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Contact Us

1875 Eye Street NW, Suite 582

Washington, DC 20006

Phone: (202) 429-2080

Fax: (202) 540-9019

info@tash.org

www.tash.org

Ruthie-Marie Beckwith, PhD, Executive Director

rbeckwith@tash.org

Bethany Alvaré

Director of Marketing & Communications

balvare@tash.org

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Table of Contents

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

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

Articles from our Contributors

Reflections on Autonomy

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.”

Articles from our Contributors

Reflections on Autonomy

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

Articles from our Contributors

Reflections on Autonomy

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