

Supported Decision-Making

FEEDBACK FROM FAMILIES BY PARENT TO PARENT USA



Introduction

Parent to Parent USA has been a partner with the National Resource Center on Supported Decision-Making (NRC-SDM) to promote Supported Decision-Making and Alternatives to Guardianship. <http://www.supporteddecisionmaking.org/> With other parent organizations, we brought a parent voice to the project.

For some parents, Guardianship is considered a safety net. Because it legally takes the right away from an individual, others consider Guardianship an unconscionable decision.

What are parents to do?

They often feel caught between the need to protect and the desire to support an individual to achieve independence.

Parent to Parent programs are a point of contact for parents who learn their young child has disabilities or special health care needs. The focus of parents, new to the disability world, moves from learning about their child's diagnosis to managing their child's needs, care coordination, and advocating and coordinating needed services. These are added challenges parents face in addition to the typical day to day fast pace of supporting a family. The challenges are many, and care and concern for their children is always in the forefront. As a young child grows and matures, the focus gradually moves to planning for the future. In high school, focus moves to transition to adult life.

Ask any parent who just helped move their young adult into a college environment for the first time what emotions they experienced. The answer undoubtedly includes a spectrum of emotions.

Ask any parent who has a son or daughter with disabilities exiting high school and striving towards independence what emotions they experience, and they too will be experiencing a spectrum of emotions.

Gradually, states are changing Guardianship laws to incorporate Supported Decision-Making as a legal alternative to Guardianship. Alaska, Indiana, Maine, Missouri, New Mexico, Rhode Island and Tennessee have updated laws regarding Guardianship and Supported Decision-Making (SDM). Some states require that SDM at least be considered.

For individuals in states other than those referenced, it does not preclude a person with disabilities from using alternative tools for their own situation. Many individuals successfully navigate decision-making with support, without Guardianship being a factor.

We hope the information included here helps to raise awareness of Supported Decision-Making as a viable alternative to Guardianship.

Transition to Adult Services and Employment

Between the ages of 18 and 21, youth may transition from pediatric care to adult health care services and from school to employment, college or other day activities, and often to different residential or living environments. *Age 18 is the legal age when decision-making is owned by the young adult.* Guardianship is often recommended by physicians and school personnel to enable a parent to continue involvement in decision-making. Every aspect of health care requires providers to protect the patient's right to privacy and consent to care. To ensure this privacy, health care providers need to ensure they have documentation in place regarding an individual's appointed or authorized representatives to support or make decisions for when the individual is incapacitated. This protection is not taken lightly.

Parents carry the "lion's share" of responsibility when parenting a person with disabilities. These rules and laws protecting privacy are important and needed, but they put parents in a difficult situation, one that tends to force them to pursue Guardianship.

Guardianship and Guardianship Alternatives

Guardianship is a legal process, requiring court appointment of a person to assume the duties for decision-making and handling the necessary affairs of a person who the Court has deemed incompetent or incapacitated. A standby or Alternate Guardian is the person or entity designated to make decisions if or when an appointed Guardian is no longer able to fulfill their duties. Guardianship laws differ by state, but the goal is the same: to have someone appointed to make decisions for another person.

Supported Decision-Making is a custom-designed Toolbox. An individual with disabilities and their team develop a system of support, customized to assist with decision-making in areas where additional support is needed. Using multiple tools helps to preserve an individual's right to make their own decisions, to the best of their ability. These tools are helpful for establishing protocols

that are followed to assist a person with disabilities in making decisions. Supporters are individuals who may assist and guide in decision-making.

Advance Directives are tools that a person can set up to articulate and ensure their choices are honored. These documents can include Power of Attorney, Health Care Power of Attorney, Health Care Proxy, and Advance Health Directives.

Parent to Parent USA encourages families to explore alternatives to guardianship. All people have the right to make decisions, and we urge parents to learn and explore options to ensure a person's wishes are honored.

A Note from Parent to Parent USA Regarding Family Caregivers

Family caregivers of individuals with disabilities are in a position of providing more care than ever anticipated. For many, at home care is the only option; for others, it is the first choice.

Countless numbers of times, caregivers are in the position of decision-maker for another person, and they sometimes second-guess their decisions. There are more questions than answers. Sometimes, caregivers are judged for the required decisions they make regarding the care of their son or daughter. Remarks and comments from friends, relatives, and professionals about what a parent should or should not do, can be counterproductive. Time, knowledge, and expertise are limited for parents. How do they juggle and manage a household, family, and job and then take on the additional care of a person with health care needs or a disability? How can they possibly add responsibilities of nurse, care coordinator, bill payer, benefits manager, and report preparer and still have time to also be a parent? This work is not to be taken lightly. Parents do the best they can with the time, knowledge, and resources they have. As parents age, fear for the future is a reality.

In the past, Service Provider agencies were depended on to provide direct support. In recent years, they are becoming more and more constrained as to their capacity. With staffing shortages, reimbursement rates, and budget reductions reduced, there is an increased uneasiness about the future among aging parents. With moves to self-determination, more of the work and management are placed in the hands of and on the shoulders of families.

As parents age, concerns and fears escalate for who will make decisions and manage finances for their son or daughter with significant disabilities when they die. Parents may seek family members or close family friends to participate in this process, or they may turn back to Service Provider Agencies to ask, "If not us, who will care for our child?"

Feedback from Families

During July-August 2019, Parent to Parent USA reached out to families for feedback about Supported Decision-Making. Our goal was to learn from parents, gather information from parents on their knowledge and experience regarding Supported Decision-Making, and gain advice to share with others. We wanted to hear from families about SDM, about how they have taught

decision-making to their son or daughter with disabilities, and how they have supported their son or daughter in making decisions.

In all, 60 parents responded to our request for feedback. The ages of their children ranged from 1 month to 36 years of age, with an average age of 17.5 years. Families are exploring options and striving to plan for the future.

The following summarizes what we have learned.

Were you advised to pursue Guardianship for your child as they exited school or at another point in time?

Yes: 59% No: 41%

Are you a court-appointed Guardian for your son or daughter?

Yes: 28% No: 72%

Parents identified costs incurred to apply for Guardianship ranged from \$20 to \$2,500. Reasons for establishing guardianship included being advised to do so, concerns regarding lack of capacity to make decisions, and medical professionals not willing to keep parents involved.

Is there a formal Supported Decision-Making plan and team to assist your son or daughter?

Yes: 26% No: 74%

Regarding Supported Decision-Making Plans

Eight of 60 respondents indicated there was a formal Supported Decision-Making plan for their son or daughter, and a team to assist with decision-making. (Those who responded yes, reside in WI, CO, TX, MT, MA, and NY).

Regarding Establishing Guardianship

"Families should be encouraged to find the least restrictive option for their child. Supported Decision-Making is a wonderful option when it is applicable. Parents shouldn't feel shamed by other parents saying that they are "taking the rights of their child away".... I have to provide a high level of support for my son, and that (Guardianship) is what's in his best interest."

Jackie M, Wisconsin

Some respondents indicated that as alternatives to Guardianship, they have informal plans and utilize tools such as Power of Attorney.

Families Supporting and Mentoring Decision-Making Skills

Parents who responded to this survey shared examples of how they have mentored and supported their son or daughter in decision-making and how they assist in the process. When

their children were young, they taught and offered choice and decision-making throughout life with natural consequences, validated their child's voice and then helped to guide them.

"I taught Henry how to make a pros and cons list and think critically when he comes to a fork in the road and must make a decision. We practiced. I modeled, gave examples, and explained. Then I put him in scenarios and situations where he had to make decisions."

Karen, Connecticut

"When it comes to our son making his own decisions, we treat him just as we do our other sons. Mostly through trial and error, our son learns how to make his own decisions about what he wants. We have learned to be patient while he attempts to do things on his own and to intervene with redirected guidance when he begins to get frustrated."

Flip, Virginia

"From a young age, we offered Ben choices and provided feedback based on his choices. We let him experience logical consequences when safe and appropriate for not making the right choices and positively reinforced sound decision-making."

Jackie, Wisconsin

On decision-making and medical care, *"Matt maintained a notebook for questions that he wanted to ask his doctors, and brought it to all appointments. He listed 1 question per page, so he had room to write the answers."*

Mary, Massachusetts

Decision-Making in School

"I had the school start including him in his IEP meetings and using a modified MAPS meeting when he was transitioning to middle school at the end of 5th grade. I have always informed him about his disability and how it impacts his life so that he can begin to self-advocate. He chooses who to disclose his disability to (ASD) and when, and to take the reins in his IEP meetings. It's hard though."

Robin, California

"I have kept my child in inclusive educational and care settings with her age peers, which has supported her independence. We model and support age-appropriate independence skills with her at home and in the community."

Christi, Virginia

About Communication Styles - Honoring Alternative Forms of Communication

"Brooke has multiple disabilities requiring lots of support. She doesn't use words to communicate. She and I have established some rudimentary ways to communicate choice (slaps my hand, claps, waves her hand), including using that to vote for presidential election choice."

Dana, Virginia

"My son is non-verbal...and, I have spent his lifetime trying to give him a voice. He uses an AAC (Augmentative & Alternative Communication) device to communicate and continues to become better at using it. He has opportunities to make many choices at home: what he wants to do, what

to wear, what to eat and when, who he wants to hang out with, etc. I honored his decisions regarding a significant surgery and other medical issues. He has also had opportunities to advocate for others - again, always his choice: about what to say and when and where. He actually self-directed a speech regarding the benefits of Medicaid for people who have disabilities and when invited, chose to give his speech on the lawn of the U.S. Capitol. It was videotaped by Now This Politics and to date has had over 1,133,000 views.”

Cindy, Pennsylvania

Regarding Supporting Their Son’s or Daughter’s Interests and Post-High School Choices

“Matt completed a vocational evaluation from a local agency, and they deemed him unemployable. Matt seemed to enjoy a social/rec program and attended 5 days per week. He enjoyed meeting new staff and interacting with them. They incorporated some of the things he likes to do into his day. After a few years though, he seemed restless and bored. After talking with him, we changed it up so he attends Monday, Tuesday, Thursday, and Friday. This way, he is only ever there 2 days in a row. He still gets to meet and interact with new staff, but he and I go out on Wednesdays and do things HE wants to do. Some of those things have been going to the movies, going shopping, visiting family members, going out to eat, exercising at the pool, attending advocacy rallies, musical events, etc.”

Cindy, Pennsylvania

“I ensured that my son’s IEP in Grades 10, 11, and 12 included job shadows and internships. My son had completed interest inventories as part of his Grade 9. The school found businesses that would allow my son to visit for an hour or two to observe and ask questions about a job or environment. The school found businesses that would allow my son to be hands on. For example, one job shadow was at a small manufacturing that makes pressure gauges. My son got to try his hand at assembling 20 pieces, ask questions, and understand the process end to end. My son had internships during his school day once or twice a week at different types of employment, e.g., restaurant, sporting goods chain store, retail outlet, and warehouse. These were all very valuable experiences in that they helped my son identifying the types of environments and the types of work he would prefer versus not prefer to do.”

Karen, Connecticut

“Letting go is the most difficult thing to do. He wanted to go to spend time with his grandparents out of town when he was 12 and we couldn’t take him. I thought he was too young to fly by himself but I let him go... I made arrangements to make sure (as sure as I could be) he would be ok. He did wonderful and now that he is 20, I understand that this is a learning process that takes years. If we do not support and help them to make things happen, we are not providing them with tools to make more serious decisions later on in life.”

Rosalba, Texas

“My son lives in supported living and has 24/7 supervision, but he has a lot of leeway in his decisions about how to spend his time, what to eat, wear, where to go, etc. He attends an amazing day program at the Alpha Resource Center that could be a model for the whole country.”

Margaret, California

Organizations Identified by Families as Supportive in Assisting with Transition and with Supported Decision-Making

- Parent to Parent of CO and Arc of Arapahoe/Douglas (CO)
- HMEA Autism Resource Center of Central Massachusetts
- Family TIES of Massachusetts, the Federation for Children with Special Needs, and Mass. Department of Public Health CYSHN Program
- Brockton Area ARC (MA)
- Rural Institute (MT)
- Disability Rights Montana (MT)
- Parent's Let Unite for Kids (MT)
- Partnership for People with Disabilities and the disAbility Law Center
- The Arc (The Arc South of the James) (VA)
- Vermont Family Network
- CESA #1 (Cooperative Educational Service Agency, WI)
- Family Voices at Children's Hospital of WI
- Down Syndrome Association of WI (DSAW)
- Children's Hospital of Wisconsin-Palliative Care and Complex Care programs
- YIPPEE training (Youth in Partnership with Parents for Empowerment, WI)
- Family Support and Resource Center (WI)

Tools and Publications Parents Referenced as Resources Regarding Guardianship and Alternatives to Guardianship

- The Rural Institute Alternatives to Guardianship
- The National Resource Center for Supported Decision-Making
- The ACES program at Temple University's Institute on Disabilities (for assistance with Augmentative Communication)
- The Arc of Texas - <https://www.thearcoftexas.org/alternatives-to-guardianship/>
- Texas Parent to Parent
- UMKC Institute for Human Development - checklist Identifying Alternatives to Guardianship Appendix 1, pages 42-45 Guardianship: Understanding Options and Alternatives
<https://mo-guardianship.com/MO%20Guardianship%20RESOURCE%20GUIDE%20rev%20Sept%20%202013.pdf>
- National Council on Disability – Turning Rights into Reality
- https://ncd.gov/sites/default/files/NCD_Turning-Rights-into-Reality_508_0.pdf
- Several families identified reading blogs and researching online as their guide for further understanding of Guardianship and Alternatives.

Regarding Barriers to Formalizing SDM

When asked about barriers to formalizing Supported Decision-Making, responses included:

- Lack of legislation, and medical professionals who do not understand an individual's right to self-direction and autonomy.
- Lack of knowledge in the general community.
- The closed-mindedness of some professionals, and underestimation of a child's abilities
- Lack of legislation in most state
- Courts lack an understanding and willingness to implement options, other than Guardianship
- Stigmas and bias are continually a challenge at all levels, from family and the community up to decision-making authorities at local, state and federal levels
- Getting all of the partners together in the planning process (i.e. parents, school, and agency staff) and obtaining a consistent message from all parties.
- Resource tools that are family friendly (non- jargon) and simple to understand choices and educate vs dictate on the process.

Recommendations from Respondents:

- A workbook-style guide that offers youth/young adults to explore the various aspects of adult life for which they might need or seek assistance would be great to offer to all families (via download, with print copies available if preferred). Please promote/advertise such an item through Parent to Parent members and Family Voices affiliates (and parent organization websites). Mary A., Massachusetts
- A tool to better inform team members including school administration and doctors about SDM and Guardianship alternatives. "Many are still telling parents that the only way to be involved in their child's decisions after age 18 is to get full guardianship. A friend recently took her 18-year-old to the hospital for care, and despite having all the necessary documentation on her person, and on file, the doctor wouldn't talk with her until a patient advocate stepped in." Lia, Virginia

Questions Parents Asked Regarding Needing Assistance included:

- Plans for my daughter after my death?
- Are there suggestions of how to assist our children as they age? I.e. if there should be changes in their capacity to make important decisions on their own?
- How to start and how to make a plan?
- How do I plan for supported decision-making when I, and others on the current informal team, are no longer living?

- How to have discussions with medical professionals who insist that Guardianship be in place for those over age 18 with an ID/DD diagnosis?
- When should a family start? How difficult is it to reverse Guardianship? How often is it reviewed and with whom?

Note: Parent to Parent USA has responded to these requests individually.

Response Representation by State:

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|---------------|---|--------------|----|
| California | 3 | New Jersey | 1 |
| Colorado | 1 | New York | 5 |
| Connecticut | 3 | Pennsylvania | 4 |
| Indiana | 2 | Tennessee | 1 |
| Massachusetts | 3 | Texas | 2 |
| Michigan | 2 | Virginia | 7 |
| Minnesota | 1 | Vermont | 1 |
| Missouri | 1 | Washington | 1 |
| Montana | 1 | Wisconsin | 20 |

Resources

Parent to Parent USA has compiled a listing of resources that may be of assistance to families and individuals with disabilities at:

<http://www.p2pusa.org/resources-on-supported-decision-making-and-alternatives-to-guardianship/>

About Parent to Parent USA

Parent to Parent USA is a national alliance of parent to parent programs. The Parent to Parent network is a growing national resource for families. Statewide, regional, and local community-based programs continue to emerge out of grassroots efforts, and new statewide Parent to Parent programs are being developed to support the efforts of local programs. The strength of Parent to Parent comes directly from the parents who dedicate themselves to its continuing success. Parent to Parent programs support parents of individuals with disabilities or special health care needs. This support includes a peer to peer network of trained volunteer support parents who have made the commitment to offer emotional support and assistance to other parents.

Each family's journey has value and can offer hope and inspiration to others. Peer support fosters mutual growth and resilience in families and among programs. Evidence-based practices ensure consistency and quality throughout the network.

For more information about Parent to Parent USA and state programs www.p2pusa.org

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