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## Table of Contents

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### 4 Letters from TASH

#### Introduction

6 Introduction by Guest Editors Ruby Moore and Mark Friedman

### Articles from Our Contributors

- 8 Supported Decision Making and Deinstitutionalization: Lessons Learned from the Autistic Self Advocacy Network's Invitational Summit by Kelly Israel
- 15 Supported Decision-Making for People with Disabilities: International Origins and Influences by Robert D. Dinerstein
- 19 Supported Decision-Making: Legal Basis and Practical Application by Robert D. Fleischner
- 24 Reflections on Autonomy by Dohn Hoyle
- 28 Supported Decision-Making in Tennessee by Lauren Pearson
- 34 Supported Decision-Making and Alternatives to Guardianship by Families by Kathy Brill

## 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

## Articles from our Contributors

### *Supported Decision-Making and Alternatives to Guardianship by Families*

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

## Articles from our Contributors

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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!

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### 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