

# Tales from a Supportive Guardianship

Robert D. Dinerstein

For a number of years now, I have been a committed advocate of supported decision making as an alternative to guardianship for people with intellectual disabilities. In writings, presentations, classes, and meetings,<sup>1</sup> I have argued that supported decision making is not only less restrictive than guardianship but more consistent with principles of client-centered counseling and person-centered planning that animate approaches to lawyering and the delivery of services to people with intellectual disabilities. Even the most humane and limited forms of guardianship shift decision-making focus from the individual with a disability to his or her guardian or other surrogate decision maker. In contrast, although the person with an intellectual disability may get significant support from one or more supporters, that person remains the primary decision maker in his or her life.

In a prior article, I defined supportive decision making 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. . . . [S]upported decision-making [relies] on peer support (for example, ex-users of psychiatric services for people with psycho-social disabilities), community support networks and personal assistance, so-called natural supports (family, friends), or representatives (pursuant to a representation agreement) to speak with, rather than for, the individual with a disability.<sup>2</sup>

Supported decision making in one form or another has been around for over 20 years in areas of the world such as British Columbia, Canada, Sweden, parts of Australia, and Germany. It has received a major boost from the adoption of the United Nations Convention on the Right of Persons with Disabilities (CRPD), which the U.N. General Assembly adopted in December 2006 and entered into force on May 3, 2008.<sup>3</sup> Article 12 of the CRPD, "Equal recognition before the law," provides that all people with disabilities enjoy legal capacity, and that states "shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity."<sup>4</sup>

But even though the U.N. Committee on the Rights of Persons with Disabilities has taken the position that any form of guardianship is inconsistent with Article 12 of the CRPD,<sup>5</sup> almost all countries in the world, and all states in the United States, continue to authorize it. To be sure, guardianship law and practice have evolved to emphasize the importance of exploring less-restrictive alternatives to guardianship (such as supported decision making, powers of attorney, health-care proxies, and advance directives), as well as less-restrictive alternatives *within* guardianship (preferring limited over general or plenary guardianship), and to stress that the role of the guardian is to seek to maximize the autonomy and self-determination of the person under guardianship.<sup>6</sup> Not all of these reforms have taken hold, however, and guardianship remains a subject of intense interest for people with disabilities, older persons, allies of both groups, academics, courts, and lawmakers, among others.

Whether one views guardianship as performing an important and even admirable function for society, or as a necessary evil, guardianship is here to stay, at least for now. In my view,

## Footnotes

1. See, e.g., Robert D. Dinerstein, Esme Grant Grewal & Jonathan Martinis, *Emerging International Practices in Guardianship Law for People with Disabilities*, 22 ILSA J. INT'L & COMPARATIVE LAW 435-60 (Winter 2016); Robert D. Dinerstein, *On Torture, Ill-Treatment and People with Psychosocial and Intellectual Disabilities: Some Thoughts About the Report of the Special Rapporteur*, in TORTURE IN HEALTHCARE SETTINGS: REFLECTIONS ON THE SPECIAL RAPPORTEUR ON TORTURE'S 2013 THEMATIC REPORT 219-26 (Center for Human Rights & Humanitarian Law Anti-Torture Initiative) (2014); 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(2) HUMAN RIGHTS BRIEF 8 (Winter 2012).
2. Dinerstein, *Implementing Legal Capacity*, *supra* note 1, at 10 (Winter 2012).
3. CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES, G.A. RES. 61/106 (Dec. 13, 2006) (hereinafter "CRPD"). President Obama signed the CRPD in July 2009, but the U.S. Senate has not yet ratified the treaty. As of May 30, 2017, 172 countries (and the Euro-

pean Union) had done so. See <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> (last visited May 30, 2017).

4. CRPD, Art. 12, ¶ 3.
5. See Committee on the Rights of Persons with Disabilities, General Comment No. 1 (2014), Article 12: Equal recognition before the law. U.N. Doc. CRPD/C/GC/1 (adopted April 11, 2014), available at <https://documents-dd-ny.un.org/doc/UNDOC/GEBN/G14/031/20/PDF/G1403120.pdf?OpenElement>, and the Committee's Concluding Observations for a number of states that have appeared before it, cited in Dinerstein, et al., *Emerging International Practices*, *supra* note 1, at nn. 58-64 and accompanying text.
6. See, e.g., the proposed National Conference of Commissioners on Uniform State Laws, Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act (March 2017 draft), § 301(b). The proposed draft uniform law, which amends the existing Uniform Guardianship and Protective Proceedings Act (1997), is due to be presented to the Uniform Law Commission in July 2017.

those who seek to reform guardianship make a big mistake if they see it as a lost cause and put all of their eggs in the basket of supported decision making and other alternatives to guardianship.

My perspective on this issue is affected significantly by the fact that I am the guardian for my younger sister A.D.<sup>7</sup> (two and one-half years younger than me), who is a person with an intellectual disability. Her level of intellectual disability is considered in the moderate range. In addition, she has mild cerebral palsy, which affects her coordination and gait, and has difficulties in articulation that can make her speech difficult to understand. In her early 20s she had the first of several incidences of psychiatric distress, and later was diagnosed with schizo-affective disorder, which continues to flare up from time to time. Although these diagnostic categories provide some information about her, they do not come close to capturing who she is as a person. They do not—and cannot—convey that she has an excellent sense of humor and a remarkable memory (which sometimes gets her into trouble, as she thinks of incidents from 40 years ago as if they happened yesterday). She also is extremely gullible, obsessive, and always seeking the approval of peers and staff. She can be extraordinarily thoughtful and empathetic one moment, and highly focused on herself to the exclusion of others the next. As is characteristic of many people with intellectual disabilities, her thinking can be highly concrete, though within the limited sphere of her daily concerns she can be remarkably logical and clear-thinking. Over the years I have learned never to take for granted what she knows nor what she does not.

We grew up together in the family home on Long Island<sup>8</sup> from the mid-1950s until I went away to college in the fall of 1970. My sister was in special classes in regular public schools until age 16, when, because the high school did not have a class for those in need of special education, she switched to the Rosemary Kennedy Center, a special school within New York's Board of Cooperative Educational Services system. My sister was keenly aware of being separated from non-disabled students<sup>9</sup> and, indeed, would bring home notices from school having crossed out the word "Center" on the school's letterhead because to her "Center" meant "Separate School for Children with Intellectual Disabilities."<sup>10</sup> My parents raised my sis-

ter in as "normal" a way as they knew how.<sup>11</sup> We took family vacations (including a cross-country car trip when we were 13 and 11, respectively), went out to dinner every Sunday night, and, in general, lived the conventional life of a middle-class family in 1950s and 1960s suburban America. My sister and I watched the classic 1960s sitcoms (Andy Griffith, Danny Thomas, Lucille Ball, *The Flying Nun*) and listened to the Beatles, the Rolling Stones, the Beach Boys, and all of the rock-and-roll music that WABC-AM and, later, WNEW-FM, played. In those benighted days, when educators thought that a 16-year-old with a "mental age" of eight should be treated as a chronological eight-year-old, my mother marched into the school one day to complain that playing "Here Comes Peter Cotton Tail" to my sister's class was rather absurd when she (and presumably at least some of her classmates) were listening to The Beatles' *Sgt. Pepper's Lonely Hearts Club Band* album at home. That was the end of "Here Comes Peter Cotton Tail" at the Rosemary Kennedy Center.

My sister and I were very close growing up. We certainly fell into some of the patterns of older brother-younger sister relationships: she may have had an intellectual disability (for which I not only felt sympathy but, if I am honest, some guilt for not having a disability myself) but she could be as annoying as any younger sister. Still, I know she looked up to me and consistently sought my approval. As I prepared to leave for college, I wondered how my sister would adapt to my absence. But it was I who had tears in my eyes, not her, as I got into the car to go to school.<sup>12</sup>

Once my sister graduated from the Rosemary Kennedy Center, in 1977 (the same year that I graduated from Yale Law School), the rhythms of her daily life changed significantly. During the day, rather than attend school, she went to a sheltered workshop in a neighboring town. For a variety of reasons, the workshop was a stressful experience for her. Increasingly, my sister became emotionally dependent on my parents, especially my mother. She had few friends and craved attention

**I am the guardian for my younger sister A.D., who is a person with an intellectual disability.**

7. Because some of the stories I recount in this essay are rather personal, I am using initials in lieu of my sister's full name.

8. As was not uncommon in the 1950s, the neurologist who treated my sister when she was a toddler advised my parents to institutionalize her, believing that it would be too hard on the rest of the family to raise a child with an intellectual disability in the community. Fortunately for all of us, my parents disregarded this advice and raised my sister and me together in the family home.

9. She moved to the Rosemary Kennedy Center in 1971, four years before enactment of the then-called Education for All Handicapped Children Act (now the Individuals with Disabilities Education Act, or IDEA). IDEA requires that students with disabilities receive a free appropriate public education in the least restrictive environment. Were she in school today, she almost certainly would have been in a special class in the public high school.

10. In this essay, I use the current usage of "intellectual disability" in lieu of the terminology of the time, "mental retardation" or "the

mentally retarded." People with intellectual disabilities and their allies objected to the term "mental retardation" because of the stigma associated with it. My sister is very aware of that stigma, and when she loses her temper, or is angry with her housemates or day-program companions, she is not above using it as an epithet.

11. One phrase my mother said to my sister during this period that continues to resonate with my sister to this day was "Nobody's Perfect." The phrase has allowed my sister to recognize that although she may have problems (indeed, her variation of the phrase is "Everyone has problems"), so does everyone else.

12. During my freshman year at Cornell University, I wrote an essay about growing up with my sister for my Psychology 101 class. As I recall, the assignment was open-ended, and my choice of topic undoubtedly reflected the importance I ascribed to my relationship with my sister.

**She did not understand why she could not continue to live at home with my parents.**

from my parents. After two years, my parents were concerned that my sister would never develop the independence and confidence she would need in adulthood if she continued to live at home. Having her at home was also beginning to take a toll on their health as they were aging. In 1980, they moved her to a rela-

tively new program in Loch Sheldrake, New York, called New Hope Rehabilitation Center. The New Hope facility was on the grounds of the former Green Acres Hotel in the Catskill Mountains;<sup>13</sup> the main living area was the former main hotel building, and the residents lived in single or double bedrooms. Over time, New Hope (now known as New Hope Community), led for many years by a charismatic executive director, Daniel Berkowitz, evolved along with the field of intellectual disabilities, and changed from a private residential school to a community residential program. Residents like my sister moved from the main facility to houses and apartments in the local community. Since the late 1980s, she has lived in four different group homes, and currently lives with five other people with intellectual disabilities on a cul-de-sac in a nearby town. Direct-care staff provide 24-hour/7-day-a-week coverage of the home.

AD has always been somewhat ambivalent about living in New Hope and the surrounding community. She still talks about not having liked living in the main building, which she saw as institutional in nature. She was very aware of the difference between living at home with her parents and brother and living with 90 other people with intellectual disabilities in a congregate setting. Indeed, she took some pride in not having come to New Hope from Willowbrook and Letchworth Village, two notorious New York institutions for people with intellectual disabilities (now, fortunately, closed), as a number of New Hope residents (including her long-time boyfriend) had. She did not understand why she could not continue to live at home with my parents. It was always important to her that she still had a home outside of New Hope. Even though she visited home often, and my parents came to visit her frequently (New Hope was about two and one-half hours by car from their home), she expressed her ambivalence by, among

other things, insisting that she keep her extensive record collection in the family home, as if bringing the records up to New Hope would somehow communicate her abandonment of home.<sup>14</sup>

In 1985, about five years after my parents placed my sister in New Hope, they consulted a lawyer about the steps they needed to take to protect my sister's personal and financial interests. Among other things,<sup>15</sup> the lawyer suggested that my parents become my sister's co-guardians, pursuant to Surrogate's Court Procedure Act, Article 17-A.<sup>16</sup> I was named my sister's standby guardian in case my parents were unable to serve as her guardians. The transition from being parents of a minor child to being guardians for an adult with an intellectual disability did not seem difficult for them (though her continued expressions of wanting to come home certainly tore at them emotionally). It was rather a continuation of the relationship with my sister that they always had. Indeed, from the time my sister went to New Hope until my mother's death, my mother (and often my father) and sister spoke by telephone approximately five days a week.

Because this is an essay about being a supportive guardian, and not a biography of my sister, I will pass over the years between 1985, when she became subject to guardianship, and 2007, when our mother passed away suddenly. Our father was still alive but was suffering from advanced dementia, so he was in no condition to function as my sister's guardian. I took over as standby guardian and then, after our father's death in 2008, retained a lawyer who represented me in my petition to become my sister's guardian. I discussed the nature of the proceedings with my sister (who was represented by her own counsel), explaining that I was seeking to become her guardian so that I could help her make decisions. I was very proud of her when, at the conclusion of the rather pro forma hearing, the judge asked her if she had anything to say, and she said, "I want my brother to help me make decisions." The court granted the petition and I became my sister's guardian in 2009.

I did not seriously consider refraining from petitioning to become my sister's guardian. My lawyer recommended that I become her guardian (it seemed to her to be an almost automatic decision) but I knew enough to know that I could have sought an alternative such as supported decision making. But because my sister had been under my parents' guardianship for almost 25 years, and I had already functioned as a standby

13. New Hope Community's programs are described at [newhopecommunity.org](http://newhopecommunity.org). New Hope's history, from its opening in 1975 to the present, is presented at <http://newhopecommunity.org/our-family/a-legacy-of-trust/>. My family had, over the years, taken several vacations in the Catskills, so the area was familiar to my parents and my sister.

14. My parents were consistent contributors to New Hope and eventually joined the board of the New Hope Foundation, the fundraising arm of New Hope Community, Inc. I joined the New Hope Community, Inc. Board of Directors in March 2015 and remain on the board currently.

15. My parents also set up a special-needs trust for my sister, at a time when it was far from clear that such trusts would be effective in allowing the beneficiary to continue to receive Supplemental Security Income, Medicaid, and other governmental benefits.

16. Article 17-A guardianships, designed specifically for people with intellectual disabilities, are accompanied by many fewer safeguards for the person for whom guardianship is sought than exist under the general guardianship statute, N.Y. MENTAL HYG. L. § 81 (Article 81). Article 17-A has come under criticism for its lack of due process and failure to keep up with changing practices regarding the rights of people with intellectual disabilities. (The statute was enacted in 1969.) See Rose Mary Bailly & Charis B. Nick-Torok, *Should We Be Talking?—Beginning a Dialogue on Guardianship for the Developmentally Disabled in New York*, 75 ALB. L. REV. 807 (2012); *Revisiting S.C.P.A. 17-A: Guardianship for People with Intellectual and Developmental Disabilities: A Report of the Mental Health Law Committee and the Disability Law Committee of the New York City Bar Association*, 18 CUNY L. REV. 287 (2015).

guardian, I thought that continuing the guardianship was the right option. I also knew, or hoped, that I would not function as an overbearing guardian but rather as a supportive one.

As our parents' health had deteriorated in the years before their deaths, I took more of an "official" role in my sister's life at New Hope. I made sure I attended New Hope's annual family barbeque, even though its timing frequently conflicted with my law-teaching schedule. I had always reviewed my sister's annual individual habilitation or support plans (the names have changed over the years) but started attending her semi-annual meetings. But although my parents had often consulted with me over the years regarding my sister's situation,<sup>17</sup> I was not legally responsible for her decisions until I became her guardian. I had to consider what kind of guardian I wanted to be, and, more importantly, what kind of guardian my sister needed for me to be.

In the stories that follow, I want to illustrate some of the ways in which my sister and I interact and how that affects the way I see my role as her guardian. To be honest, it is very difficult for me to distinguish my role as her older brother from my role as her guardian. Other than signing off on her annual flu shots, and approving her yearly behavioral support and programming plans, I am not sure that my status as her guardian makes any difference in her day-to-day life. Because I do not live with my sister and cannot visit easily (she lives about a six-hour car ride away from me), I could not exercise control over her day-to-day life<sup>18</sup> even if I wanted to, which I do not.

I also have thought a great deal about how my relationship with my sister differs from that of my parents with her. My parents were not shy about telling my sister what to do when she had questions, or even when she did not. (They sometimes tried to do this with me, but with less success.) That is not my style. Consistent with my commitment to client-centered counseling,<sup>19</sup> I do not believe in telling my sister what to do, but rather try to help her understand her choices and their consequences. Some of the most interesting interchanges I have had with my sister involve her telling me that our mother thought something in particular and my telling my sister that she could make a different decision.<sup>20</sup> Her response in these

situations—"Really?"—reflects how difficult it can be for people with intellectual disabilities to really believe they have the right to make their own choices, no matter what others have said to them.

I have organized the stories that follow around a series of themes that I hope will illustrate some of the challenges (and joys) of serving as my sister's guardian.

**What I have learned as my sister's guardian is to listen not only to what she says, but what she does not.**

### **1. The importance of listening—what does the person under guardianship really want or mean?**

Listening carefully to someone—whether a client or a loved one—is not only an important interpersonal quality but a critical lawyering skill.<sup>21</sup> Listening is no less an important skill for a guardian. What I have learned as my sister's guardian is to listen not only to what she says, but to what she does not.

Several years ago, A.D. told me over the telephone<sup>22</sup> that a friend had invited her to a birthday party but that she was not sure she should go. My sister can have challenges in relating to other peers so I thought it was a good sign that a friend had invited her to her party. I asked her why she did not think she should go, and at first she said, "I don't know." After I asked again, she said, "Well, I am not sure she really invited me." I pursued the matter and asked her how she had been invited (the friend had asked her) and tried to reassure her that unless the friend had withdrawn the invitation, she could assume that the invitation still stood. My sister still was skeptical. Some instinct made me ask her, "Is there some other reason why you don't want to go?" She answered, "Well, yes. Linda lives on the second floor of her house." I said, "So you are concerned that you would have to go up the stairs to get to her apartment?" She said yes. Even though my sister can climb stairs, the unsteadiness of her gait makes her lack confidence when climbing or descending stairs. I reassured her that (1) she could in fact climb the stairs if she took her time; (2) staff would assist her, so that she would not fall; and (3) because it

17. I have worked in the field of disability-rights law since 1977. After serving as a trial lawyer in the U.S. Department of Justice, Civil Rights Division, Special Litigation Section, from 1977 to 1982, I left for a clinical teaching position at American University, Washington College of Law, where I still teach. I have taught a disability-rights seminar since 1985 and, since 2005, have directed the law school's Disability Rights Law Clinic, which I founded. From 1994 to 2000, I served on the President's Committee on Mental Retardation, now called the President's Committee on People with Intellectual Disabilities.

18. Compare the very detailed and restrictive rules for visitation adopted by the parent and step-parent of Jenny Hatch (who were serving as temporary guardians) in *Ross & Ross v. Hatch*, Case No. CWF-120000-426-P-03 (Va. Cir. Ct. 2013). I testified as an expert witness in the case in favor of supported decision making as an alternative to guardianship for Ms. Hatch. The court rejected the parent and step-parent's petition for guardianship and instead appointed two friends of Jenny's as temporary co-guardians for

one year with the explicit goal of preparing Jenny for supported decision making after one year. The Jenny Hatch case has spurred much commentary and was instrumental in establishing the National Resource Center for Supported Decision-Making, <http://www.supporteddecisionmaking.org/>.

19. I have written about client-centered counseling in Robert D. Dinerstein, *Client-Centered Counseling: Reappraisal and Refinement*, 32 ARIZ. L. REV. 501 (1990), and other publications.

20. One of several examples: my sister has told me she does not like to drink milk because, as she puts it, "Mom says it doesn't agree with her." I can hear my mother saying that. I tell my sister that our mother was a wonderful woman but that my sister can make her own choices. She has not taken up drinking milk, however.

21. STEPHEN ELLMANN, ROBERT D. DINERSTEIN, ISABELLE R. GUNNING, KATHERINE R. KRUSE, & ANN C. SHALLECK, *LAWYERS AND CLIENTS: CRITICAL ISSUES IN INTERVIEWING AND COUNSELING* 23 (2009).

22. Unlike my parents, I am unable to speak daily with my sister but I do speak to her about two or three times a week.

**[O]nce given more information, she was able to make a reasoned decision.**

was the summer time, it was possible that the party would be outside and would not involve her having to climb the stairs. At that point, my sister said she would go to the party.

Someone with greater cognitive capacity might have been

able to say from the beginning why she was uncomfortable going to the party. But that was not—and generally is not—my sister's way. It may be that she is not adept at weighing the pros and cons of a particular decision without being prompted. Or she may have thought at some level that her reason for not attending the party would not stand up to scrutiny. Either way, if I had just taken her answer at face value, she might well have not attended the party and missed out on a pleasurable experience.

Shortly after our mother's death, one of the first medical consent issues that arose with respect to my sister concerned whether she should have a colonoscopy. When my sister turned 50, New Hope staff approached our mother about consenting to the procedure, which was being proposed as standard preventive treatment. Mom declined to give consent, apparently because she did not believe the procedure was necessary and might be difficult for my sister. I was aware of my mother's decision, and urged her to reconsider, but she did not change her mind. After I became guardian, the staff approached me about approving the procedure. My perspective differed from that of my mother: I had had a colonoscopy at 50 (which in fact revealed a condition that now requires more frequent follow-up) and thought it made sense for my sister to have one as well. But even though I had the authority simply to approve the procedure, I did not want to do so without discussing it with my sister.

I first explained that the doctor wanted to perform a colonoscopy. As I wrote earlier, my sister can have difficulty with articulation,<sup>23</sup> and "colonoscopy" can be a difficult word to pronounce for people with typical pronunciation ability. More challenging was trying to explain what the procedure was. As is my practice, I tried to be accurate without being too technical in my language. I told her that it was a procedure where the doctor looked inside to see how her intestines—where food goes after leaving the stomach—were doing. She said, "I don't want to have it." Shamelessly playing the older brother card, I told her that I had had a colonoscopy and that it was not too bad. Still she resisted. Again I asked her, "Is there some reason you don't want a colonoscopy?" She said, "I just don't like needles." She apparently associated visits to the doctor with injections, and she was not about to put herself through that unless she was required to do so.

Well, now I had my opening. The dialogue went something like the following:

Robert<sup>24</sup>: OK. So there's some good news and some bad news. Which do you want to hear first?

A.D.: The good news.

Robert: OK, the good news is that there is no needle in the procedure. And it is not painful at all, especially on the day you have it.

A.D.: Good.

Robert: Now for the bad news.

A.D.: OK.

Robert: The day before the colonoscopy, you won't be able to eat your regular meals. You'll only be able to have liquids and you are going to have to go to the bathroom a lot to clean yourself out. You'll be miserable, but it won't hurt.

A.D.: OK, I'll do it.

And, indeed, she had the colonoscopy.

As with attending the party, my sister was not about to disclose at first the underlying premise of her thinking. But as was true in that case, once given more information, she was able to make a reasoned decision. I was prepared to forgo the procedure had she continued to object; absent an emergency or serious medical situation, I would not exercise my authority as her guardian to override her decision.

I have written that my sister and I speak frequently on the telephone. Our conversations (from her end) are mostly about what she had to eat, whether she had gone to either the Dollar Tree Store or Walmart, whether she had seen her boyfriend, what movie she saw at her day program, and similar issues. She will ask me how I am doing, how my wife and grown sons are doing, and when I will next be coming up to visit her. The subject matter of the conversations is unremarkable but they allow her (and me) to maintain an important connection. My sister is uncomfortable ending the conversation, no matter how repetitive it might become. What I learned, though, is that when she asks, "What else do you want to talk about?," it is her signal that she has no more to say. But it is up to me to say, "Well, maybe we should say good-bye and we'll talk again next time." She never objects, but if I did not take the initiative we would probably still be on the telephone.

What these interactions suggest, I submit, is that the guardian has to know the person for whom he is serving as guardian extraordinarily well. He or she has to listen to the person carefully and focus on what is not said as well as what is said. I do not pretend to be able to understand perfectly my sister's true desires or choices. But if I approach her in a true mode of inquiry and humility, I can get it right most of the time.

23. My sister is quite aware that she can be difficult to understand. Although I can figure out almost all of her speech, there are some times when I cannot. She has a remarkable capacity to provide an analogy or alternative terminology that will assist me in understanding her. For example, one time she was trying to tell me something about someone named Lawrence, but I could not understand her. She tried a few more times and then said, "You

know, Lawrence, like Steve Lawrence and Eydie Gormé." It helps to know what her cultural references are.

24. Most of my friends and colleagues call me Bob. When my sister was very young and had trouble pronouncing my name she called me Bobby but as she got older she switched to Robert, which is what my parents called me. It can be a bit confusing for staff when I call because AD's boyfriend is also named Robert.

## 2. The power of a person's will—agreement is not always what it seems

People with disabilities are often in situations in which they believe they have to agree to something for fear of displeasing someone with power over them, whether it is a staff person or a family member (or a guardian). I have learned that my sister sometimes appears to agree to a course of action only to undermine it, or take advantage of a chink in the armor of the decision-making process.

A.D. loves drinking soda. It is one of the supreme pleasures in her life. Some years ago, staff persuaded her to drink diet soda, but they still try to get her to limit her intake. Over the years, they have tried to come up with different rules about how much soda she should drink. The staff tries to negotiate these rules with my sister, who appears to agree with them. She will call me and say something like, "New Hope says I can have one diet soda a day. Is that OK with you?" I don't really care whether this particular rule is the best one for her, but if the staff have proposed it and she has agreed, I am happy to go along with it. (I certainly would intervene if I thought the proposed rule or guideline was unreasonable or overly restrictive.) What I do know is that my sister (apparently) likes rules and that a response such as "You can do what you want," would not satisfy her.

But the human will is powerful and my sister is quite capable of undermining the rules, or her prior acquiescence to them, when it suits her. I recall the time that we were having dinner at the Liberty Diner, her favorite restaurant. The dinner occurred during a period when she was trying to limit herself to drink no more than one diet soda a day. Earlier that day she had had a diet soda at lunch so as we sat down in the booth, and before we ordered, we discussed whether she should have a diet soda with dinner. She volunteered that since she had had a diet soda at lunch she would not have one at dinner. I was pleased that she was able to understand "the rules" and plan her behavior to conform to them.

The waitress came to our table to take our drink orders. To be honest, I would have liked to have a diet soda myself, but I was not going to order one when my sister was abstaining. So I told the waitress that water would be fine for me. The waitress, who knew my sister, turned to her, and, without waiting for her order, said "Do you want a diet Coke, hon?" My sister's eyes lit up as if she had just been released from custody—she immediately answered yes, and then looked over at me, triumphantly, as if to say, "Just try to enforce the rule now." We laughed at what was now clearly an amendment to the rule: no more than one diet soda per day unless the waiter or waitress offers you one.<sup>25</sup>

More recently, and more seriously, at her annual meeting A.D. expressed concerns about the day program she attends. Her service coordinator suggested that she might like a different program, and proposed that she might visit that program to see if she preferred it. As the meeting proceeded, A.D. seemed

to back off of her criticisms of the existing program. She said she might not like the new program. She didn't want to disappoint the people in the current program. She clearly had some ambivalence, even though the team (including me) assured her that visiting the program did not mean that she had to move if she did not want to do so. She agreed to visit the new proposed program.

Not two days later, however, she told her house manager in no uncertain terms that she did not want to visit the new program and would stay at the existing program. For all of her criticisms (including of past programs or her residence), she is averse to making changes in her life. As noted, she does not want to disappoint people, even when they reassure her that no one will criticize her if she makes the proposed change. But it also might be that because she has difficulty articulating, let alone weighing, the pros and cons of a particular situation (e.g., "I like aspect x of the workshop but do not like aspect y"), it is only when a change becomes concrete that she really examines whether, all things considered, a change is what she wants. For now, she remains in the current program.

My sister can be very insightful but is not above taking advantage of a situation when it suits her. At one of the first annual meetings I attended, when she had just moved to a new house (not the one in which she currently lives), the staff person leading the meeting asked her a series of questions about her experience at the home. We all sat around a long dining-room table. Other than A.D. and me, everyone else at the meeting was a staff person: direct care staff, house manager, nurse, service coordinator, and clinician. There were about 20 people around the table, and I wondered whether A.D. would be intimidated by their being so many staff there. I need not have worried. The service coordinator initiated the following dialogue with her:

Service coordinator: A.D., you can choose the clothes you wear each day. Are you doing that?

A.D.: No, the staff does that for me.

Service coordinator: A.D., you can make your lunch each day before you go to your program. Are you doing that?

A.D.: No, the staff does that for me.

[I look around the room and notice that the direct-care staff is looking somewhat uncomfortable]

**I have learned that my sister sometimes appears to agree to a course of action only to undermine it . . . .**

25. Another quality of my sister is that, although she is not above making up things when it serves her interests, she is almost a compulsive truth-teller. A more strategic person might have kept from the staff that she had had a second diet soda that day. (I was

not about to rat her out.) However, as soon as we arrived at her home, she told the staff on duty that she had a second soda. The staff assured her that it was OK that she had had the second soda (at least in the company of her family).

**[T]he bifurcation of decision making between guardian and person under guardianship does not always capture the actual decision-making process at work.**

Service coordinator: A.D., you can gather your laundry and put it in the washing machine. Are you doing that?  
 A.D.: No, the staff does that.

Service coordinator: But A.D., you were

doing all of these things at your prior house. Why aren't you doing them here?

A.D.: [Smiling and looking triumphant]: Because I am a guest here.

The group cracked up (as did A.D., who appreciated the apparent absurdity of the situation). But although the staff was appropriately trying to foster her independence, and while I was fully in support of this goal, A.D. was not above getting other people to do things for her if they were willing to do them. I am sure the service coordinator had a conversation with the direct-care staff after the meeting, but for one moment, at least, A.D. was able to assert her independence, ironically by being willing to take advantage of her dependency. Was it in her best interest not to do things for herself when she could do so? I don't know, but the sense of agency she had by being defiant was priceless.

**3. Seeking validation rather than a decision: difficult—and not so difficult—conversations**

Guardians struggle (or should) with what criteria they should use in making decisions for the person for whom they serve as guardian. Many guardianship statutes urge or even require the guardian to use the substituted-judgment standard: that is, the guardian should make the decision the person under guardianship would make if he or she was able to decide (or was able to communicate his or her decision).<sup>26</sup> The standard of decision making for supporters in a supported decision-making regime, when the person is unable to communicate a decision, is to give the best interpretation of the person's will and preferences.<sup>27</sup> Both standards require the decision maker to ascertain what the person would want to do and then seek to implement the decision.

In my experience with my sister, the bifurcation of decision making between guardian and person under guardianship does not always capture the actual decision-making process at work. Sometimes my sister wants me to make a decision for her (no matter how much I emphasize that it is her decision to make). Other times, she is not looking to me so much for a decision as validation for a decision she wants to make, or, in

fact, has already made. One story illustrates this point.

I've already noted that the Liberty Diner is my sister's favorite restaurant. Left to her own devices, I believe she would almost always choose to eat there whenever my wife and I, or I alone, come up to visit her. She also often chooses to go there for lunch or dinner with her boyfriend, accompanied by staff who, I have learned, are not always so eager to eat there. I am happy to eat at the Liberty Diner but I also am happy to eat elsewhere if she wants to go to another restaurant.

More than once, as we've prepared to go to lunch after one of her meetings, she will ask me, "Where do you want to go to eat?" I will respond, "Wherever you want. It's your choice." Most times she will answer, "Let's go to Liberty Diner," and we will go there. But every once in a while she will say, "Maybe we should go somewhere else." I will say, "That's fine with me. Where do you want to go?" She'll say, "How about Pizza Hut (which is right next to the Liberty Diner)?" and I will say "OK. Let's go to Pizza Hut." But as we are on our way to Pizza Hut, she'll start reconsidering her decision. "Maybe we should go to Liberty Diner." I will say, "We can go wherever you want to go." She will then say, "Where do you want to go?" and I am likely to respond, "It's your choice." We could go on like this for a long time, and sometimes have.

What I have come to realize, though, is that sometimes she wants me to make the decision for her. I think if I made a decision with which she did not agree, she would certainly express her disagreement or otherwise resist the choice. But if I say to her something like, "We can go anywhere you like, but I am thinking that you want to go to Liberty Diner. We can go there," she will readily agree, especially if I add, "We can go to Pizza Hut next time if you like." That seems to satisfy her need to keep options open while at the same time going to the restaurant at which she really wants to eat. If I make the decision for her in this way, am I overstepping my bounds and undermining her autonomy? Or am I in fact honoring her autonomous choice to let someone else (someone she trusts) make a decision for her, as long as she can object?

**4. Helping my sister figure out what others mean and serving as her advocate**

Often my role as guardian/brother is to help my sister understand language or situations to which she is exposed. I do not always know what she understands, and I have learned that a combination of questions and clarifications can assist her in living her life more or less the way she wants.

As I have noted, my sister likes to talk, and often is frustrated when others are not interested in talking with her. She loves to talk about the food she had at prior meals, but does not understand why others may not be that interested in what she has eaten. Over time, I have suggested some topics she might raise with her peers or with staff—she could ask them about their families, what staff do on weekends, what sports or music they like, which presidential candidate they like, or about other issues that appear on the news. Sometimes these

26. As defined in D.C. CODE § 21-2011 (25A): "Substituted judgment" means making a decision that conforms as closely as possible with the decision that the individual would have made based upon the

knowledge of the beliefs, values, and preferences of the individual."  
 27. See Committee on Rights of Persons with Disabilities, General Comment No. 1, *supra* note 5, at 5, ¶21.

suggestions are successful but she still complains that not everyone wants to talk about these topics.<sup>28</sup>

One time I tried a different tack with her. I explained that in successful conversations, the person asks the other person in the conversation what he or she is interested in. My sister thought for a moment and said, “But I am not interested in what they want to talk about.” “Well, that may be your problem—unless you show interest in what the other person wants to talk about, the other person probably will not be interested in your topics.” That seemed like such a basic point but her reaction to my statement suggested that she did not really know the “rules” of conversation and now had to consider a different approach to interacting with others.

A.D. has a keen ear for language and sometimes has strong reactions to terms that she thinks are pejorative, even when they may not necessarily be intended negatively. But I have learned that sometimes her instinct about the negative intent is pretty close to the mark.

For example, one of her housemates, noting A.D.’s desire to talk a lot, called her a “chatterbox.” I know this housemate is very fond of A.D. and is always looking out for her. I don’t think she meant “chatterbox” to be a negative description. But apparently my sister thought that she was being criticized for being too talkative, and she resented the use of the term. No amount of discussion about the relative harmlessness of the term has satisfied her, though she continues to have a good relationship with this housemate—as long as she does not use the term again. She also objects to the use of the word “behavior.” I have explained that behavior can be a neutral word describing how one is acting, but she associates it with “negative behaviors” or with actions that need to be addressed. In this case, her insight seems correct, and because she associates the term with a negative judgment about her, she reacts viscerally to it, even when it is not being used negatively.<sup>29</sup>

One of the reasons I think it is important that I attend every semi-annual meeting of my sister’s interdisciplinary team is that I see my role as her advocate as well as wanting to help her understand why things are the way they are. One time, we were at a meeting and the nurse was recounting for my sister all of the medical visits she had had in the prior six months. The language was fairly technical; the nurse would say, “You went to see your psychiatrist and she reviewed your medications. You saw the neurologist and he conducted x, y, and z tests. You went to the cardiologist and he conducted an electrocardiogram.”

At this point, I intervened and said that I was having some difficulty in understanding all of these technical terms and I

was pretty sure A.D. did not understand them either. I turned to her and asked her if she was following the conversation, and she said cheerfully, “No.” I then said to the nurse that if she used less technical language my sister might be able to understand her and participate more fully in the meeting. So rather than describing the above visit to the cardiologist as she had, if the nurse had said, “AD, you went to the heart doctor and he connected all these wires to you, which were connected to a machine that made squiggly lines,” she would remember the visit.

The nurse thanked me for the intervention and promised to use less technical language. Things improved for a bit, but, sure enough, she lapsed back into medical jargon, indicating that my sister had seen the OB/GYN who had indicated that she was beginning to develop signs of osteoporosis. I was just about to intervene again and ask that she use plain language when my sister perked up and said, “Oh, you mean like Sally Field?” My sister, an inveterate consumer of television shows and commercials, recalled that the actress had been on a commercial dealing with a product that addressed osteoporosis. If nothing else, her ability to make this connection showed that she really was listening and trying to follow the conversation.

As I noted above, it is within the medical sphere that my role as guardian, as opposed to brother, seems clearest, and being my sister’s guardian makes it easier for medical professionals to speak with me about her care. Here, I try to approach medical decisions as I would when inquiring about my own medical needs or those of a loved one (which, of course, she is). For example, a few years ago, the house staff told me that my sister’s gastroenterologist wanted to perform another colonoscopy and needed my consent. I told the staff that I was surprised the doctor was seeking to perform this procedure since my sister’s prior one had been only five years earlier, and as I understood the protocol she would not be due for another for another five years. It took a few days but the gastroenterologist finally reached me and explained what he wanted to do. I asked him why he was asking to do a colonoscopy on my sister after only five years. He said that when they do not have a history they like to do the procedure sooner than ten years apart. I asked why the New Hope staff had not provided him with a history, or, if they had not, why

**. . . I see my role as an advocate as well as wanting to help her understand why things are the way they are.**

28. Some staff do not like talking with her about their private lives, seeking to limit their interactions to those related to their job. Although this desire is understandable on their part, it is frustrating to my sister who thinks of the staff as her friends, at least for certain purposes.

29. For many years, I served on the board of directors of the Quality Trust for Individuals with Disabilities, Inc., in Washington, D.C. One of our board members was a self-advocate (a person with an intellectual disability) who periodically would complain about others’ use of the word “individual” to describe people with dis-

abilities. One time I asked him why he reacted so negatively to a word that most people saw as at least neutral if not respectful when used to describe someone. He said that in his experience, when staff from the local developmental disabilities services agency interacted with him and others they only used the word “individual” to refer to people with disabilities receiving services, whereas they used different words to describe others. For this colleague, “individual” connoted a person who receives services, and he was offended by the term. Context is everything.

**I have learned that my sister can take disappointment, as we all must, as long as she can continue to raise an issue of concern.**

he or someone on his staff had not contacted me to provide the necessary family history. I asked him whether my sister's prior colonoscopy had turned up any problems that would have suggested the need for an early colonoscopy and, after reviewing her records, he said there were none. We agreed that she did not need a colonoscopy for another five years.

It would have been an easy matter to approve the colonoscopy, which, while unpleasant (as discussed above), was not a dangerous procedure. But just as I would not accept uncritically my own doctor's suggestion of such a procedure for myself, I was not about to consent to it for my sister. More recently, my sister's psychiatrist wanted to change one of her psychotropic medications. Again, as my sister's guardian, my consent was needed. Because it was, I was able to speak with the psychiatrist and satisfy myself that he had thought through his recommendation carefully.

#### **5. A person under guardianship does not always get to have things her way—we all live within constraints**

As noted above, the substituted-judgment standard, while an important principle of decision making, cannot provide answers to all of the situations that guardians and the people under guardianship face. If you asked my sister where she would like to live, her choice would be to live with my wife and me. We probably have the conversation about once every month or two. If I saw my role as implementing her decision about where she wants to live, I would have her move in with me. I understand emotionally why she wants to live with me; now that our parents have passed away, my home is really the only other home she has. Even though on balance she is happy where she lives, she gets frustrated with not having other options if she were to decide she did not like New Hope any more.

I always try to be straight with my sister, and not give her false hope or suggest she has choices when she does not. I have learned that she can take disappointment, as we all must, as long as she can continue to raise an issue of concern.

One of our conversations about her desire to live with me reflects both her ongoing desire and, notwithstanding her intellectual disability, her intelligence:

A.D.: Robert, can I come live with you?  
Robert: A.D., you know that's not realistic.

A.D.: Why not?  
Robert: Well, for one thing, I work all day and couldn't take care of you.  
A.D.: What about Joan [my wife]?  
Robert: She works too.  
A.D.: Oh. . . . When are you going to retire?  
Robert: Not for a while. But even when I do, I don't think I could take care of you as well as they do at New Hope. Don't you like it there?  
A.D.: It's alright. But I miss you.  
Robert: I miss you too.  
A.D.: I wish you lived closer.  
Robert: I do too. But we do talk a lot and I come up to visit you pretty often.  
A.D.: I know.<sup>30</sup>

Probably the most difficult thing I have had to do since becoming my sister's guardian—though, again, the difficulty had little to do with my being her guardian and more about being her older brother—was to talk to my sister about our parents' deaths, especially our mother's. Death is a difficult concept for people of typical intelligence to understand and accept; for a person with an intellectual disability, the abstract concept of death can be especially ineffable.

Although my sister in time came to accept our mother's death, at first she could not understand why she had died. Our mother, who was 89, had a massive heart attack on a Friday evening and died the following Monday. The suddenness of her death was difficult for my sister to understand. She would ask me why everyone had to die. I told her everyone had not died. She then said, "Milton Berle died. Jack Benny died. George Burns died." She was channeling all of the cultural figures of her childhood, a childhood she spent with our mother watching these iconic entertainers.

How should I respond? She was, of course, correct that these comedians had died<sup>31</sup> but I wanted to reassure her that others' deaths were not imminent. I told her, "These men died a long time ago. They were very old. No one close to you is going to die soon." She asked, "Why do people have to die?" I said death is a part of life, and that everyone who is born will die. She asked, "Are you going to die?" I said, "I don't plan to die any time soon." After one of these conversations, when she was dealing much better with our mother's death, she declared, "Well, I don't want to die. I am not going to die." I told her, "If you don't die, you will be the only person ever born who didn't die." At that, she laughed, recognizing perhaps that her desire for eternal life might not be possible to satisfy.

My father was still alive at the time of my mother's death, but his dementia had progressed to the point that he did not

30. Sometimes we will speak by phone on a Thursday and she will ask me, "Can you come over tomorrow?" When she first asked me that question I would point out that, as she knew, I lived about six hours away from her and could not just come over to see her as if I lived nearby. I wondered whether she did not realize that I lived far away. Over time, though, I came to realize that her question was another way of saying that she missed me and wished that I

lived closer to her, knowing very well that I did not.  
31. Over the course of several months, she would ask me whether x or y celebrity was still alive. These actors or singers were often people who were performing in the 1960s. Sometimes I knew the person was dead or alive, and I would tell her what I knew. Other times, my wife would check the Internet while I was speaking with my sister so I could give her accurate information.

recognize anyone.<sup>32</sup> It seemed cruel to tell him that his wife of 60 years had died, even if he could have understood the information, and I declined to do so. My sister, who always thought of my parents as a twosome, could not comprehend how he could not know she had died.

But if my sister had trouble at first accepting our mother's death, she was from the first in touch with the emotional side of her loss and mine. She would talk about missing our mother,<sup>33</sup> and, after our father died nine months later, missing him as well. She particularly missed telling them what she had done each day, and transferred that reporting function to her conversations with me. I told her that I also missed them, and missed telling them about important things in my life as well. I found that talking with her about my parents' deaths allowed me to be in touch with my own emotions.

And that leads me to my final conclusion about the relationship between guardian and person under guardianship. The relationship need not be a one-way street from guardian to the person under guardianship. The guardian can learn from the person under guardianship as well. I have learned a lot about people with intellectual disabilities from my sister, even as I recognize that she does not represent all such people. I also have learned about the complexities of decision making and how challenging it can be to determine what a person's authentic interests and desires are. At its best, we might treat the guardianship relationship less as a top-down relationship and more as a form of partnership.

## **SOME LESSONS FOR GUARDIANSHIP**

Though it might be a bit presumptuous, I believe the above stories can provide some valuable lessons for judges who preside over guardianships.

### **1. More care should be taken at the time of appointment of the guardian to clarify the guardian's role**

Even though I knew a lot about guardianship before applying to be my sister's guardian, including abuses, neglect, and conflicts of interest that can exist in the relationship, I was struck by how little information is communicated to prospective guardians about what is involved in becoming a guardian and how one should behave in the role. While the court may assume that the petitioner's attorney will explain the duties of

the guardian, in my experience lawyers do not always perform this function well. Lawyers can be expected to explain to their clients whether they have to make reports to the court and how often they need to do so. But it is less clear that they spend sufficient time discussing how the guardian should make decisions for (or with) the person under guardianship. Many statutes require the guardian to give

the person under guardianship as much independence as possible.<sup>34</sup> I think too many guardians believe that the person under guardianship is to be protected in all respects, which is inconsistent with supporting the person's autonomy to the maximum extent feasible.

### **2. The standard of decision making guardians use needs to be more nuanced than substituted judgment or best interest**

As some of the above examples reflect, determining the appropriate standard of decision making the guardian should use is no easy matter. The substituted-judgment standard is a useful corrective to the best-interest standard, which can be overly paternalistic, or the decision that the guardian would make for himself or herself. But taken literally, the substituted-judgment standard could lead a guardian to make unrealistic or unwise decisions, or to make decisions that, while conforming to the wishes of the person, do not take into account the constraints that all decision makers face.<sup>35</sup>

I don't have a convenient name for the decision-making standard I have tried to use with my sister, but it is a mix of shared decision making and supported decision making. Although as a formal matter I have made certain decisions for her—such as authorizing certain medical treatments or medications—I have done so only after consultation with her. On many matters, she has made decisions on her own, without consulting me. On others, I have executed a decision of hers for which she has sought validation and reinforcement.

**I don't have a name for the decision-making standard I have tried to use with my sister, but it is a mix of shared . . . and supported decision making.**

32. Before he lost all awareness, my wife and I went to visit him at his assisted living facility. He spoke to me for a while and seemed to recognize me. He started talking about my sister, and somehow had concluded that she was a wonderful person because "she did such good work with handicapped people." My wife said, "Your son is pretty wonderful, too." My father looked at her quizzically and said, "I don't know him very well." I told my sister this story and she was tickled that my father remembered her (however imperfectly) and not me.

33. From time to time, my sister has told me that she talks to our mother before she goes to bed. She will ask me if it is alright to do that. After I suggest that she do it before going to bed, and that it's a private matter that she should probably not do when others are around, she seems satisfied. But sometimes, to confirm that it is acceptable behavior, she will ask me again if it is OK to speak with our mother. I tell her that as long as Mom doesn't answer, it's fine.

She laughs.

34. See, e.g., D.C. CODE § 21-2047(a): "[A] general or limited guardian shall: . . . (7) Include the ward in decision-making process to the maximum extent of the ward's ability; and (8) Encourage the ward to act on his or her own behalf whenever he or she is able to do so, and to develop or regain capacity to make decisions in those areas in which he or she is in need of decision-making assistance, to the maximum extent possible."; D.C. CODE 21-2047(b): "A general or limited guardian may: . . . (6) If reasonable under all of the circumstances, delegate to the ward certain responsibilities for decisions affecting the ward's well-being."

35. For a criticism of both the substituted-judgment and best-interest standards, see Linda S. Whitton & Laurence A. Frolik, *Surrogate Decision-Making Standards for Guardians: Theory and Reality*, 2012 UTAH L. REV. 1491.

**The standard for imposing guardianship . . . is vague enough that people with quite different abilities can come within its purview.**

Guardianship statutes require a guardian to know the person for whom he or she is making decisions,<sup>36</sup> but even with my having a lifetime of experience with her, my sister continues to surprise me. Many family members serve as guardians for love not money. But good intentions are insufficient, and guardians need constantly to be aware of their proper role and be prepared to provide the right level of support

for the person they are serving.

### **3. Not all guardianships are the same—even for people who have the same diagnosis**

Guardianship is not a one-size-fits-all proposition. Even within the same category of guardianship—e.g., guardianship for a person with an intellectual disability—there are significant differences between being a parent guardian versus a sibling guardian, being a guardian over a person living with the guardian versus being one for someone living hours away, and being a guardian for a person who is verbal and communicative versus being a guardian for one who is not. As I noted earlier, I could not begin to control many aspects of my sister's life even if I wanted to because she lives far away from me. I would hope I would support her autonomy and self-determination to a similar extent even if she lived close by and I had the capacity to intervene in her life more.

The standard for imposing guardianship, roughly that the person lacks capacity to manage her affairs,<sup>37</sup> is vague enough that people with quite different abilities can come within its purview. Many statutes have provisions for limited guardianships,<sup>38</sup> but commentators have noted the significant under-usage of this less-restrictive alternative to general or plenary guardianship.<sup>39</sup> Even the imposition of a limited guardianship should be subjected to the least-restrictive-alternative principle, and a court should not order it if arrangements short of guardianship, such as supported decision making, are available.<sup>40</sup>

36. See, e.g., D.C. CODE § 21-2047 (a): “[A] general or limited guardian shall: (1) Become or remain personally acquainted with the ward and maintain sufficient contact with the ward to know of the ward’s capacities, limitations, needs, opportunities, and physical and mental health[.]”

37. See, e.g., D.C. CODE § 21-2011(11), which defines an incapacitated individual as “an adult whose ability to receive and evaluate information effectively or to communicate decisions is impaired to such an extent that he or she lacks the capacity to manage all or some of his or her financial resources or to meet all or some essential requirements for his or her physical health, safety, habilitation, or therapeutic needs without court-ordered assistance or the appointment of a guardian or conservator.”

38. See, e.g., D.C. CODE § 21-2044(c), which authorizes a court to appoint a limited guardian in lieu of a general guardian. Section 21-2044 (a) requires the court to exercise its authority “so as to encourage the development of maximum self-reliance and inde-

pendence of the incapacitated individual” and to order the type of guardianship that is least restrictive of the incapacitated individual in scope and duration.

### **4. Nothing is—or should be—forever, including guardianship**

Guardianship is a powerful decision-making tool, one that may be more powerful than needed. But even if the order appointing a guardian is valid at the time of initial entry, circumstances can change, especially for people under guardianship not suffering from dementia. While nothing prevents a guardian from assisting the person under guardianship in seeking restoration of some or all of that person's decision-making rights, meaningful court-supervised periodic review would provide needed oversight over the process. A more thoroughgoing reform would provide a time limitation on guardianships (perhaps with an exception for those people with dementia) so that the burden of persuasion was on the guardian to demonstrate that guardianship in its then current form continued to be needed.

## **CONCLUSION**

Every parent of a child with an intellectual disability worries about what will happen to the child when the parent is no longer around. When the child has a sibling, there is at least the possibility that the sibling will step up and continue to be a presence in the life of the person with a disability. I have met many siblings who have accepted this responsibility willingly and without question. In becoming my sister's guardian, I have sought to carry out this responsibility faithfully and to do so in a way that recognizes my sister's individuality and desire to live her own life in her own way.

An intellectual disability is not a tragedy. People with intellectual disabilities, such as my sister, can bring great joy into

pendence of the incapacitated individual” and to order the type of guardianship that is least restrictive of the incapacitated individual in scope and duration.

39. See Lawrence A. Frolik, *Promoting Judicial Acceptance and Use of Limited Guardianship*, 31 STETSON L. REV. 735, 741 (2002).

40. In August 2017, the American Bar Association House of Delegates is expected to consider a resolution urging it to recognize that, consistent with the principle of the least-restrictive alternative, courts should not order guardianships without first considering supported decision-making arrangements. The resolution is being proposed by the ABA Commission on Disability Rights, Section of Civil Rights and Social Justice, Section of Real Property, Trust and Estate Law, and the Commission on Law and Aging. I have been working with an ad hoc group of academics and practitioners in drafting the resolution and an accompanying report.

41. See sources cited in note 16, *supra*.

the life of their families and generate laughter far more often than sorrow. I don't know that my involvement in my sister's life would be much different if I were not her guardian, but since the roles of brother and guardian are inevitably intertwined, I embrace my dual roles in all of their contradictions and complexity.



*Robert D. Dinerstein is Professor of Law and Associate Dean for Experiential Education and the Director of the Disability Rights Law Clinic at American University's Washington College of Law in Washington, D.C. Dinerstein specializes in disability law, especially mental disabilities (including issues of consent, choice, capacity, and guardianship), the Americans with Disabilities Act, the United Nations Convention on the Rights of Persons with Disabilities, legal representation of clients with mental disabilities, and disability and international human rights. He has taught at the Washington College of Law since 1983. He has an A.B. degree from Cornell University and a J.D. degree from Yale Law School.*

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