. This critical protection for third parties is important.

There are some differences, however. The Texas law, for example, places no restrictions on who may be a supporter. Delaware, by comparison, does not allow a person's employer or paid support staff to act as supporters. Also, the Texas law includes a model (though not mandatory) SDM form, while Delaware delegates design a form to a state agency.

Advocates in the other 48 states and the District of Columbia without specific statutory authorization for SDM, can look

¹⁴ Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making As A Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. Colo. L. Rev. 157, 157–58 (2010); see also Sean Burke, *Person-Centered Guardianship: How the Rise of Supported Decision-Making and Person-Centered Services Can Help Olmstead's Promise Get Here Faster*, 42 Mitchell Hamline L. Rev. 873 (2016).

¹⁵ Tex. Estate Code § 1357.001 et seq. Disability Rights Texas has many useful SDM resources available at <https://www.disabilityrightstx.org/resources/supported-decision-making>.

¹⁶ 16 Del. Code §§ 9401A – 9410A.

¹⁷ 5-E D.C. Code Municipal Regs. § 3034.

to existing state laws for support. Typically, guardianship laws encourage using guardianship as a last resort when other less restrictive alternatives are not available.¹⁸ Many states also encourage or require the use of limited guardianship.¹⁹ SDM is consistent with concepts that people may be competent in some areas even if not in others. Even more helpfully, some states define a person's incapacity in terms that include concepts of support. For example, Pennsylvania law requires a court to consider “the availability of family, friends and other supports to assist the individual in making decisions” before granting a guardianship.²⁰ These and similar statutory provisions are very useful in arguing that state laws not only do not prohibit SDM, but encourage it.

E. Cases

Judges have shown a willingness to use SDM even without clear statutory authorization. The earliest SDM decision may be *In re Peery*, in which the Pennsylvania Supreme Court held that Ms. Peery did not need a guardian because of her strong network of caretakers. Importantly, it was immaterial whether Ms. Peery was incapacitated.²¹

Perhaps the two most influential cases have been those involving Jenny Hatch and a woman identified as Dameris L. The Jenny Hatch case,²² which received national press attention, is described elsewhere in this issue and on-line.²³ It is enough to say here that Ms. Hatch's courageous battle to free herself from guardianship provided the inspiration for much of the SDM activity in this country.

In *In re Dameris L.*,²⁴ the court terminated a guardianship because Dameris was “able to engage in supported decision-making.” Judge Kristin Booth Glen cited to and discussed the CRPD and New York law and concluded that “[t]o the extent that New York courts have recognized least restrictive alternative as a constitutional imperative... proof that a person

¹⁸ See, e.g., N.H. Rev. Stat § 464-A:9 (guardian may not be appointed unless there is no less restrictive alternative).

¹⁹ See, e.g., 755 Ill. Comp. Stats. 5/11a-12 (permitting limited guardianships).

²⁰ 20 Pa. Stat. and Cons. Stat. Ann. § 5512.1.

²¹ 556 Pa. 125, 727 A.2d 539 (1999).

²² *Ross v. Hatch*, No. CWF120000426P-03, slip op. at 7 (Va. Cir. Ct. Aug. 2, 2013), available at http://jennyhatchproject.org/docs/justice_for_jenny_trial/.

²³ See, e.g., <http://jennyhatchjusticeproject.org/jenny>.

²⁴ 956 N.Y.S.2d 848, 856 (Sur. Ct. 2012)

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with an intellectual disability needs a guardian must exclude the possibility of that person's ability to live safely in the community supported by family, friends and mental health professionals.”

Other Surrogate Court judges have followed Judge Glen's lead:

- ◆ In *In re Guardian for Hytham M. G.*, the judge held that “it has not been demonstrated ... that guardianship ... is the least restrictive means to address Hytham's needs where the presence of supported, instead of substituted, decision making is available.”²⁵
- ◆ In *In re D.D.*, a judge held that the New York guardianship statute must be read to require that supported decision-making must be explored and exhausted before guardianship can be imposed.²⁶
- ◆ In *Guardian for Michelle M.*, the judge recognized that Michelle's parents, who petitioned for her guardianship, “deeply love and care” for her and understood their “desire for peace of mind and natural instinct to protect [her].” But, the judge found that despite her “cognitive limitations,” Michelle, with the support of family and supportive services can make decisions for herself.²⁷

Judges in some other states have followed suit.

- ◆ A Probate and Family Court judge in Massachusetts discharged a young man both from guardianship and from a psychiatric medication treatment order when the court was presented with an SDM agreement. The young man's guardian supported the discharge.²⁸
 - ◆ Ryan King had his rights restored after 15 years with a guardian. His parents did not want to be his guardians – they had been told they had to be when he turned 18. In 2007 a court refused to discharge the guardianship. Ryan and his family tried again in 2016 and this time they were able to tell the court about SDM. The guardianship was discharged.²⁹
 - ◆ In a 2012 case, an Iowa appeals court, recognizing SDM principals, ended a guardianship, finding that “although there
- ²⁵ 52 Misc. 3d 1211(A), 41 N.Y.S.3d 719 (N.Y. Sur. April 14, 2016).
- ²⁶ 50 Misc. 3d 666, 19 N.Y.S.3d 867 (N.Y. Sur. 2015).
- ²⁷ 52 Misc. 3d 1211(A), 41 N.Y.S. 3d 719 (N.Y. Sur. July 22, 2016).
- ²⁸ Guardianship of Cory C., Berkshire Probate & Family Court (2015) described at <http://www.supporteddecisions.org>.
- ²⁹ The case is described at http://bbi.syr.edu/news_events/news/2016/12/Freedom-Ryan-King.html.

are many things [the person under guardianship] can no longer do for himself, he is financially able and personally willing to secure third party assistance when needed.”³⁰

IV. Delivering SDM.

With these strong legal underpinnings, implementation of SDM has spread throughout the country. No two SDM projects are the same. The differences are evidence of the vitality of the theories and the flexibility of the models. Each is a laboratory for testing and discovering the potential of SDM to change people's lives. Some of the projects in the United States are briefly described below.

- ◆ One of the first initiatives was a joint project of Nonotuck Resource Associates, a shared living provider, and the Center for Public Representation (CPR), a public interest law firm.³¹ With financial support from OSF and some local foundations, Nonotuck and CPR designed and implemented an innovative pilot with nearly a dozen individuals with a range of intellectual and developmental disabilities. The independent evaluation of the project by the Human Services Research Institute, is one of the first and most in depth empirical studies of the SDM.³²
 - ◆ A University of Texas Austin Law School project targets students with disabilities transitioning from high school to adulthood. Law students assist individuals and their families to draft SDM agreements.³³ This project has the advantage of operating within the context of the Texas law described above.
 - ◆ Supported Decision-Making New York (SDMNY) is an ambitious, state wide, five year project funded by the State's DD Planning Council. SDMNY is made up of four partner organizations and has a staff that is located at the Silberman School of Social Work at Hunter College. Disability Rights New York is one of the project partners. Like the Texas project, SDMNY has prioritized youth in transition.³⁴
 - ◆ The Saks Institute at University of Southern California is setting up a pilot promoting SDM for adults with mental
- ³⁰ *In the Matter of the Guardianship and Conservatorship of F.W. Jr.*, (Iowa Ct. App. 2012).
- ³¹ <http://www.supporteddecisions.org>. For a more in depth description see Cathy Costanzo's article in this issue.
- ³² Human Services Research Institute conducted the evaluations, available at <http://www.supporteddecisions.org>.
- ³³ <https://law.utexas.edu/probono/opportunities/texas-law-include-project/>
- ³⁴ <http://sdmny.org/about-sdmny/>.

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illness. This may be the first project in the United States that is designed specifically for people with mental illness.

- ◆ Disability Rights Maine has convened a broad coalition to implement SDM in Maine. The project has provided trainings and represented individuals in guardianship cases.³⁵
- ◆ The American Civil Liberties Union's Disabilities Rights Program has prioritized SDM and is providing very useful information and representation in California.³⁶

Other projects, some with funding from the National Resource Center,³⁷ are being established across the Nation.

³⁵ A report of the project's activities is at <http://supportmydecision.org/news/2017/check-out-our-2015-2016-grant-report-1>.

³⁶ <https://www.aclu.org/issues/disability-rights/integration-and-autonomy-people-disabilities/supported-decision-making>.

³⁷ The first recipients of grants from the National Resource Center were in Delaware, Maine, Wisconsin, North Carolina, and Indiana.

V. Conclusion

The legal support for SDM as a meaningful alternative to guardianship is more than sufficient. Indeed, the support is growing as legislatures and courts firmly plant SDM into statutes and court opinions, rules and practices. At the same time, projects and programs are starting around the country to assist people to design and implement SDM arrangements, thereby avoiding substituted decision-making, expanding decision-making rights, and ensuring the dignity of all people regardless of disability.

About the Author

Bob Fleischner has represented people with disabilities for more than 40 years. He has written a book and published many articles about guardianship. He helps to direct the Center for Public Representation's Supported Decision-Making Project.



Robert D. Fleischner

Reflections on Autonomy

Dohn Hoyle

In my, going on, 47 years at this business, few recurring problems have been as vexing as the pervasive use of and blind acceptance of guardianship (or conservatorship for California and Tennessee). Parents, professionals and advocates have a conveniently benign attitude and many times are even complicit in this overt removal of rights.

Some are surprised upon learning that the undoing or termination of guardianship is known as “Restoration of Rights”. However, few are really fazed by the information or change their behavior as a result of learning this. As one who is clearly a product of the 60s and who cut their teeth in the Civil Rights struggle, such a disregard of people’s rights is far more than disconcerting. For persons with a history of being oppressed, it is unconscionable.

In the early 70s, when guardianship statutes were merely a hold-over from old English law and covered guardianships of the estate, we sought better statutes. Rather than indicating that a Guardian of the Estate could also be named guardian of the person if necessary, the earliest fix, we sought guardianship designed for persons with disabilities, usually cognitive disabilities, or who were aging. We sought the greatest procedural and due process protections and hoped to, at least, limit the number of persons, for whom, guardians were appointed.

While we were successful in establishing great statutes, not only did the numbers not go down, they went up. And, most disturbing, the very paternalistic probate courts (or their equivalent) largely nodded in or ignored the direction of the protections and due process provisions. In most places, it is a very sad departure from a vigorous adversarial proceeding with a blindfolded lady justice. It more closely represents a mill for producing guardianships with a minimum of time or consideration.

I clearly saw that my time and effort on this problem were more effective when I tried to stem the incessant flow of petitions to the courts. I have therefore for the past 30 plus years been trying to convince those in the field, especially parents, to “try another way”. Rather than label what I talk about as alternatives to guardianship, giving guardianship more credibility and substance than it deserves, I talk about Autonomy, Rethinking Guardianship, and Supporting Persons in Decision Making. I believe this approach far more closely aligns with the American’s with Disabilities Act, my sensibilities as a supporter of human and civil rights and efforts, all these years, attempting to empower persons with disabilities.

It is not permissible to remove persons’ rights for the crime of having a disability or, for my quite immediate future, the crime of aging and gaining disabilities. Our status as a person, human being, or a citizen shouldn’t change due to either circumstance. We should not be relegated to losing our “inalienable rights” or to third class citizenship.

One seldom mentioned or even seldom recognized effect of imposing guardianship is the promotion of or affirmation of stigma. That a person has a guardian is certification or proof that a person is “less than”. Talking to the person who accompanies a person with a disability and not the person themselves is now permissible. The person has, after all, the court’s imprimatur of incompetence or incapacity. Of course then, the one who counts is the person without the disability.

One only needs to hear “I’m my own guardian” or “I’m not conserved” to recognize the loss of status and stigma persons with disabilities associate with guardianship. Everyone, from merchants to providers and doctors are now excused from any need to talk to, explain things, or seek permission from the person. They deal with the guardian, their agent or others instead. This outright infantilization of persons with disabilities does not serve them well. It promotes the “caring for” model and the concept of “mental age”, neither of which is acceptable.

I don’t doubt that most providers would rather deal with a guardian to whom they send a form once a year. They don’t have

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to break things down to concrete language or explain things. If necessary, a phone call can clear anything up and the guardian's signature on the form now guarantees that the slot in a program or bed in a residential setting will be occupied for a year AND the provider will be paid. No need to convince the participant to come back to the program each day. No need to explain options or why a particular residential program. The organized, very legal stripping of dignity and choices preserves, usually, the status quo with a minimum of fuss or effort, by eliminating any role for the person. Even if a guardian chooses to involve or consult with their ward, it will most likely be cursory and no burden to the provider.

In 2012, thanks to Judge Kristen Glen, a number of us met, in her courtroom, invitees of the American Bar Association Commission on Disability Rights and on Law and Aging in partnership with the Administration on Intellectual and Developmental Disabilities within the Administration for Community Living in the U.S. Department of Health and Human Services “to participate in a pioneering Roundtable discussion, *Beyond Guardianship: Supported Decision-Making by Individuals with Intellectual Disabilities*. The aim of the Roundtable is to empower and support the decision-making of the growing population of individuals with intellectual disabilities, moving beyond the current guardianship model.” “Specifically, participants will examine problems with the current system of decision-making, propose possible solutions, and recommend initial steps for getting there. The Roundtable is intended to advance a national symposium that will be framed by the recommendation from the Roundtable.”

That meeting was not only affirmation that a number of people had moved “beyond guardianship” but were also committed to doing something about it. The group included many old friends as well as many new ones who felt as strongly or nearly as strongly as I did about the subject.

In October of 2013, Quality Trust for Individuals with Disabilities, the Council on Quality Leadership and the Burton Blatt Institute sponsored a one-day invitational symposium on “Best Practices in Supported Decision-Making”. The goal of the symposium was to “develop specific recommendations for advancing the legal, policy, research and practical aspects of Supported Decision-Making”.

November, two years later, saw the 2015 Supported Decision-Making Symposium, sponsored by the National Resource Center

on Supported Decision-Making “a national effort to advance the use of supported decision-making in practice for people needing assistance in making decisions”. The very impressive Symposium Vision follows: “Expand and advance the use of SDM [supported decision-making] by creating a new paradigm focused on ensuring that older adults and people with disabilities have a TRUE opportunity to (1) be and remain equal members of their communities throughout the lifespan, (2) actively use practices and supports that preserve and advance their personal vision for life; and (3) achieve positive life outcomes (e.g., integrated employment, full inclusion, access to health care, individual flourishing, etc.) that reflect personal desires, choices and preferences.”

In 2016 I was honored to be invited to a two-day summit on supported decision-making by the Autistic Self-Advocacy Network. The Summit was held in partnership with the Open Society Foundation. The movement of the concept and practice was now evident, from the including of Supported Decision-Making in the latest Texas statutes on guardianship to the increasing awareness and use of less formal versions, we have moved considerably from “beyond guardianship”. The vigorous discussions at the Summit confirmed same.

One danger in concentrating on Supported Decision-Making is viewing this concept as a goal. I have always held that the goal for persons with disabilities, for persons gaining disabilities with age and each of us has always been autonomy. All efforts need to be directed at what I believe are the essential elements of autonomy. These include equal rights, equal standing and status under law, equal citizenship, and equal opportunity. They also include freedom from oppression, freedom from segregation and even freedom from the undue influence of others. These are all things we would seek for ourselves. We should seek nothing less for our fellow citizens who have disabilities.

It is useful to stand guardianship up against each of these items I consider the elements of autonomy. Rights, status and standing under the law, citizenship and opportunities are not equal for persons under guardianship. A person with a guardian does not have standing under the law. They cannot employ an attorney; they cannot sue or even bring an action in the courts. As the Convention on the Rights of People with Disabilities recognizes in Article 12, 1) “States Parties affirm that persons with disabilities have the right to recognition everywhere as persons before the law.”

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When it comes to citizenship or the constitution, the Connecticut Supreme Court in *Oller v Oller-Chiang*, 1994 said, “Guardians appointed by the court whether limited or plenary can be vested with substantial powers over a respondent. Therefore the appointment of a guardian implicates a respondent’s constitutional rights...” Many states automatically disqualify a person from voting if they have a guardian. One is clearly not a full citizen when, among others, constitutional rights are abridged.

The right to make decisions and choices are clearly no longer invested in the person. They have been usurped by the court and granted to another. The right and power to decide the course of one’s life, to determine how, with whom, where and other facets of living are in the hands of another, who has full authority. Even when a guardian permits their ward to make some decisions, it is temporary, usual partial, and requires the concurrence of the guardian and their authorization. A very long way from equal opportunity. Guardian determination is a far cry from self-determination.

The ultimate responsibility for a guardian is to act in a person’s best interest. That is a standard most of us would not be willing to live up to in our own lives. We have other interests, desires and activities which make us happy or we prefer which are not necessarily in our best interest. We would be unwilling to give those up or especially allow another to determine our participation. The issue of control is very important in anyone’s life. We expect unhappiness, possible depression or unusual behavior when people lose control over what is important to them. Imagine then how it feels to have little, if any control. We have learned that much of what is labeled maladaptive behavior is the result of persons believing that they had or experienced a lack of control in their lives. What better way to ensure that lack of control than the appointment of a guardian.

As I’ve stated, I don’t view the utilization of supported decision-making as an alternative to or substitute for guardianship. I see it as our obligation to support persons with disabilities, including in making decisions. Subscribing to the idea that individuals need supports in their lives, rather than services or “care” leads to some rather logical conclusions. Viewing the providing of support as our obligation to put persons with disabilities on a par with those without disabilities means a change, not just in the “system” but also in thinking.

Not only is it logical, I believe it is imperative that we include,

in the supports a person might need or desire, supports around decision-making. Inherent in the spirit and letter of the ADA, as well as the transformation we are engaged in or seeking, is the concept of supporting people. It is contrary to this “movement” and all the ADA promises, to stop, remove a person’s rights, deny their aspirations and desires, remove choices and opportunities and make them subject to the decisions of another.

One major difference in the support we are talking about here, is the need to have unpaid persons available to provide some or all of the support. Avoiding potential conflicts of interest which arise by having only paid persons in the life of the person who wants and/or needs support in this area makes this necessary. I believe and we have found, that authentic person-centered planning, with a majority of unpaid allies and supporters participating, is the way this is best addressed.

A rich variety of persons not paid to be in one’s life is enriching to most. Varying levels of relationships and friends benefits most of us. Persons with disabilities are not unique in this regard. Our history of discrimination toward and segregation of persons with disabilities has mitigated against this naturally occurring. Some aspects of disability, in the area of communication especially, may also mean there needs to be more intentional help to establish relationships. The same is true where reciprocity isn’t usual for persons in relationships.

We need to assure that time and effort are expended to accomplish what we know is important for quality of life for all of us, including persons with disabilities, and to afford the supports needed for decision-making. My presentations on the subject always entreats parents and family members to attend to this goal. This always includes the admonition to be sure a number of these relationships are with persons your child’s age, not yours. I believe it also needs to be a responsibility of the “system”, including schools. It can’t be ignored, it is essential for the full generation people with disabilities who will live a generation past their parent’s lifetime.

A few additional thoughts: Those of us who have been at this for some time now recognize that, despite whatever planning parents have done to try to assure a family member will assume guardianship throughout their son or daughter’s lifetime, the likelihood is at some point in the 35 plus years their child outlives them, a stranger will assume guardianship. While parents don’t envision this, the reason for guardianship corporations, public guardians, charitable guardians and the appointment of so many

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involved others, is just that. The selected family member(s) predecease their sibling or relative, move, leave the state to follow a spouse, become ill or have significant financial difficulties or find it a burden. Whatever the reason, the all too frequent outcome is a stranger in charge of their child's life.

Restoration of Rights is a difficult, uncertain process. Once the need for a guardian is established it is hard to provide evidence to the contrary, especially to the judge who found it necessary in the first place – on the record. Otherwise, in most cases, especially when a plenary or full guardianship is appointed, guardianship will last a person's lifetime.

One of my sore points in all of this is the frequent recommendation of school personnel urging parents to seek guardianship. If anyone lacks familiarity with adult life or is least likely to be there, some 35 years past the parent's lifetime, it is those who work in schools. Many times persons who have never read the statutes, don't realize the implication and consequences and perhaps don't recognize their students as equal citizens make the recommendation. They may not realize that finding the person incompetent or incapacitated and requiring a guardian, removes their rights. If so, shame on them. If any of those elements are true, they are complicit in this damaging, destructive direction and are a part of the problem.

The movement, to this point, away from automatic guardianship to provide supports for decision-making, is splendid and heartwarming. This author encourages you, even implores you, to advance this far more empowering and enlightened approach on behalf of persons with disabilities.

About the Author

Dohn Hoyle is the former Director of The Arc of Michigan and long-time advocate for the rights of people with disabilities. A respected leader and innovator in the disability movement, Dohn has provided leadership on issues regarding the overuse of guardianships, closing the state institutions for people with developmental disabilities, person-centered planning, self-determination, inclusive education, services/supports for people with developmental disabilities, eliminating the use of seclusion and restraint in school and adult systems; criminal justice issues, Fetal Alcohol Syndrome, SSI/SSDI hearings and appeals; and estate planning.



Dohn Hoyle

Supported Decision-Making in Tennessee

By Lauren Percy, Public Policy Director, Tennessee Council on Developmental Disabilities

Over the past few years, Tennessee's disability community has joined together to learn about the concept of Supported Decision-Making. We really got hooked on the topic after we invited national legal expert Jonathan Martinis to visit and talk to us about it. "What is more fundamental to our humanity than the right to make choices?" Martinis asked during a talk in Tennessee. And, "What good are your rights if you cannot exercise them by making choices about your life?" These questions resonated deeply with us. This article is about Tennessee's collaborative approach to introducing Supported Decision Making to Tennessee's disability community on two fronts: legislative advocacy and information dissemination.

Phase 1: Laying the Groundwork

In early 2016, several Tennessee disability organizations formed a workgroup, initiated by one of our state's two University Centers for Excellence in Developmental Disabilities (UCEDDs), the Vanderbilt Kennedy Center. The workgroup initially included the UCEDD; the Tennessee Council on Developmental Disabilities; the state's Protection & Advocacy agency, Disability Rights Tennessee; the Statewide Independent Living Council; The Arc Tennessee; and Family Voices Tennessee. Over time, our group expanded to include representatives from Tennessee's Parent Training and Information Center Support and Training for Exceptional Parents (STEP) and the Tennessee Disability Coalition.

Around the same time as Tennessee's Supported Decision Making Workgroup came together (2016), Texas passed one of the nation's first laws enacting Supported Decision Making. A member of the Tennessee Supported Decision Making Workgroup, Council on Developmental Disabilities Executive Director Wanda Willis, met with leaders in Texas to learn as much as we could from their experience. The Tennessee Council on Developmental Disabilities



Tennessee's Supported Decision Making Workgroup with Jonathan Martinis (center; 6 from the left) and Senator Becky Massey (immediately right of Jonathan Martinis), Senate Sponsor of the Supported Decision Making bill.

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also contracted directly with national expert Jonathan Martinis for a national perspective to guide our collaborative work¹. Meanwhile, we are fortunate that the State Medicaid agency, TennCare, and the state DD agency, the Dept. of Intellectual and Developmental Disabilities, were already familiar with the concept and supportive of it. This broad base of perspectives helped us build a foundation of knowledge and expertise for Supported Decision Making in Tennessee.

In the spring of 2017, Tennessee's Supported Decision Making Workgroup assisted with the introduction of a bill that replicated Texas' successful legislation². As the bill made its way through the state legislature, the Workgroup doubled down on efforts to educate policymakers and the public about the concept. Below, we explain how we approached each effort.

Information Dissemination – Phase 1

Several workgroup organizations worked on written materials for families and one-pagers for policymakers as an initial action step. For example, Disability Rights Tennessee led an effort to develop a White Paper, and The Arc Tennessee drafted one-pagers for legislators to read. We met with targeted entities like the Tennessee Administrative Office of the Courts (a recommendation from Texas) and the Tennessee Commission on Aging and Disability. Then, in March 2017, we sponsored a 3-day visit from national expert Jonathan Martinis with Tennessee stakeholders. On day 1 of these meetings, the Council hosted a group of other state agency representatives from 10 state departments³ that serve people with disabilities. Day 2, included

¹ Jonathan Martinis bio: http://bbi.syr.edu/news_events/news/2016/03/j-martinis-joins-bbi.html

² Texas' legislation: <http://www.legis.state.tx.us/tlodocs/84R/billtext/html/SB01881E.HTM> Tennessee's original legislation: <http://wapp.capitol.tn.gov/apps/BillInfo/Default.aspx?BillNumber=SB0264>

³ Tennessee Employment Roundtable participants: 1. Council on Developmental Disabilities; 2. Department of Children's Services; 3. Department of Education, Division of Special Populations; 4. Department of Health, Maternal and Child Health; 5. Department of Human Services; Vocational Rehabilitation and Adult Protective Services; 6. Department of Intellectual and Developmental Disabilities; 7. Department of Labor; 8. Department of Mental Health and Substance Abuse Services; 9. Department of Treasury, ABLE Tennessee program; 10. Division of TennCare, Long-term services and supports. Also joining the Roundtable are the DD Network partners:

targeted care coordinators and senior leadership from the state's Managed Care Organizations (MCOs). MCOs in Tennessee administer the state's managed care long-term services and supports programs for people with intellectual and developmental disabilities and for adults who have physical disabilities or are over 65 years old.⁴ We witnessed the look of shock on many faces when care coordinators realized that there are less restrictive alternatives to conservatorship (also called "guardianship" in many states). The second meeting on day 2 was with a group of lawyers from state departments and targeted private law firms specializing in "special needs" and conservatorship.

During this meeting, a comment was made by a conservatorship lawyer that although conservatorship is supposed to be limited, more often than not well-meaning families choose "full" conservatorship over every area of the person's life. Indeed, Martinis shared national statistics that show 90% are plenary (full conservatorships).⁵

On day 3, Martinis addressed the Council's Partners in Policymaking⁶ Annual Reunion Conference, reaching over one hundred Tennessee self-advocates and family members. Many individuals expressed relief in knowing there is a way to receive assistance both in the present and plan for the future through Supported Decision Making. State policymakers recognized Supported Decision Making as perfectly consistent with existing best practices in their fields: student-led IEP meetings; person-centered planning in long-term services and supports; and informed choice in Vocational Rehabilitation, for example. The next question from our stakeholders was: how do we make this happen? (More on that later).

Legislative Advocacy – Phase 1

The Arc Tennessee led efforts to introduce legislation about Supported Decision Making in early 2016 and continued as lead point of contact with the bill's sponsors. We were fortunate

Disability Rights Tennessee; and Vanderbilt Kennedy Center. Read more: <https://www.tn.gov/cdd/article/employment-roundtable>

⁴ Read more about Tennessee's managed care LTSS programs here: <https://www.tn.gov/tenncare/section/long-term-services-supports>

⁵ Jonathan Martinis, "Supported Decision-Making: From Justice for Jenny to Justice for All!" Tennessee Grassroots Meeting, 9/13/2017, Slide 8

⁶ Read more about Partners in Policymaking: <https://www.tn.gov/cdd/article/partners-in-policymaking>

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that the bill's sponsors lent incredible value and credibility to the effort: Senator Becky Massey (R-Knoxville) is a Home and Community-Based Service provider for people with intellectual disabilities and extremely knowledgeable about the field of disability. Representative Mike Carter (R-Ooltewah) is a former judge and an attorney by trade who is extremely knowledgeable about Tennessee's legal community and legal implications of the bill. Under their leadership, the bill advanced to the Senate Judiciary Committee during the 2017 legislative session. There, a panel of Tennesseans testified: a self-advocate, a parent, and the lead attorney for Disability Rights Tennessee.

Members of the Committee and outside groups expressed concerns about two things: 1) a fear that "supporters" of a person with a disability who do not have court supervision (like guardians/conservators do) could exploit the person who enlists them for support in decision making; and 2) resistance to a new form proposed in the bill, called "The Supported Decision Making Agreement Act". This new form was considered unfamiliar, confusing, and unrecognized by the legal community and general public. Encouragingly, the Committee agreed with the philosophy of Supported Decision Making. One of the recurring questions was, "Does Supported Decision Making need to become a law?" Instead of voting on the bill, it was sent to Summer Study, affording the opportunity to hold an extra hearing between Tennessee's two-year legislative sessions.

Phase 2: Listening to feedback from the community

Legislative Efforts – Phase 2

Shortly after the 2017 legislative session ended, the Supported Decision Making workgroup, the state's DD agency, and Jonathan Martinis met via conference call to discuss amending the bill to address the feedback it received during session. We also participated in meetings with the bill's sponsors and outside groups who had expressed concerns, and listened carefully to their ideas for resolving those concerns. And, we kept coming back to the question, "Does Supported Decision Making need to become a law?"

We know from Tennesseans that many individuals and their families do not necessarily want to pursue a resource intensive and restrictive option like conservatorship, but they simply do not know there are any other options for supporting a person

who needs assistance making decisions⁷. We know that many individuals and their families are advised that the best thing to do is seek conservatorship as soon as the person who needs assistance turns 18 years old, sometimes even if the person is perfectly capable of making their own decisions. It is what Jonathan Martinis calls, "just because". Just because_____ (someone has a certain type of disability; someone needs help in one area of decision-making; someone turns a certain age; etc.). One of the things that Jonathan Martinis stresses, and we believe in, is that decision making is a learned skill. No one is very good at making decisions until they have the opportunity to do so; to learn from mistakes, and to learn from others. That's what support and advice does for all of us. In this light, it seems unfair to remove one's right to make decisions without sufficient opportunity to learn. Martinis' presentations taught us that needing assistance is not the same thing as lacking capacity to make the final decision. He asks a potent question in his presentations: "If people can make decisions with assistance or support, are they 'in need of supervision?'" And the next slide says, "ARE YOU?" in all capital letters.⁸

Amending the Original Legislation

In discussing the question, "does Supported Decision Making need to become a law?", our workgroup's answer was: no. We recognize that Supported Decision Making is already in use and can continue (and expand) without a new law. However, the workgroup agreed that a statement in Tennessee Code would be valuable for ensuring Supported Decision Making is recognized as an option for people to consider. It is also valuable in prompting the "system" to change; for examples, prompting lawyers who handle conservatorship petitions and judges who grant them to ask about Supported Decision Making. This led us to look at Tennessee's current law regarding conservatorship⁹. Thanks to a relatively recent legislative reform effort in 2015, Tennessee law currently states, "The court has an affirmative duty to ascertain and impose the least restrictive alternatives upon the person with a disability that are consistent with adequate protection of the

⁷ In Tennessee, we use the term "conservatorship," which means the same as the term "guardianship" used by other states.

⁸ Jonathan Martinis, "Supported Decision-Making: From Justice for Jenny to Justice for All!" Tennessee Grassroots Meeting, 9/13/2017, Slides 40, 41

⁹ Title 34, Tennessee Code annotated <https://www.lexisnexis.com/hottopics/tncode/>

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person with a disability and the property of the person with a disability.” [TN Code 34-1-127, emphasis added].

At Jonathan Martinis’ suggestion, we decided to move away from the bill’s original approach and, specifically, the Supported Decision Making Agreement that would have created a new form. Not only was this form the source of some angst from stakeholders and legislators, it created a prescriptive view of Supported Decision Making rather than recognizing that Supported Decision Making can look different for each individual who uses it. It can be formal or informal. And when formalized, the “form” itself can take different forms. There is an entire library of model Supported Decision Making agreements available¹⁰. As a result, The Arc worked with the bill’s sponsors to significantly change the bill. The amended version adds only one sentence to current law, plus a definition of Supported Decision Making:

Added sentence (see italics): The court has an affirmative duty to ascertain and impose the least restrictive alternatives upon any person with a disability that are consistent with adequate protection of the person and the person’s property. *“Less restrictive alternatives” include supported decision-making, which may be formalized in writing through a document such as a power of attorney, as provided in chapter 6 of this title.*

Proposed Definition for TN Code: “Supported decision-making” means a less restrictive alternative available to any person with a disability that provides a plan for supporting and accommodating a person with a disability in a manner that enables the person to make life decisions, including where the person wants to live; the services, supports, and medical care the person wants to receive; how the person uses the person’s own money; with whom the person wants to live; and where the person wants to work, without impeding the self-determination of the person with a disability. A supported decision-making arrangement and relationship may be formalized as provided in chapter 6 of this title.

Summer Study

On September 11, 2017, the Tennessee Senate Judiciary Committee revisited the Supported Decision Making bill, as promised. Testimony was presented by Jonathan Martinis, a workgroup member with Family Voices Tennessee who is also a parent of young adults with disabilities, and a Council member who is a young adult with a developmental disability.

¹⁰ <http://www.supporteddecisionmaking.org/node/390>



Above from left to right: Clancey Hopper, Tonya Bowman, and Jonathan Martinis prepare to give testimony.

The Summer Study video stream is [here](#) (fast forward to the 2 hour, 47 minute mark).

The Senate Judiciary Committee members responded positively to the amended version of the bill. Senate sponsor, Senator Becky Massey, kicked off the session by introducing the bill, explaining the bill’s amendments, and emphasizing the topic’s relevance for Tennesseans. She referenced individuals with intellectual disabilities she knows personally who could benefit from Supported Decision Making. One woman, she said to the Committee Chairman, “could run circles around you, I bet, in making decisions”, and yet has a conservator. She acknowledged that other folks might truly need conservatorship, and emphasized that the option would always be there. One thing we have continually emphasized is that conservatorship does not “go away” because of Supported Decision Making.

After the testimony concluded, the Tennessee Bar Association spoke in support of the amended bill. Additionally, the Administrative Office of the Courts (AOC) spoke about the bill, stating that judges and courts are interested in learning more about how it will impact court processes and expectations of judges. In the testimony, the representative stated that she is pleased to be working with the Council and The Arc Tennessee to understand the concept, and the bill, and believes she can work with us to develop guidance for judges. We are so grateful for the advice from Texas to engage the AOC, and we are even more grateful for Tennessee’s AOC team’s willingness to work with us and try to find solutions when they have questions.

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Information Dissemination – Phase 2

In the days immediately following the Summer Study committee hearing, we held another round of in-person forums with Jonathan Martinis, reaching over 100 Tennesseans. Our goals were two-fold: to reach new audiences for education about Supported Decision Making and to communicate the changes made to the bill.

The second round of in-person meetings followed the same general pattern of the first, but with more of a focus on turning theory to practice. We started with a follow-up presentation to the 10 state agency representatives who participated in Martinis' presentation back in March. They are part of a standing group convened by the Council that focuses on disability employment, which we call the Employment Roundtable.¹¹ After the Roundtable meeting, we facilitated a smaller meeting with staff from the Department of Education and included two of their key advisory bodies via phone: the Tennessee Association for Administrators of Special Education and the Students with Disabilities Advisory Council. This allowed Special Education directors from school districts across Tennessee to participate. In these meetings, we had a chance to talk about what's happening from program administrators' perspectives and how state government practices might change to better support decision-making skills and self-determination in Tennessee schools. We found these meetings to be extremely valuable, recognizing that passing a law can only take us so far – it is that law's implementation and everyday practice that will really impact Tennesseans.

With Martinis' help, we were able to dive deeper into how Supported Decision Making can be operationalized within the processes discussed back in March: student-led IEP meetings; person-centered planning in long-term services and supports; informed choice in Vocational Rehabilitation. We spent time addressing their question –how do we make this happen? – by looking at examples Martinis brought from other states who have already operationalized it in school districts (Washington, DC) and Powers of Attorney forms (Maryland). State agencies shared ways that they are already using Supported Decision Making and ways that they might start. The Council is already planning a smaller, focused follow up meeting to flesh out these ideas further.

¹¹ Read more about the Tennessee Council on Developmental Disabilities' Employment Roundtable here: <https://www.tn.gov/cdd/article/employment-roundtable>

One lesson we learned is the benefit of approaching information dissemination as an iterative process: the very first meeting focused on high level philosophy, and the subsequent meetings have built on that foundation. It was extremely encouraging to see the groups grow each time as the participants recruited others from their departments. One participant from the Roundtable commented, "As a result of this meeting, I now have a better understanding of how all state agencies involved in this meeting can coordinate efforts to better teach and promote a culture of supported decision-making." A participant from the education-focused meeting shared, "This meeting has truly helped me have a deeper understanding of supported decision-making and allowed me to make decisions on how to bring this message and mindset to more educators in Tennessee."

On day 2, we started by meeting with a small group of judges, court staff and the General Counsel from Tennessee's Administrative Office of the Courts. During this meeting, we were able to further flesh out concerns from their perspective and brainstorm how to provide guidance for judges and courts. We are encouraged by the open and willing approach from this group, who seem to genuinely like the idea of Supported Decision Making and just want to know "how to do it". One judge commented, "I am here because I want to do everything I can to protect people and their rights."

The grand finale of the in-person meetings was a 'grassroots' group of more than 60 individuals with disabilities, family members and advocates from across the state. It took coordinated efforts among the entire Supported Decision Making workgroup to pull this off: first, each organization identified invitees from our networks and, although there is much overlap, we each created our own lists of invitees. When we saw the overwhelming response of "yes" RSVPs, we had to get creative about how to host the meeting so that we reached as many interested people as possible. Ultimately, we decided to host a limited number of people in-person and offer a remote option, too, with video conferencing and phone capability provided by Disability Rights Tennessee. This allowed us to have approximately 30 people gather at Disability Rights Tennessee's Nashville Office to see Jonathan Martinis' presentation in person, plus more than 70 callers from across the state. Many callers were gathered together to listen; for example, an HCBS provider in Knoxville Tennessee gathered individuals and staff members to listen remotely; The Arc Tennessee gathered their staff to listen from their offices; and DRT's regional offices did the same. People commented that the

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information was very exciting and useful, but difficult to digest in one afternoon. The workgroup is now brainstorming ways to follow up and help people internalize the message – and use it!

What's next?

The organizations involved in Tennessee's workgroup view Supported Decision Making as a top priority going into next year; not only following the legislation and helping to inform and educate policymakers, but in helping Tennesseans use Supported Decision Making.

As we look ahead, we try to keep our eye on the prize, the ultimate outcomes we want. It is our hope that Supported Decision Making will empower the next generation of 18 year olds with disabilities to believe that they are capable of learning how to be adults, even if they aren't there yet (just like all 18 year olds). We hope families start looking at more restrictive and resource-intensive options for decision making as last resorts, trying Supported Decision Making first. We hope that even for people who do not make many of their own decisions today, either because of capacity or because of an overbroad conservatorship, that Supported Decision Making can help increase that person's control of their own life – even if it starts with decisions like whether to wear a green or blue T-shirt. With increased awareness about Supported Decision Making and

its benefits, we think this is possible. Ultimately, we hope that Supported Decision Making will give anyone who needs help with decision-making new tools about how to receive assistance without allowing someone to make decisions for us. After all, "We are our choices", said renowned philosopher Jean-Paul Sartre.

About the Author

Lauren Pearcy has worked as the Tennessee Council's Director of Public Policy since Fall 2016. Before joining the Council, she most recently worked at Tennessee's Medicaid agency in the Long Term Services and Supports Division. Prior to moving to Tennessee, Lauren worked as a senior policy analyst for the National Governors Association in Washington, D.C.



Lauren Pearcy

for six years. While there, Lauren helped produce the landmark publication, *A Better Bottom Line: Employing People with Disabilities*. Lauren is an honors graduate with a Master's Degree in Public Policy from George Washington University and a Bachelor's Degree from the University of California, Davis.

Supported Decision-Making and Alternatives to Guardianship by Families

By Kathy Brill, Executive Director, Parent to Parent USA

Our youngest daughter is now 28 years old and has been living in her own home for two years now. She has personal attendant supports, uses a power wheelchair, home automation, and other assistive adaptations to support her independent living, employment, and community activities. We, her parents, are not her guardians. The story could have been different, though, had we, as parents, not sought out educating ourselves on this topic. Families have beliefs and assumptions, based upon our experiences. I think it would be safe to say that most families try their best to do the right thing for their children. Sometimes, however, our assumptions and beliefs lead us to make unintentional bad decisions. There are other factors that enter the picture, also. Families who have children with disabilities and/or special healthcare needs, just like ALL families, have other time commitments that challenge their ability to do all the things they need and want to do. The difference, though, is that the decisions we need to make as families whose children have disabilities can have a lifelong impact on our children's future independence. We are often unaware of that fact.

Supported Decision Making and Alternatives to Guardianship are very important topics for families to learn about and consider. We can learn about it from various sources, which is great. We have options of learning from the advocacy and family organizations, conferences and trainings, Internet, social media, peer support, etc. The important part is to realize that there are a lot of ways for us to better understand this topic and how it ultimately impacts our family, and the future of our children.

I had been a special education teacher before my third daughter was born premature, and diagnosed with Cerebral Palsy. I was already knowledgeable about disability advocacy and was fighting for inclusion of my students long before I realized I would be fighting for it within our own family. Inclusion was always viewed as a civil rights issue to me, and I felt very strongly about it.

Now, on to the future! While my husband and I had always raised our daughter to be independent, self-determined, and self-confident, I recall his return from an advocacy conference (TASH) where an attorney had informed him that parents do not have to become guardians to their adult child just because he or she has a disability. He was in shock, as he remembers being told during an IEP meeting that guardianship was recommended. He went to that particular conference session to learn the steps to becoming a guardian. I, on the other hand, ignored the comment during the IEP, but I didn't realize he was assuming that to be true. We hadn't discussed it afterwards, so I was unaware of him mentally processing this as a future to-do item. He says, "I thought it was our obligation to our daughter, to protect her safety". As a matter of fact, in a recent survey on alternatives to guardianship, done by Parent to Parent USA and Family Voices, 65% of P2P and FV staff in states across the nation stated that they "hear that families are sometimes instructed by school personnel or health care providers to seek guardianship in order to assure that their

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children will continue to be eligible for school and to access adult services.” We were not surprised to see this data outcome, but it does show us that there is a huge need to educate both professionals and families about this topic.

Families can learn so much from one another! We can help each other to identify solutions to issues and barriers, including our children’s ability to live as adults successfully without us being their guardians. My husband often talks about his own personal inner turmoil over the years regarding barriers facing our daughter, and decisions that needed to be made. His story is an interesting one, because he never shared it with me until just a few years ago as I was prepping to present on the topic at a conference. He was always supporting me as I fought the good fight for full inclusion for our daughter since birth. However, unknown to me at the time, he didn’t have faith that our relentless requests for inclusion would always work. He now writes stories about his inner struggles as a dad, starting each subject with “This will never work.” Today, after 28 years, and still going strong, he tells me he is absolutely amazed at the successes we’ve had with our planning and persistence, regardless of his secret belief that our requests would either never happen, or would sadly fail. His stories are many, including our daughter’s learning to use the computer, playing with neighborhood kids, going ice skating on a public rink, being fully included in elementary school, going on vacation to Cape Hatteras, being able to drive her first power wheelchair at age 4, having the school district put a lift on the regular full-size bus, flying to Disney, going to college, and the latest...living on her own with all the necessary supports and services. I’m so glad that he didn’t show me his pessimism at the time, so I could keep my vision positive! All of these experiences have played a part in building upon each other, adding to her (and my husband’s) confidence to move out of our home and into one of her own. Each of these experiences can help to create the “can do” attitude for future things to come, whatever they might be.

When we discover and experience these successes, families are always eager to share their stories with other families, not to brag, but in hopes that they can assist a family to have similar successes and ah-ha moments. Peer to peer support “matching” can be incredibly useful in helping families to realistically envision a future for their child that does not include guardianship. How did other families, whose children have similar service and support needs, succeed using supported

decision-making or another alternative to guardianship? How did they avoid becoming guardians? How did they make that a reality? Peer support from an experienced person who has “walked the walk and talked the talk; been there, done that,” can motivate, model and guide, and offer that emotional and informational support that is needed by families who are not sure how to proceed forward toward a goal, or assume that guardianship is the only option, based on information they’ve been given. There are many other families who think the same way my husband did, assuming they need to become their child’s guardian in order to protect their child’s welfare and safety. Call a parent to parent organization in your state and ask to talk to a trained Support Parent who has similar needs to your own, about alternatives to guardianship, or any other topic. So often, we assume something can’t be done, and then lo and behold, we find another family who has done it! If they did it, so can we.

Most families have great fears about the future of their child’s well-being. We become confused by all the jargon, acronyms, agency responsibilities, waivers, rules, regulations, laws, meetings, paperwork, etc. Whew! Are we making the right decisions? We worry a lot about that. But in years to come, we want to be able to look back and know that our adult children are protected by their civil rights, and have the ability to live safely and comfortably with needed supports and services in the community of their choice.

In the same survey, when asked, “Are families that you work with aware of other options, other than seeking guardianship for the family members they care for?” 52% responded “rarely”, and 39% responded occasionally. Only 7.4% responded “never”. The most common alternative to guardianship that parents are aware of is “Power of Attorney”. Some parents assume it’s “all or nothing,” which makes many lean toward guardianship.

What barriers do families face that prevent them from considering alternatives to guardianship? Our survey indicates numerous barriers facing families, such as not understanding the processes and reasons, timeliness of processes, and costs. In addition, in one state, some families fear transition, unsure of how medical decisions will be made if their child’s provider is “strict” about following HIPAA when youth turn 18. What if a complex medical situation arises? Another fear faced is that their child will be taken advantage of, that someone else might file for

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Supported Decision-Making and Alternatives to Guardianship by Families

guardianship, and occasionally (but not always willing to admit) that their child may make a decision that they don't agree with. There is a lack of knowledge of the implications of guardianship and the fact that there are other options. There are also myths that are perpetuated, that create confusion and fear, which

then leads to choosing guardianship. Another survey response to barriers is the lack of interaction with families who have successfully chosen alternatives to guardianship, and conversations with them on how they proceeded. This barrier is one that we will be working on developing with our peer support networks!

About the Author

Kathy Brill, Executive Director of Parent to Parent USA, is mom to three daughters. Her youngest, Alexa, age 28, was born three months premature and uses numerous personal and assistive technology supports to assist her in being successfully and fully included in all aspects of her home, school, and community. Kathy was the director of Parent to Parent of PA until 2002. She assisted with the founding of Parent to Parent, USA. P2P “matches” families who have children with disabilities and/or special healthcare needs of all ages and all topics/issues of concern. She holds master's degrees in Education, with certification in Special Education, and Political Management, with a concentration in Grassroots Advocacy. She lives in Pennsylvania and works at the P2P USA office in Washington, DC.



Kathy Brill



TASH Membership Form

Organization Name (If applicable): _____

Organizational members fill out the following fields for the Primary Contact only.

First Name: _____ Last Name: _____

Address: _____

City/State/ZIP: _____ Country: _____

Phone: _____ E-mail: _____

Membership Level

TASH offers membership at a variety of levels. Please review the details below and choose the membership level that is appropriate for you. Individual and organizational memberships are available. Membership is valid for a 12 month term. A complete summary of member benefits can be found at www.tash.org/join.

	Regular	Reduced			Organization \$385
	Professional \$165	Associate \$85	Self-Advocate, Family & Supporter \$35	Student \$45	
Research and Practice for Persons with Severe Disabilities, the official TASH research journal (print copy)	X				1 COPY
Research and Practice for Persons with Severe Disabilities, (online access to current and archived issues)	X	X		X	X
Connections, the quarterly magazine written by and for TASH members	X	X	X	X	X
Connections Library (includes access to 10 years of Connections archives)	X	X			X
TASH webinar archive	X				X
Reduced registration rates for TASH conferences and events	X	X	X	X	5 STAFF
Discounts for TASH Training webinars, publications & other offerings	X	X	X	X	5 STAFF
Access to TASH's professional network, forums & blogs	X	X	X	X	X
Affiliation with a TASH Chapter (includes policy and expertise, Capitol Hill Days, Chapter communications & activities)	X	X	X	X	X
Advocacy Alerts & Updates	X	X	X	X	X
	<input type="checkbox"/> Select	<input type="checkbox"/> Select	<input type="checkbox"/> Select	<input type="checkbox"/> Select	<input type="checkbox"/> Select

Demographic Information

This information is collected for TASH's use only so that we can better serve our members' needs.

What is your race or ethnicity? (Optional; select all that apply)

- American Indian or Alaska Native
- Native Hawaiian or Pacific Islander
- Asian
- Black or African American
- White/Caucasian
- Hispanic/Latino
- Other _____

Which of the following best describes you? Select all that apply. (not applicable for organizational members)

- | | | |
|--|--|---|
| <input type="checkbox"/> General Educator | <input type="checkbox"/> Person with a disability | <input type="checkbox"/> Government – Federal |
| <input type="checkbox"/> Special Educator | <input type="checkbox"/> Parent of a person with a disability | <input type="checkbox"/> Government – State |
| <input type="checkbox"/> Education Administrator | <input type="checkbox"/> Sibling of a person with a disability | <input type="checkbox"/> Government – Local |
| <input type="checkbox"/> Transition Educator | <input type="checkbox"/> Other family member of a person with a disability | |
| <input type="checkbox"/> University Faculty | | <input type="checkbox"/> Attorney |
| <input type="checkbox"/> University Researcher | <input type="checkbox"/> Early Intervention Service Provider | <input type="checkbox"/> Public Policy Advocate |
| | <input type="checkbox"/> School-Aged Related Service Provider | <input type="checkbox"/> Other Advocate |
| | <input type="checkbox"/> Adult Service Provider | <input type="checkbox"/> Other _____ |

Please indicate your areas of interest. Select all that apply.

- | | | |
|---|---|--|
| <input type="checkbox"/> Early Childhood | <input type="checkbox"/> Community Living | <input type="checkbox"/> Assistive Technology |
| <input type="checkbox"/> K-12 Education | <input type="checkbox"/> Aging Issues | <input type="checkbox"/> Communication |
| <input type="checkbox"/> Transition | <input type="checkbox"/> Advocacy | <input type="checkbox"/> Diversity & Cultural Competency |
| <input type="checkbox"/> Post-Secondary Education | <input type="checkbox"/> Public Policy | <input type="checkbox"/> Human Rights |
| <input type="checkbox"/> Employment | <input type="checkbox"/> International Issues | <input type="checkbox"/> Other _____ |

Additional Information

Your Date of Birth (Optional): ____/____/____

If you are a family member of a person with a disability, fill out the date of birth of your family member: ____/____/____

If you are a student, please fill out the following fields:

University Name: _____ Expected Completion Date: _____

Major/Department Name: _____

If you are a university educator, what is your field of study? _____

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Credit Card (select card type)

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Would you like to make a tax-deductible donation to TASH?

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Total Payment (add membership total and donation, if applicable) \$: _____

Please submit this membership form via mail, fax or e-mail. With questions, contact (202) 540-9020.

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TASH Amplified

A podcast series



NEW!

Welcome to **TASH Amplified**, TASH's new podcast series. This series seeks to transform research and experience concerning inclusion and equity for people with disabilities into solutions people can use in their everyday lives.

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Reflections on 40 Years of Agency Community Supports

Faith and Flourishing: Equipping Your Church to Reach Out to People with Disabilities

Faith and Flourishing: Welcoming Children with Disabilities and their Families

Faith and Flourishing: Hidden in Plain Sight

Special Education Teachers and the General Education Curriculum

What Matters to Family Members when a Relative Transitions to Community Living

Building Communities to Support People with Disabilities

Presentations on Recreation and Leisure for People with Disabilities at the TASH Annual Conference

Barb Trader Reflects on a Lifetime of Accomplishment in Disability Rights

www.tash.org/amplified



TASH Connections

Equity, Opportunity and Inclusion for People with Disabilities since 1975

TASH is an international leader in disability advocacy. Founded in 1975, TASH advocates for human rights and inclusion for people with significant disabilities and support needs – those most vulnerable to segregation, abuse, neglect and institutionalization. TASH works to advance inclusive communities through advocacy, research, professional development, policy, and information and resources for parents, families and self-advocates. The inclusive practices TASH validates through research have been shown to improve outcomes for all people.

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities. Items in this newsletter do not necessarily reflect attitudes held by individual members of the Association as a whole. TASH reserves the right to exercise editorial judgment in selection of materials. All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement. For a copy of TASH's publishing and advertising policy, please visit www.tash.org.

TASH Mission & Vision

As a leader in disability advocacy for more than 35 years, the mission of TASH is to promote the full inclusion and participation of children and adults with significant disabilities in every aspect of their community, and to eliminate the social injustices that diminish human rights. These things are accomplished through collaboration among self-advocates, families, professionals, policy-makers, advocates and many others who seek to promote equity, opportunity and inclusion. Together, this mission is realized through:

- ♦ Advocacy for equity, opportunities, social justice and human rights
- ♦ Education of the public, government officials, community leaders and service providers
- ♦ Research that translates excellence to practice
- ♦ Individualized, quality supports in place of congregate and

segregated settings and services

- ♦ Legislation, litigation and public policy consistent with the mission and vision of TASH

The focus of TASH is supporting those people with significant disabilities and support needs who are most at risk for being excluded from society; perceived by traditional service systems as most challenging; most likely to have their rights abridged; most likely to be at risk for living, working, playing and learning in segregated environments; least likely to have the tools and opportunities necessary to advocate on their behalf; and are most likely to need ongoing, individualized supports to participate in inclusive communities and enjoy a quality of life similar to that available to all people.

TASH has a vision of a world in which people with disabilities are included and fully participating members of their communities, with no obstacles preventing equity, diversity and quality of life. TASH envisions communities in which no one is segregated and everyone belongs. This vision will be realized when:

- ♦ All individuals have a home, recreation, learning and employment opportunities
- ♦ All children and youth are fully included in their neighborhood schools
- ♦ There are no institutions
- ♦ Higher education is accessible for all
- ♦ Policy makers and administrators understand the struggles of people with disabilities and plan – through laws, policies and regulations – for their active participation in all aspects of life
- ♦ All individuals have a way to communicate and their communities are flexible in communicating in alternate ways that support full participation
- ♦ Injustices and inequities in private and public sectors are eradicated
- ♦ Practices for teaching, supporting and providing services to people with disabilities are based on current, evidence-based strategies that promote high quality and full participation in all aspects of life
- ♦ All individuals with disabilities enjoy individualized supports and a quality of life similar to that available to all people
- ♦ All individuals with disabilities have the tools and opportunities to advocate on their behalf