



***Beyond Guardianship: Toward Alternatives That Promote  
Greater Self-Determination for People with Disabilities***

**Qualitative Research Report Summary  
(Interview Data Coding and Analysis)**

**Acknowledgments:** NCD would like to thank the Institute on Disabilities at Temple University for its work on this qualitative study and this report summary.

**Sample**

During the months of March and April 2017, forty-six qualitative interviews were conducted in total. Specific categories of participants interviewed were: six people with disabilities under guardianship; twelve people with disabilities using alternatives to guardianship; sixteen family members and/or supporters; and twelve representatives chosen for their expertise in advocacy, law, court operations, and professional services for people with disabilities. Participants were identified through extensive outreach to the members of the advisory boards established for this project and the National Resource Center for Supported Decision-Making, public and private guardians, and national and local disability and aging networks. Researchers employed a snowball sampling process, in which existing participants recruited future participants from among their acquaintances. This nonprobability sampling technique is crucial to access difficult to identify or locate populations. Selection of participants took into account geographical diversity, individual characteristics, need for support, and individual experience.

The original aim was to interview a purposefully balanced sample of 10 participants from each category. However, the Quality Trust recruiters experienced challenges finding people under guardianship able to be interviewed. Reasons for this likely are related to complications associated with getting the “go-ahead” from the guardians involved, constraints associated with conducting the out-of-area interviews remotely, and possibly the severity of disability experienced. Additionally, if a person with disabilities under guardianship has a disability that affects phone or video conferencing access, having a remote conversation often requires social support, complex equipment, and expensive technology (Lancioni, et al., 2013). Eligibility for participation

may have been inadvertently minimized based on access to these types of supports. As an example, in Pennsylvania of the 5460 people with intellectual and/or developmental disabilities interviewed through the Independent Monitoring for Quality (IM4Q) project 33% do not communicate effectively using speech (Institute, 2016). The combination of these factors related to accessible telecommunication access and effective verbal communication could have contributed to the limited number of participants in the guardianship category.

**People with Disabilities under Guardianship:** Researchers interviewed six participants with disabilities under guardianship located in Florida (2), Kentucky (2), New York (1), and Wisconsin (1). Disability demographics were identified during recruitment and/or self-reported and represented a cross-disability perspective: Prader-Willi Syndrome with learning disabilities, acquired brain injury, multiple developmental disabilities, mental illness, and substance abuse. Two of the people were under limited guardianships; the rest were under “full” or “plenary” guardianships. Analysis in this section is very limited given that each participant responded in reference to the questions about their own experiences, yet sometimes was not able to address the concepts entirely. Responses have been organized and sorted in groupings related to the question.

**People with Disabilities using Alternatives to Guardianship:** Researchers interviewed twelve people with disabilities using alternatives to guardianship from Delaware (2), Kentucky (2), Washington, DC (3), Virginia (2), Massachusetts (1), and Pennsylvania (2). Disability demographics including cerebral palsy (4), Down syndrome (2), acquired brain injury, a combination of intellectual disability, cerebral palsy and Sickle Cell Anemia, a combination of intellectual, sensory, and physical disabilities, a combination of Autism Spectrum Disorder and Obsessive Compulsive Disorder, a combination of cerebral palsy and Generalized Anxiety Disorder, and a combination of mental health and learning disability. Two of the people interviewed had been under guardianship, but had gone to court to have guardianship removed. Analysis in this section is very limited given that each participant responded in reference to the questions about their own experiences, yet sometimes was not able to address the concepts entirely. Responses have been organized and sorted in groupings related to the question.

**Family Members and/or Supporters:** Researchers interviewed sixteen family members and/or supporters of people with guardianship from Massachusetts (2), Florida (1), Delaware (2), Utah (2), Kansas (1), Washington, DC (1), Texas (1), Pennsylvania (5), and Virginia (1). Participants identify as the mother (11), father, sibling (3), and guardian of a person with guardianship. Participants reported the people with guardianship to have developmental disabilities (2), cerebral palsy (2), Hirschhorn Syndrome, a combination of Autism Spectrum Disorder and Attention Deficit Hyperactivity Disorder (2), Oral-facial-digital syndrome Type I, a combination of ASD and intellectual disability, a combination of intellectual/developmental disability and cerebral palsy, and two did not disclose disability demographics.

Professional Experts: Researchers interviewed twelve professional experts for this study from Illinois (2), Minnesota (1), North Carolina (1), Washington (1), Massachusetts (1), California (2), Georgia (1), New York (2), and Virginia (1). Professional participants include attorneys, law professors, professional guardians, a long-term care professional, and a judge. The professional participants have an array of previous experiences including drafting guardianship policies and serving on guardianship-based organizations. One participant researches and writes articles about guardianship.

Given that the total numbers of interviews conducted exceeded the original goal and the fact that there was diversity in representation both by group and within groups, the sample provides a vivid and genuine set of qualitative data to be sorted, coded and analyzed.

### **Research Questions, Data Collection, and Methods**

The data were collected using the interview protocol developed by staff from Quality Trust in collaboration with staff from the Institute on Disabilities at Temple University and with input from this project's advisory committee and the National Council on Disability. The interviews were semi-structured to allow the interviewer and respondent to engage in a formal interview with opportunities to explore unique issues and topics that emerged through the interview process. The interview questions were designed to elicit responses to address five research questions developed by the National Council on Disability. The data collectors were all law students at the American University School of Law's Disability Rights Law Clinic. The data collectors were trained by Institute staff by phone in how to use the interview protocol.

### **Data**

The data analyzed for this report consisted of electronic transcripts of each interview, the notes that the interviewer took in response to certain questions and sub-questions (the interview protocol) during the telephone conversation, and some email communications about aspects of the interviews from interviewers to the project coordinator. After reading and analyzing the interviews and other documents we can comfortably highlight some salient themes that reached levels of saturation in the data across all categories.

### **Analysis**

Research Question 1: Are people with disabilities receiving fair treatment within the legal system with respect to guardianship?

People with disabilities under guardianship expressed positive, negative and neutral reactions regarding their treatment within the legal system with respect to guardianship.

Interviewees described positive experiences with their lawyer, in court and/or with their guardian, who made them feel well cared for. Interviewees also defined negative experiences which include being prohibited from accessing money and implementing a different guardian, inattentive lawyers and lack of explanation of rights. Finally, one interviewee had a neutral response to her brother as her guardian, who helps her understand her rights but concomitantly makes all of her decisions.

People with disabilities using alternatives to guardianship had no positive responses to their treatment within the legal system with respect to guardianship. In terms of negative responses, interviewees reported society's taken-for-granted expectation that every person with disabilities requires guardianship. Additionally, interviewees stated that the legal system, courts, lawyers, and evaluators did not spend enough time to adequately assess an individual's level of function. Interviewees remarked at the lack of education they received on their civil and legal rights, and defined guardianship as the taking away of a person's rights. Neutral responses included learning rights through alternative sources including a case manager and Quality Trust.

Family members and/or supporters expressed positive, negative, and neutral reactions regarding how persons with disabilities are treated within the legal system with respect to guardianship. Multiple interviewees described the court experience as positive, wherein the person with disabilities was respected (though sometimes they were absent), and while guardianship was defined as a removal of rights, a person's rights were reviewed along with the right to revoke guardianship. Some interviewees declared that the person under guardianship still had the right to make decisions, while guardianship existed to support the person's decision making or act on their behalf when they were incapable. Many interviewees expressed that the person with disabilities didn't understand the legal proceedings; the legal process, rights, and guardianship (including the right to revoke it) were not adequately explained; and legal counsel had limited communication with the person. Interviewees described the person under guardianship as regarded as "not a full person" and "doesn't exist in the eyes of the law" and defined guardianship as the "closest thing to the death sentence" and "like being in prison." Some interviews netted neutral responses.

Professional experts reported positive, negative, and neutral reactions regarding how persons with disabilities are treated within the legal system with respect to guardianship. Professionals declared that the legal system is designed to protect the rights—including due process and representation—of people with disabilities, but noted that research is needed to better understand the practice of law and the experiences of people with disabilities. A few professionals noted that the trend toward limited guardianships and/or conservatorships is positive. Within the legal system, professionals remarked that people with disabilities (1) are not treated as individuals but rather as stereotypes, stigmatized with a lack of dignity; (2) receive variable due process and are not adequately represented in court; and (3) are not adequately assessed in terms of their

ability to make decisions and function. Interviewees also reported that lawyers have inadequate training, understanding and experience with the needs of persons with disabilities. Additionally, in terms of guardianship, professionals argued that the a priori expectation should always be (1) the least restrictive and (2) a presumption of competence. In terms of neutral responses, professionals noted that education about rights should be personalized.

Salient themes:

- Judges do not understand what guardianship is, how it limits people, and what other alternatives are available.
- There is a difference in legal rights and processes and how people experience the legal system, actors, and spaces in practice.
- People with disabilities are not adequately assessed in terms of their ability to make decisions and function.

Research Question 2: Is supported decision-making a viable alternative to guardianship? If so, does it lead to better outcomes or are there some negative unintended consequences to using this alternative?

People with disabilities under guardianship expressed positive and neutral reactions regarding supported decision-making as a viable alternative to guardianship. Interviewees responded positively to the definition of supported decision-making as defined in the interview protocol and supplied by the interviewers. Many interviewees were not previously acquainted with the term.

People with disabilities using alternatives to guardianship expressed positive reactions regarding supported decision-making as a viable alternative to guardianship. Interviewees recognized that all people rely on natural supports to understand and make decisions, and occasionally make poor decisions and that people with disabilities should be no different.

Family members and/or supporters expressed positive, negative, and neutral reactions regarding supported decision-making as a viable alternative to guardianship. Family members described supported decision-making as a form of self-determination. They reported that most people can and should have the right to make their own decisions, and that involving the person with disabilities in the decision-making process ensures higher levels of engagement. Additionally, family members contended that supported decision-making's reliance on natural supports emphasizes a sense of community, which (1) enables the individual to gain skills in eliciting information, weigh the pros and cons of potential decisions; (2) holds its members accountable and protects against conflicts of interest. Family members and/or supporters expressed concern that providers, such as doctors, may be less likely to listen to people with disabilities engaged in supported decision-making as opposed to their guardians. One interviewee

remarked that supported decision-making is not ideal for people with zero verbal communication but believed that experiential decision-making is imperative. Finally, an interviewee noted that supported decision-making only works when everyone involved is “open, honest and [believes] in community.”

Professional experts expressed positive, negative, and neutral reactions regarding supported decision-making as a viable alternative to guardianship. Positive responses regarded supported decision-making as the “gold standard,” “starting point” of becoming an adult, which empowers and maximizes agency, self-esteem, autonomy and self-control. It allows people to make decisions that match their goals and values to lead happier and healthier lives. Negative responses resoundingly expressed that supported decision-making, as well as alternatives like power of attorney and representative payee, still offers opportunities for abuse and exploitation. Neutral reactions included a call to action for supported decision-making training and safeguards against abuse and exploitation. They also noted that the transition into supported decision-making may be a particularly difficult adjustment for parents.

Salient themes:

- No support system as yet, including guardianship and supported decision-making, is free from risk of exploitation or abuse.
- For people with significant support needs, supported decision-making may not be as easy to implement well.

Research Question 3: Are people with disabilities who may need decision-making assistance and their families being provided with sufficient information about the guardianship process and possible alternatives to make informed and appropriate decisions?

People with disabilities under guardianship expressed positive and neutral reactions regarding information about guardianship and its alternatives. People under guardianship responded that their guardian provides them with information as needed. Many respondents explained that they were not familiar with alternatives to guardianship or uncertain they were ever offered or explained.

People with disabilities using alternatives to guardianship expressed positive, negative, and neutral reactions regarding information about guardianship and its alternatives. Some interviewees had received information about guardianship and its alternatives through the school system or community-based programs; others did not specify how they learned about guardianship and its alternatives. Negative reactions to the information provided about guardianship and its alternatives noted the need for more personalized education and training on decision-making and money management for people with disabilities, those that support them, the education system, and the

community. Some identified the education system as pushing parents into becoming guardians without presenting alternatives.

Family members and/or supporters received a range of information about guardianship and its alternatives. Some learned about decision-making alternatives like supported decision-making, power of attorney, and representative payee through community programs, case managers, and their own careers. Others only received information about guardianship by school or legal actors, and were never presented with alternatives. Some reported that they had been engaging in supported decision-making but were not familiar with the term as a formal process. Others expressed concern at the potentiality for abuse and exploitation outside of guardianship.

Professional experts also had a range of positive, negative and neutral responses regarding information about guardianship and its alternatives. Some professionals contended that the public is generally aware of limited and full guardianship and noted the import of self-advocacy as many learn about guardianship through their peers and organizational affiliations. Others stated that information on decision-making processes is inadequate or altogether nonexistent, and should be presented in schools and health settings rather than relegated to legal settings alone. Other professional experts remarked that information dissemination varies from case to case and state to state.

Salient themes:

- People with disabilities, family members, and professionals all agree that there is not enough information (quality, quantity, accessibility) about alternatives to guardianship. There is particularly little information about supported decision-making. Often people are presented with guardianship as the only option.
- Many people are not familiar with supported decision-making as a formal concept but are engaging in it and benefiting from it.

Research Question 4: How does guardianship impact people with disabilities and their families? Does guardianship help improve outcomes of health, safety, and protection for people?

People with disabilities under guardianship had positive, negative, and neutral reactions to how guardianship impacts them and their families and improves health and safety outcomes. Interviewees described positive experiences in which their guardians provided financial assistance, answered questions, and protected them from making poor decisions. One individual reported that guardianship led people to underestimate their intelligence. Another did not perceive any significant change to their life since being under guardianship.

People with disabilities using alternatives to guardianship had negative and neutral reactions to how guardianship impacts people, and their health and safety. Many

interviewees disliked the lack of control one has over their decisions and finances under guardianship. One interviewee recounted that under guardianship they were psychologically, verbally and physically abused by staff. Neutral responses remarked that the impacts of guardianship vary case by case.

Family members and/or supporters had positive, negative and neutral reactions to how guardianship impacts people, and their health and safety. Positive reactions included that guardianship entails court oversight which provides some protection from exploitation and gave guardians greater peace of mind. Others perceived guardianship as a support for the person under guardianship's own decision-making. Many negative responses argued that guardianship, nor any support system, cannot completely protect an individual from exploitation and the extent and lack of checks and balances with guardianship can even foster exploitation and abuse. Many perceived guardianship as negatively impacting the health and happiness of people's lives and forcing individuals into the lives their guardians wish them to live. Neutral responses reported that the pros and cons of guardianship vary on a case by case basis.

Professional experts had positive, negative and neutral reactions to how guardianship impacts people, and their health and safety. Professionals held that guardianship ensured that individuals (1) had their needs met; (2) were served by third parties like health care, housing and financial providers; and (3) were protected from exploitation and abuse. One argued guardianship can empower the person with disabilities while others declared that guardianship improved the lives of those surrounding the person with disabilities without improving the person with disabilities' life. Negative reactions stated that guardianship does not eradicate abuse but can create hostility, demean and dehumanize the person with disabilities, make people more dependent, and destroy the natural supports of the family unit. Neutral reactions contended that any support system requires a process for ensuring there are no conflicts of interest.

Salient themes:

- Guardianship is overly restrictive.
- Guardianship can improve the lives of those supporting the person with disabilities but does not necessarily improve the life of the person under guardianship.

Research Question 5: How does the current use of guardianship align or conflict with other US national disability policy goals and initiatives, including the goals of the American with Disabilities Act (ADA) and its community integration mandate and principles of due process under the law?

People with disabilities under guardianship had positive, negative and neutral reactions to how guardianship currently aligns or conflicts with national disability policy goals and initiatives. Multiple people under guardianship reported that guardianship did not affect

their day to day lives, where they lived, or their involvement within the community while one felt they had a lack of rights and choice.

People with disabilities using alternatives to guardianship had negative and neutral reactions to how guardianship currently aligns or conflicts with national disability policy goals and initiatives. Interviewees stated that guardianship affects where you can live, who you can interact with, how you're treated, and community integration. Interviewees reiterated that without a guardian they have freedom in where they reside, with whom they interact, and what they do. Neutral responses argued that any form of decision-making requires a sliding scale of support based on the severity of the person's disability.

Family members and/or supporters had positive, negative and neutral reactions to how guardianship currently aligns or conflicts with national disability policy goals and initiatives. Some expressed that guardianship kept an individual safe, upheld their civil rights, and ensured they could grow as a decision-maker and member of the community. Others declared that they supported the person with disabilities to live wherever, vote, get married, and do activities of their choosing. Multiple interviewees described guardianship as an infringement of civil and human rights. They remarked that guardianship leads to stigma, lowered expectations, and changes how individuals interact with people with disabilities. Interviewees contended that people under guardianship are inhibited from living a full, integrated life. Neutral responses recognized the variability of experiences under guardianship; specifically that guardianship can empower some and belittle others.

Professional experts had positive, negative and neutral reactions to how guardianship currently aligns or conflicts with national disability policy goals and initiatives. Some interviews argued that guardianship aligns with disability policy goals in that that good guardians support and advocate for an individual's integration into the community. Other interviewees contended that guardianship infringes on a person's civil rights, correlates with social isolation, and therefore conflicts with disability policy goals like the ADA. A neutral reaction noted that emphasizing dignity and autonomy can repair the problems of guardianship and inequality faced by people with disabilities.

Salient themes:

- Good guardians support and advocate for people under guardianship in ways that align with disability policy goals however guardianship can also inhibit an individual from living a full, integrated life.

## **Limitations**

In reviewing the data and analysis of the people with disabilities under guardianship, people with disabilities using alternatives to guardianship, and family members and/or

supporters groups, their responses typically represented their lived experiences. Participants' positive responses, and in reverse their negative recollections of past systems, seem to reflect those of their own experiences generating a theme of confirmation bias throughout the data. Researchers, however, can facilitate participants' critical consideration of other possibilities to yield more comprehensive answers and, therefore, a richer data set. Literature shows that people tend to gravitate toward information that confirms their current beliefs because it makes complex cognitive processes more efficient (Friedrich, 1993; MacCoun, 1998); however doing so limits critical thought that can lead to less objective, thorough information seeking for decision making (Hernandez & Preston, 2013). Studies have shown that disrupting potentially biased thought processes with alternative stimuli or information that's inconsistent with current opinions can lead to more objective, informed decisions (Hernandez & Preston, 2013; Schwind & Buder, 2012). Because participants' answers are essentially formulated decisions about what information to share and with whom to share it, future researchers in this area might consider this when developing their methods and questioning patterns during interviews.

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## Appendix A: Data from Interviews

Terms: G = guardianship, POA = power of attorney, RP = representative payee, SDM = supported decision-making, PWD= people with disabilities

## **People with Disabilities under Guardianship**

Researchers interviewed six participants with disabilities under guardianship located in Florida (2), Kentucky (2), New York (1), and Wisconsin (1). Disability demographics were identified during recruitment and/or self-reported and represented a cross-disability perspective: Prader-Willi Syndrome with learning disabilities, acquired brain injury, multiple developmental disabilities, mental illness, and substance abuse. Two of the people were under limited guardianships; the rest were under “full” or “plenary” guardianships. Analysis in this section is very limited given that each participant responded in reference to the questions about their own experiences, yet sometimes were not able to address the concepts entirely. Responses have been organized and sorted in groupings related to the question.

### RQ 1. Are people with disabilities receiving fair treatment within the legal system with respect to guardianship?

#### *Positive Responses:*

1. Feels her lawyer was there for her, was a good lawyer, her court experience was good; she affirms she knows her rights
2. Guardian helps him with things he can't do; having a guardian makes him feel cared for, everyone treats him well; he knows his rights; sister and mom help him understand his rights
3. It was my choice, somebody available to help with things, and am glad I do, I don't think I would change it. Witnessed her parents go through a lot with aging grandparents and how guardianship helps with paperwork. Mother and father handled all the legal process to guardianship. She met the lawyer before the hearing. Probably could reverse it (guardianship) but comfortable with how things are.

#### *Negative Responses:*

1. When I got my rights back, the lawyer at the time said can I make a suggestion and suggested we get someone to help you with your money; lawyer appointed by legal services; she liked the lawyer, he understand what she wanted, yet now I always ask what my money is (how much I have) and they say no. I've been told I can't get a different guardian or get my money back.
2. Lawyer never checked that about me; no one explained their rights; wants to go back to court to remove guardianship

#### *Neutral Responses:*

1. Brother is guardian, he is lawyer, represented her/them, doesn't remember specifics of experience in court, brother helps her understand her rights. She is not sure what guardianship means; placed under guardianship after her parent's death; guardian makes all decisions

RQ 2. Is supported decision-making a viable alternative to guardianship? If so, does it lead to better outcomes or are there some negative unintended consequences to using this alternative?

*Positive Responses/Outcomes:*

1. Not familiar with SDM but thinks it's good; she makes decisions to go to the store and do what she wants; her brother (her guardian) helps her; he makes some of her decisions and talks to her first
2. SDM sounds okay. Sometimes if I'm not sure about something, I call my uncle and ask him. He gives me advice. Someone said I was stalking them so I asked for advice from my uncle and Mr. Tony to sign the paper and they gave me good advice

*Negative Responses/Outcomes:*

None

*Neutral Responses/Outcomes:*

1. Not familiar with/No opinion on SDM. But she says she makes her own decisions; at another point she says she and guardian talk about decisions.
2. SDM means the same thing as having guardianship, giving support in various areas, financial, medical, legal. Decision-making is always discussed with me and I always have a say it's about it. If I disagreed with my guardians, we would discuss it and come up with a midway point

RQ 3. Are people with disabilities who may need decision-making assistance and their families being provided with sufficient information about the guardianship process and possible alternatives to make informed and appropriate decisions?

*Positive Responses:*

1. Guardianship is limited to financial, but if I have medical questions, I can always ask them. I make all my decisions. Guardian tells me what is in my bank account. I never disagree with my guardian. If I don't understand something, Ms. [Guardian] helps me. Not familiar with POA or RP
2. Guardianship is not different from what I thought, I thought they would help rekindle our money

*Negative Responses:*

None

*Neutral Responses:*

1. She's not familiar with alternatives
2. Doesn't remember if alternatives to G were offered/explained; no one talked to her about limited G, not familiar with POA or RP
3. Parents talked to me about guardianship, don't remember any other options at the time. Familiar with POA, not sure if she has, Mom is RP

RQ 4. How does guardianship impact people with disabilities and their families? Does guardianship help improve outcomes of health, safety, and protection for people?

*Positive Impact Responses:*

1. Guardianship means they help me with my money and stuff and make sure my bills are paid;
1. My new one goofed up, but I still like her. Guardian is an angel. I don't mind having someone to pay my bills because I don't drive
2. Had G a long time. I met a guy who said he wanted to marry me and then took everything I owned. I got insurance money when my daddy got killed. With guardian I got away from all the bad people in my life
3. Anytime I call up there, they will try to help me. Sometimes I get aggravated because no one calls me back. When I want to do something, I tell Ms. [Guardian] and she looks and tells me if I can do it or not. If I don't have enough money, they tell me I can do something later.
4. Guardian acts as a guide to help keep him from making wrong decisions; he makes decisions about what to eat, etc.; help him take his meds, hasn't really disagreed with them.

*Negative Impact Responses:*

1. Sometimes I think people underestimate my intelligence or ability of what I can/can't do until they get to know me all of that, then they realize that nothing worrying me to get past her.
2. She was happy when her mother was alive. Brother doesn't call me too much and that makes her sad. Other than that there is not real change; she can't make the decision herself. She doesn't know what decisions guardian makes

*Neutral Responses:*

None

RQ 5. How does the current use of guardianship align or conflict with other US national disability policy goals and initiatives, including the goals of the American with Disabilities Act (ADA) and its community integration mandate and principles of due process under the law?

*Positive Responses to Community Integration Principles*

1. Yeah I can live where I want to live and go where I want to, goes to church, votes. People are good to me, don't take advantage of me

#### *Negative Responses to Community Integration Principles*

1. Lack of rights/choice: One of her housemates doesn't treat her good. She won't talk about weekends; wants brother to call more often; they don't let her talk to her boyfriend every day. Her boyfriend can't hear well.

#### *Neutral Responses to Community Integration Principles*

1. Having a guardian doesn't affect his day to day activities; in the process of finding his own place to live, spends time with people at bingo, he feels good about himself
2. Doesn't feel G affects her integration in the community, where she lives, day to day, talk and visit with people she wants

### **People with Disabilities using Alternatives to Guardianship**

Researchers interviewed twelve people with disabilities using alternatives to guardianship from Delaware (2), Kentucky (2), Washington, DC (3), Virginia (2), Massachusetts (1), and Pennsylvania (2). Disability demographics including cerebral palsy (4), Down syndrome (2), acquired brain injury, a combination of intellectual disability, cerebral palsy and Sickle Cell Anemia, a combination of intellectual, sensory, and physical disabilities, a combination of Autism Spectrum Disorder and Obsessive Compulsive Disorder, a combination of cerebral palsy and Generalized Anxiety Disorder, and a combination of mental health and learning disability. Two of the people interviewed had been under guardianship, but had gone to court to have guardianship removed. Analysis in this section is very limited given that each participant responded in reference to the questions about their own experiences, yet sometimes were not able to address the concepts entirely. Responses have been organized and sorted in groupings related to the question.

#### RQ 1. Are people with disabilities receiving fair treatment within the legal system with respect to guardianship?

##### *Positive Responses:*

None

##### *Negative Responses:*

1. Did not receive special education on rights, just learned about human rights, US citizen's rights, etc. Learned about ADA rights, etc., through Partners in Policymaking program. I started to understand what my rights are, what my legal right was, and what my civil rights are. And those are three different categories that have three different meanings. And I think a lot of parents made a decision based

on not knowing what their legal rights are, civil rights, and what the rights of people with disability are.

2. She thinks G is "a bad thing," but no elaboration. Knows G has "something to do with the courts." someone talked to her about G but no one has ever told her to get a guardian.
3. Formerly under G no longer; G started after he left school system, mom and dad questioned why G was needed, but "that was the practice". Four years later, they appealed: we're not making decisions for him, we are supporting him to make choices. Lost the appeal, but court appointed lawyer never went to job site, volunteer site, Mother spoke to him about rights, had in his ISP, "I have the right to express yourself" We got out of conservatorship. Person reflected that he did not need a guardian and he had another psychological evaluation done. The psychologist came from the GUB, spent the whole day, went to the job, interviewed him, came to the home, saw him let himself in, he has his own security code, fix his lunch, do the dishes after he's with went banking, 'cause [Mr. Interviewee] needed to the banking, came back and sat with us and interviewed us a little bit more and from him he's saying, a test doesn't necessarily reflect his functionality. That's what Quality Trust evaluated his functional level. Not necessarily his IQ but how does he function every day and everyday living. The judge said when we went to court in October, the judge said "I read the entire packet and I've determined that he no longer needs guardianship". This is 10 minutes but what we had also worked on it at the alternative that we had in place for him which took us about 2 1/2 years to work on with a power of attorney. We just never should have been on the guardianship and I just couldn't believe it, everybody got it and what I don't like is not only does the court looks at the people as individuals I think they just plain look you've got a disability and do they take the time to actually study who's coming and their functionality? How functional are they? And the court-appointed lawyers interact with them for just 2 hours, that's all that we get, 2 hours. No one's was at the job site, no one was at the bowling game, no one came in and sat in our home to talked for 2 hours
4. Mom talked to me a lot about me living my life the way I want. Learned rights from Mom, teacher, father. When I was in high school they told my mom I needed G. I know that means I lose my rights and they can make my decisions. It comes down to trust. I trust my parents to do what I want to do, whether I say it or not. They know what I like and what I want. Just because I have problems with my body, doesn't mean I am incompetent. My mom knows me better than anyone and listens to my body language. Many people would benefit from listening to others.
5. Yes, has been spoken to about her rights, she has a right to live in the community, to visit/talk to people she wants to. Guardianship is when someone else is legally in control of another's decisions; someone had suggested she get a guardian which made her uneasy the idea of someone having control over her life
6. I have the right to choose any life decisions or health care options; boyfriend and family help her with her rights. I got very angry and defensive when someone

suggested I have a guardian. The person knew her educational background. I was just shocked that they would assume I needed a guardian

7. People have talked to him about his rights, mom helps him understand them; he has a right to live where he wants, votes, talks with grandmother. He wants to make his own decisions. Mother "Not a fan of G because it takes away a person's rights. People automatically look at a disability and assume they need G

*Neutral Responses:*

1. Came to know and understand rights through case manager
2. Learned a lot about her rights and self-advocacy through Quality Trust, in response to those trying to extort her. G means that someone can choose who they want to be responsible for your things and if anything happens to her. If she gets sick and cannot make a choice, she has decided that she wants her mother to be in charge of making those decisions for her. However, no one ever suggested that she get a guardian

RQ 2. Is supported decision-making a viable alternative to guardianship? If so, does it lead to better outcomes or are there some negative unintended consequences to using this alternative?

*Positive Responses/Outcomes:*

1. I wish SDM was done a million years ago because it allows you to reach out to people to help make a decision. Delaware is the second state to pass the SDM deal. With the support from quality trust and really having the resources to educate individuals on SDM. It was almost like seeing the ADA pass because I guess - I guess people – the option to have someone making a decision and they don't lose their right. They don't lose their right as a - as a human being. They don't lose the right to get married, they don't lose the right to love who they want to love. And will still get support. Whoever came up with the word supportive decision making was phenomenal. I make majority of my decisions. And when I can't I have people there to assist me. We created a SDM video on YouTube in DE. We all go to other people for advice, natural supports, you don't have to add nothing to that, don't have to pay them, don't have to find them/wait for them, and they're natural.
2. Slightly confused about what SDM is, but her mother helps her makes decisions and this is desirable. Mother has engaged in SDM "forever" but only in an official sense 6 months ago. Interviewee says that if her mother made all her decisions for her, e.g., where to live, where to work, "what shoes to put on," that she would not like that. Mother says that sometimes interviewee and her disagree and then explains to interviewee that she has to live with her decisions.
3. Had state G twice. Refers to it as "prison on the outside of the prison," "patronizing" treat you like you don't know your rights. SDM is a better alternative because guardians don't listen to you, and better to have someone to support decisions whether they are good or bad

4. SDM sounds good. I talk to my friends and family, they help me. After parents' death moved to KY. My case manager helped me make that decision and my friends. When he has received help he didn't want he told them no and made his own decision.
5. One judge told us when we had the POT said "Three people are too many people to be guardians to make decisions for him". (parent response) With him, we're not making decisions for him. We are supporting him to make choices and for us to support him in his thinking and we want to teach him right from wrong and things that he wants to do with his choices. He does his own choice and he makes the decision. Mother, father and sister support him, he makes his own decisions but if he needs help he just asks his network; recently made the personal decision to go to movies with a friend, go clothes and food shopping, had a superbowl party and invited his friends over, created a menu
6. [Mr. Interviewee]'s the first one in the district to have won his case under the supportive decision making.
7. People with or without disabilities who have/don't have disabilities make bad decisions. Why are PWD treated differently. SDM is what good friends and family do. My grandparents do it when it comes to making a big decision. It comes down to trust.
8. Mom takes care of all of his money and they discuss how to spend it, rent, food, and entertainment. They have a joint checking account that requires both signatures. They write checks for doctors. They sit down and write checks together. He moved into supported apartment.
9. SDM is when someone helps you lay out all the options and think through so person can make final decision for themselves; it's helpful for everyone; when she faces big decisions feels better having someone to talk to
10. SDM means you have someone there to help make your decisions, help guide in the decisions process. Decisions I made myself: What college I wanted to attend, what degree I wanted to go for, what job I wanted to take. Where I wanted to live after I moved out of my parents' house; decision making supports: my friends, my family, my professors.
11. Participant likes the idea of SDM; Mother: SDM is better because the way we supported him is by building a circle of support around him so that people know and can understand what his hopes and dreams are; he makes decisions about picking friends, how he spends time and money, what he eats.

*Negative Responses/Outcomes:*

None

*Neutral Responses/Outcomes:*

1. Wants someone "to help oversee stuff", "have discussions about things"

RQ 3. Are people with disabilities who may need decision-making assistance and their families being provided with sufficient information about the guardianship process and possible alternatives to make informed and appropriate decisions?

*Positive Responses:*

1. Learned about G through Partners in Policymaking 8 month course.
2. He has enough support; doesn't feel like the help he receives he doesn't want
3. No one really presented her with information but at ISP meeting, she learned she needed to pick the right people to support her in meetings or they would write something down she didn't want. She is in process of getting POA with attorney
4. Reviewed decision making in high school, through PPTs, visuals; parents and brother are POA. Mom is RP.

*Negative Responses:*

1. There are people that have G that don't need it. BC of the educational system, parents are told that when their child turns 18 and they don't have a guardian, they won't be able to make medical decisions, they won't be able to support their loved ones. Parents will rush to get G and then once they get it, and they actually realize, oh, my goodness, my son or daughter no longer has rights, then, they can't get that overturned. And I know multiple people that have guardianship that they now regret it. But the only reason why they got it because they didn't know what they were doing.
2. In terms of POA/RP, a lot of people do have payees and now certain programs require you to have payee. But instead of taking those rights away, how about we teach individuals how to manage their money
3. Not familiar with SDM. Boyfriend helps a lot to make decisions because he can explain things to her in a way she understands. "If someone is telling another person what they should do all the time, that person isn't going to be able to think for themselves or make their own judgments and figure out their own problems."
4. he's gone through an awful lot and he'd been pushing and fighting the school system, fighting with doctors because they give you the worst scenario and really no hope and so that we've been involved with sickle cell support group; mother is medical POA (if incapacitated) but he can still sign medical papers and RP but he deposits his paycheck at the bank and withdraws cash himself we are just telling our story how we got caught up in the system. We always felt we never should have been 'cause we've always been pushing and pushing for him to be involved in everything as much as possible. Have as much as a so-called normal life as possible and we've always had very good support system of family and friends. 'Cause when he would be having his crisis, 'cause that's not sometimes a week in the hospital, he had maids, we have family members that would come and meet my husband and I to stay with him. 'Cause we never left him alone, you just don't leave him as a child alone 'cause he really can't express himself to tell. So we've always had a good network of people. They need to ask, what other alternatives do I have if

there are alternatives. And parents the community has for these educated SDM and that is why I try to steer people to SDM because it worked for us

5. No one talked with her about getting help with decision making, she has gotten intimidated because she doesn't want anyone to get mad at her.
6. A person with a disability may need info/explanations through pictures or in a different way.

*Neutral Responses:*

1. Mother had POA before SDM because of insurance companies and financial institutions requiring POA in order to speak to mother. Mother helps her with making decisions on finances and medicine and that this is very helpful.
2. Familiar with POA and has RP who pays for his rent/meals. They work well together. Parents wouldn't let him do much, neighbor helped a lot after parents' death, connected him to case manager
3. My parents have POA for medical, my mom is a POA for my grandparents. Has her own banking account because she started a dog boarding business in 2012. Mom is the cosigner and her authorized rep for SSI. Her bank account is hers even though mom's signature is on it. Does a lot of presentations across the country about doing a dog business. She doesn't like when people say people like her can't work or need a guardian >She buys music, clothes, food, and ice cream. Loves to go shopping and use her own money and makes all the financial decisions.

RQ 4. How does guardianship impact people with disabilities and their families? Does guardianship help improve outcomes of health, safety, and protection for people?

*Positive Impact Responses:*

None

*Negative Impact Responses:*

1. G takes all your rights way. There are people that guardianship works well for them, because there are people that are on guardianship or under guardianship where the individual that has their -- that has taken guardianship still gives that person the chance to make decisions. So, it's not legal - it's not a - it's not a legal decision but it's a personal decision from tweaking of what you want to wear, what you want to eat, or who you want to date, those things are personal. So really, to me, it really depends on the situation when we protect people, we shelter them. So, this is why I say, sometimes guardianship can be a hindrance because we never give somebody the chance to make even the small decisions from what they want to eat or what they want to wear. Then, you run the risk of them never ever being able to make a decision.
2. Interviewee likes that SDM allows her mother to explain complicated things so that she can decide what to do. Interviewee does not want someone else making these decisions.

3. Under guardianship hospital staff were psychologically, verbally, and physically abusive. She had to go to a brain injury program for 7 months to regain rights. Knows many who regret the decision to have G.
4. Dad was RP, She disliked not being able to control her own finances, having to go to the grocery store with her dad every time she wanted something. "I never had any money, even change in my hands"
5. Had a change in support aids which is difficult, new aide doesn't compare to previous who moved, but he still likes some of the same things. Have had up to 5 aids;
6. Because we've always been pretty much not practicing what they say that a guardian is supposed to just, he is our family member. How can we make this simple for him? He's a human being. He has likes and dislikes, we all do. And why do we not respect that? Seeing as a human being or a person with disabilities we have to respect that. We just have to.
7. You can bubble wrap people and it's not going to stop them from getting into trouble. A piece of paper saying you have a guardian isn't going to stop that. If my parents died, I guess I would have one. I hope it would be someone like my Uncle drew who would till let me live my life my way. If it was someone I didn't know, I would still be miserable
8. A couple of friends from high school have guardians. They don't have bank accounts and can't spend their money
9. G would make her feel like a prisoner, knowing all decisions would be made by someone else
10. Nothing about her life would be better under G. Family is over protective, so she's wouldn't have as much independence; guardians typically don't want to take risks; a friend works at a sheltered workshop because guardian won't let him do more

*Neutral Responses:*

1. Depends on the guardian, bad if they don't have best interest at heart.
2. Pros and cons depend on situation.

RQ 5. How does the current use of guardianship align or conflict with other US national disability policy goals and initiatives, including the goals of the American with Disabilities Act (ADA) and its community integration mandate and principles of due process under the law?

*Positive Responses to Community Integration Principles*

1. Thinks SDM or G should be reflected with severity of disability - person centered, Sliding scale of support.

*Negative Responses to Community Integration Principles (positive comments are reflective of non-guardianship situations)*

1. The more opportunities people have to make decisions, the more they become independent and the more independent you become, you now become a more member of society. Just because I need help in the bathroom, doesn't mean I need help in the kitchen. And I believe the ultimate goal for everyone in life whether they want to admit it or not is to become independent to delineate difference between the practice of rights de facto and legal rights de jure makes a comparison to gay rights - before you had right to love anyone you wanted but not legal right to marry them
2. Having a Guardian affects where you live ("you can't even have the visitors that you want," what you do during the day, whether you spend time in the community, how people treat you, and whether or not you have the right to vote.
3. Not having a guardian gives her freedom to live where she wants, do what she wants during the day, talk and visit with people, vote; she spends times with people with and without disabilities
4. Has the right to be in the community, talk/visit with people she wishes, vote, no questions about rights, very independent; if mom was guardian would have to live at home, not sure she would get to vote because mom doesn't, mom works so would probably be stuck at home. She spends time with people without disabilities at work.
5. He's out in the community, goes shopping/events, spends time with people
6. High school teacher talked to us about voting and took us to DMV and registered for us. My mom talked with us for three months helping me practice. We have a system where I slap right/left hand to make my choice, if I don't slap either one I don't like any choice. I voted 3 times now for president and governor. I knew when I was 18 I had the right to do whatever I wanted except break the law because I am an adult; I decide when I go to bed, who I vote for, who I want to be friends with, who I want to work for my business
7. She is living by herself and she does what she wants, she can have guests over, she spends time with both individuals with and without disabilities. She has a boyfriend who she goes to the movies and out to bowling with. She goes to an outpatient gym 3 days a week

#### *Neutral Responses to Community Integration Principles*

1. Change hasn't affected life that much because family modeled G like SDM

#### **Family Members and/or Supporters**

Family Members and/or Supporters: Researchers interviewed sixteen family members and/or supporters of people with guardianship from Massachusetts (2), Florida (1), Delaware (2), Utah (2), Kansas (1), Washington, DC (1), Texas (1), Pennsylvania (5), and Virginia (1). Participants identify as the mother (11), father, sibling (3), and guardian of a person with guardianship. Participants reported the people with guardianship to have developmental disabilities (2), cerebral palsy (2), Hirschhorn Syndrome, a combination of Autism Spectrum Disorder and Attention Deficit Hyperactivity Disorder (2), Oral-facial-digital syndrome Type I, a combination of ASD and intellectual disability,

a combination of intellectual/developmental disability and cerebral palsy, and two did not disclose disability demographics.

RQ 1. Are people with disabilities receiving fair treatment within the legal system with respect to guardianship?

*Positive Responses:*

1. Family G training, we go over all of the rights in the Florida Statutes and explain the rights that can never be taken away, delegated, can be taken by court, and not delegated. State agency sources through a Medicaid waiver and staff are required to provide to all recipients a list of their rights once a year.
2. PWG was not present in court proceedings. The judge was very good in explaining to us that it's serious taking people's rights away.
3. Reviewed daughter's rights during G procedure. Conversation was full or partial G Partial was described as easier. She was treated well and very respectfully.
4. Constitutional rights may be a different subject because their rights will be taken care of by someone who is acting on their best behalf  
He was treated politely in court. He had his own representation.
5. She talks to daughter about her rights, but no one else really has, though. She's guardian, daughter makes all decisions except medical. She is on the ID waiver and it's all about first and centered
6. Was told brother has rights of an adult. She helps him understand his rights.
7. G creates a power equity between him and a provider, ensures his interests are protected  
judge was terrific, had contact with brother; person has a right to revoke G, G can be inappropriate in some cases
8. People have said all along that she has the right to be an adult, the right to make decisions for herself, to live the way she wants to live, and that G is only to support her in her needs;  
her father and I help her understand/exercise her rights, help her decide, give her options, we honor her wishes as much as possible.
9. G similar to POA but more encompassing, control over person's ability to sign legal docs, make legal decisions, life decisions, when person is not capable of making them. It's absolutely necessary thing to do in their own case, for her to have a guardian.
10. When [Interviewee 1] was 18, they had no choice in MA. It was G or nothing. Several years later they heard about SDM. They contacted the center of representation and entered [Interviewee 1] into a pilot program. This program involved him and 10 people trying to get SDM. [Interviewee 1] was able to make his own decisions. G was not what they wanted. In November 2015, they went before the court, presented SDM agreement, and terminated the G in lieu of him making his own decisions.

11. She and daughter also help. They have an intuition about what he wants and he communicates to them what his decisions are. She and her daughter explain everything that is going to happen with pictures and the iPad, so that he can participate in the decision. Son makes his own day to day decisions

*Negative: Responses:*

1. Judge had said to [daughter], do you want G or do you not – I forget what the question was but she said, sure, yes, I'll have G, but I don't think [daughter] really understood what was happening in the court system at that particular time
2. He did have a lawyer. They only met right before. My lawyer shared all that information with this other attorney and they met privately before coming in, so I wasn't there. I couldn't answer questions for him or deter questions or anything like that. Was not explained in court that it could be removed but learned about it at a SDM conference
3. The reason she did not go to courts was a provider was trying to give some undue influence and came to oppose the G and I didn't want to expose her to that mess
4. Decisions were made as a family. The decisions were made together so [Interviewee 1] didn't understand that he wasn't exercising rights.
5. Daughter doesn't have any rights since she received full G at 18. But her family helps her exercise her rights. G means daughter doesn't exist in the eyes of the law. She is viewed by people as not a full person. Her parents don't feel that way but they think other people think that way. Mother wishes they didn't have G
6. The assigned attorney only spent 10 minutes talking to her. Her daughter is non-verbal and the two did not really communicate.
7. Reversing G was denied. They wrote letters to court, but court denied it. The letters stated that [Person] lives at home with her family including 5 siblings. [Person] was declared to remain incompetent, if able to get out of the G then she would get medical POA for healthcare decisions
8. There was no reason for him to have a guardian; he always had strong opinions and there was no need to take that away from him
9. She has done research and has a friend who helps out with his rights and his supports in the community. Her friend talked to her about all of her son's rights that have been violated. However, getting those rights was different. She feels like it has been impossible to gain his rights, especially in battling for his services and getting him home from Colorado. He has not had speech therapy for years and finally just got therapy. He was non-verbal and could not express himself so many of his rights were violated.
10. No one really helped her navigate, had to do research. She and his father help him understand his rights
11. G is the next closest thing to the death sentence b/c you lose all your rights, like being in prison.

*Neutral Responses:*

1. Only spoken about son's rights around medical POA, the CIL when he was younger explained he had fundamental rights, could vote, etc. Those around him help him understand his rights: his family, he works as a legislative advocate at a disability org
2. Daughter didn't go to court, would've been counterproductive and detrimental to her. If she was able to relinquish guardianship that's what we'd do.
3. Mother and grandmother have joint G where either can make decisions. Chose G for purely legal purposes. He was almost 18, he was doing things that could legally get him in trouble.
4. Brother is under full guardianship (mother). His caretaker, his mother help him understand/exercise his rights
5. She redid her will and G was a byproduct of that conversation with her attorney. Her son has IQ of 40 and wears diapers. She prepares all meals for him and cuts up his food so he can eat. His has significant limitations.
6. G = a legal determination made that that a PWD has limited decision-making capacity and needs assistance. The natural byproduct is that the individual has many rights removed and those rights are placed in hands of guardians
7. Somewhere along the way we were given information that when he turned 18 and then 21 that he's an adult and he makes his own decisions. When we've gone to different trainings about planning for the future, for like, estate planning and things like that, we were always told that we needed to get G and I was really concerned about that because my understanding is, is that to get G you have to have the person declared incompetent and I am not comfortable with that. So, we – I have not pursued G because to have someone declared incompetent is a huge matter.
8. Declaring someone to be incompetent takes away their personhood and in a sense makes them a piece of property and I want my son to have as many choices to – opportunities to pursue the things he's interested in, that opportunity to let me know what he's interested in and what he wants to do. I feel my role is to support him in doing the things that he's interested in and he wants to do
9. Father who has not always been in the picture had requested partial guardianship along the way--mother thinks it was more about visitation.
10. I don't know that an attorney would feel comfortable when they meet [M] and spend a short amount of time with him
11. From medical stand point he has to give permission for her to receive information; she (mom, POA) and sister (involved in daily care) help explain things to him. G would mean she would take over son's rights and have ultimate decision making power financially and medically. Son can speak for himself/has cognitive understanding, no need for guardian

RQ 2. Is supported decision-making a viable alternative to guardianship? If so, does it lead to better outcomes or are there some negative unintended consequences to using this alternative?

*Positive Responses/Outcomes:*

1. He can make his own decisions, he likes it; was able to go on vacation without family to CA
2. His mom, his dad or his sister helps him. If there is a disagreement, it's his decision. Supporters talk about pros and cons but he makes the final decision  
For SDM agreement he also has a healthcare proxy and POA. The purpose is if a doctor felt he was incapable of making decisions then the POA would help him get medical help needed. He has OCD and acute anxiety. They have had incidents with hospitalizations so the POA is for preventative purposes.
3. She thinks SDM should be the 1st process not the last process. It's a big thing. He was the 1st in MA to get SDM. SDM should be the way people like [Interviewee 1] to live their best life
4. Years ago, advocates for PWD tried to create/promote circles of support where individuals could have friends with strengths and abilities to help them make decisions in any field. SDM is that process with more identification of finding supporters in areas where you are weak. I encourage my family, my husband, and my children to do with her. And the staff too, involve her in the decision making. She's a very independent and likes her independence and if you don't involve her in the process, she's going to bark on you. And so it's going to be your best interest to go ahead and involve her and be much more respectful of her rights than if you don't
5. SDM is when PWD is making the decisions, but also having supporters there to advise them. The function of a supporter is to help when the PWD needs to talk things over or have things broken down to help them make a decision. The supporter doesn't make decision for them. Her daughter isn't a person who is fit for SDM due to her health, but SDM is a good approach for everyday life.
6. I know about SDM and we really apply that in our daily lives. I don't make any decisions for my son without him – without talking to him about it.
7. One of the biggest decisions he makes every day is to get up and go to school. He knows what time he has to get to school and he gets there on time.
8. I believe in SDM. Anybody with a disability has the right to make their own decisions and if they have the right circle of supports around them to guide and help them make the decisions, I think most everybody can and has the right to make their own decisions
9. Daughter makes most decisions- what to eat, wear, but guardian is still her mom, helps guide her. Daughter has psych and they make medication decisions.
10. SDM is a framework where a supporter can be trained and assisted to assist person in expressing their wants and needs or figure out best interest and assisting making those needs known. It is a substitute to G and contemplating termination of legal rights. She thinks she is doing something similar of SDM without the logistical framework
11. She engages in SDM with brother, reacting to his needs; supports him in his decisions by providing him with opportunities and experiences

12. Only time she “disagrees” with him is when safety may be involved because he is unable to assess risk at times, i.e. walking through a parking lot and not moving out of the way of a car.
13. SDM is perfect because it emphasizes a sense of community. I think overall that’s what we need to do if we really believe in community living, all of us should be able to rely on friends and connections. That’s actually very reassuring for when my husband and I die. Knowing that [Son] is the ultimate decision maker but helping him pull together all the information so it’s informed is exactly what we want
14. We have a micro-board over the house that [Son] is part of and we get together regularly. The residents and about seven people and per the rules of the house is that the guys can never be overruled. For example [Son] really wanted a screened in porch on the house and two of the other parents weren’t big on that but he kept beating that drum for two years and finally we raised the money for the screened in porch
15. Medical POA is important because then the doctors are forced to deal with us. When [Son] is in the hospital and he is really sick. We are treated as a team and we are not ignored and there are so many people who try to ignore us and it’s really annoying. I think that’s a major issue for us and the whole SDM is, are the doctors going to listen to [Son]?
16. He’s making decisions with assistance from me and caregivers who are with him which is primarily his family and some close family friends
17. With SDM the person could still keep their rights and then if there’s a small group of people, hopefully, they would hold each other accountable and there’s some level of safety in that
18. SDM is good. They don’t want to take away his ability to make his own decisions. Get all the info a person would need to make a decision and then help him look at the consequences and give advice and then he gets the final decision. No financial gain/interest in the decisions/no conflict of interest
19. Thinks SDM is like self-determination, something she wants for son, hopes they are doing this informally. Son has made medical decisions. Generally discusses his decisions/choices/options first and gather info if there is time/need but final decision is his.
20. She doesn’t think G is ever needed. She thinks everyone can make some decisions
21. I am going to in the near future the process of relinquishing daughter’s G.
22. Revoking guardianship and formal SDM would mean that [daughter] has her rights back as an individual
23. Would love SDM for son if proper supports and supporters were in place,

*Negative Responses/Outcomes:*

1. I can’t of any major life decision that he has to make. He has medication he has to take every day that’s usually prompted by me – if you want to call it a decision, to take the medication

2. With non-traditional communication, experiential decision making is imperative. SDM isn't good for a person who has ZERO verbal communication
3. Personally, I don't even think we should have a RP. I kind of go to the extreme here. I think SDM only works if in fact you are open, honest and you believe in community. But, we also work with a lot of people who are really poor. I mean, their whole family is poor and the SSI is part of the mix that helps the entire family. It's not intended that way but it's the reality and people are not open

*Neutral Responses/Outcomes:*

1. "It means a person who is not competent will have a decision made by a family member or loved one with the competency to make that choice."
2. Knew about G through work, but lawyer also explained it
3. For SDM agreement he also has a healthcare proxy and POA. The purpose is if a doctor felt he was incapable of making decisions then the POA would help him get medical help needed. He has OCD and acute anxiety. They have had incidents with hospitalizations so the POA is for preventative purposes.
4. When daughter expresses wants and needs. Mother reads daughter better than father. Mother and father on same page for decisions but mother and daughter get final decision.

RQ 3. Are people with disabilities who may need decision-making assistance and their families being provided with sufficient information about the guardianship process and possible alternatives to make informed and appropriate decisions?

*Positive Responses:*

1. Agencies and attorney advocated for G said state could seek G if something happened to mother. School never gave them info on decision making supports or alternatives to G despite IDEA regulations, went through Temple program on how to help him make choices
2. Case management through waiver discussed decision making with him,
3. Have POA, no RP, learned about ABLE act
4. I do financial planning for special needs, so I'm fully aware about G the pros and cons, and SDM
5. Through Foundation created a financial education booklet/pilot program to explain managing money, decisions and rights
6. Mom is POA and RP. Hasn't looked into alternatives because she's on the right track.

*Negative Responses:*

1. When I was looking for various options, and this is past 15 years ago, limited G was never mentioned. Least restrictive actions weren't mentioned. G was foregone conclusion.

Parents were not given any other options. The school told her family that if the parents did not assume G and if an emergency happened to her then daughter would not be able to receive medical treatment. Parents were terrified for daughter's safety and signed the G papers. No one discussed financial G at the time. In the old days, that everyone automatically get guardianship. Schools are not educated. She thinks schools need to be education on options for people with disabilities. If schools are not aware, then parents are not informed of correct options.

2. If we don't address some of the issues that come about because of POA and guardianship/conservatorship, especially with the population growing older, the amount of abuse will be significant.
3. From her understanding, there's very little that can be done if POA is serving their own self-interests,
4. There's oversight with their G--a state caseworker checks in
5. I have always used SDM but had never heard the term until probably last year;
6. Wishes there was a system where you were presented with more options--SDM, POA, RP, etc.
7. We kind of feel almost moralistic about, rarely is there a reason to do G
8. Someone in our office has a child who is turning 18 this week and at their last IP meeting, this transition team said, "Wow! Kyle is about to turn 18, you'll want to become his representative payee." Without any discussion of what it meant. Because she worked here she was kind of like, "No, I don't. There is no reason to do it." But I think that's what is missing, it's just information about what it means.
9. So much of your civil rights are completely ripped away from you under G I don't honestly think parents know that. I think parents are trying to control something and there is so much of life you cannot control when you have a kid with a disability. There is so much you can't control and that you really don't know how wide-sweeping G is.
10. SDM for some people would be good. For [Daughter] it would not. She wouldn't be able to understand the concept of the document. Explaining a document to her won't do any good because she still wouldn't understand it.

*Neutral Responses:*

1. Brother has to give full consent (like for dental work) then mother completes it with a signature.
2. I do financial planning for special needs, so I'm fully aware about G the pros and cons, and SDM
3. Family learned about POA and other alternatives, came to G under duress; full G was only viable option for him
4. Learned about SDM at conferences in passing, not in depth understanding.
5. She is POA and was RP but now his group home does it
6. G means that a court made a decision that the individual lacks capacity to make decisions in certain areas. Has removed those rights and delegated them to someone else.

7. She is RP for sister, not POA
8. In FL a guardian advocate is very similar to G but person's not determined incapacitated
9. They are also POA and RP.

RQ 4. How does guardianship impact people with disabilities and their families? Does guardianship help improve outcomes of health, safety, and protection for people?

*Positive Impact Responses:*

1. Positive of G is there's court oversight, some protection from exploitation.
2. There's some comfort in the requirement that informed consent has to come through me. I can talk to her about the situation or the decision that needs to be made and see how she feels if she does have a feeling one way or another.
3. Staff also helps with decisions generally speaking
4. Positive outcomes: PWD that aren't able to do things on their own behalf can definitely benefit from support.
5. Positively affects because it allows a guardian to be there to support them, as long as guardian is supportive
6. I've never seen others treat him any differently.
7. I can sleep profounder, I guess. Knowing that if he ever does something illegal which he's starting to get away from that stuff but with internet and technology, the way it is
8. Acts as a translator/liaison between brother and providers, ensures he has decisions/makes choices, leaves the house;
9. Pros: can ensure person is cared for, not forgotten; it's a big responsibility; family thinks it's great b/c they don't have to worry about it now
10. Without G people could take advantage. But not for daughter because she's not in the community alone.
11. Next weekend she had a choice whether to participate in special Olympic swimming or the autism balling group (which happen at same time), and she chose swimming. I asked her if she wants to go see a certain production, a play and then I asked her who she wants to invite, whether she wants to go with me or whether she wants to invite certain friends to go. I don't always agree with her decisions but, they might not be what I will choose but they are what she chooses, so that's what we do. Guardianship isn't for everyone, but daughter's welfare would be at risk without it.

*Negative Impact Responses:*

1. G cannot protect a person 100%. You do the best you can and there is a risk. You want people as independent as possible. If you get a controlling guardian who is not person-centered, it can be demeaning and can make the person frustrated. If you have someone who supports and guides, they can feel empowered.
2. Negative: the extent of authority that people have over others and the potential for exploitation/abuse.

3. The public is still paternalistic towards people under G
4. G is almost beating people down and not letting them make decisions. People under G are not as happy because they are not living life they want to live but rather the life someone else wants them to live.
5. Lives are not as full or healthy under G
6. Negative outcomes: People that are unscrupulous might use that position on their own behalf and not for the person they are helping.
7. Mother-in-law's a prior guardian took advantage of her financially, and I think to some extent physically. The system needs some checks and balances that currently does not have
8. Much more limited freedom because someone else is making decisions, can diminish self-confidence, there is stigma.
9. I never want to make decisions for him solely by myself not necessarily because maybe I'll make the wrong decision but if he doesn't have buy-in, then it's going to be a lot harder for me to deal with that decision and getting it to be accepted and make it happen.
10. Most people don't give individuals with disabilities an opportunity to make choices. Those people are left vulnerable if they cannot make own decisions. Many under G do not know they are in a G
11. Cons: can be overruled in decisions about marriage, children, residence
12. I think when you have G they just run right over the PWD. They don't even listen to him. I have seen with someone that I know whose parents they were just told by their school they had to become a guardian and they did it. Their adult child, he has strong opinions and they just run over it.
13. I don't like the G because it strips someone of their rights. I think there should be a better alternative. I think there's potential for the PWD not to be heard and for their choices in life to be limited and can have a negative impact on their health depending on caregiver
14. She thought that G can be devastating because they have already lost so many of their rights and they do not have the right to make any choices. Not every guardian talks about that with people, but it's important to understand that G means giving a lot up; and some people are taken advantage of
15. G is not a decision-making support, it's taking over their whole life; their dignity is at risk, individual will be left out, treated as invisible.

*Neutral Responses:*

1. Can be good or can be bad, it all depends on the guardian.
2. She talks over everything with daughter, and makes her decisions with her. She is not sure how much daughter understands
3. He knows if there's something he wants to do he can come and talk to me and we can talk it through, is it realistic? Sometimes it is, sometimes it isn't.
4. G going to be on a case by case basis. If there were legal concerns like I had with my son and if there's not any smaller way to do it, I would say go after G. If it's just

because you don't think that their child could make good medical decisions on their own, then maybe just get a medical POA if you think they would go out and spend all of their money on things that they shouldn't spend it on, maybe then you get the financial piece. So, I guess it all depends on the individual and where they're at and the concerns they have. If their concerns are not strong, then – and the individual is not doing anything to hurt themselves, then why do something like G? Do something more like SDM and start long before they're 18. SDM should start when they're two years old

5. G does offer some protection when guardian isn't around but even when guardian isn't around, the person can still be endangered/exploited. So I think individuals with wherewithal and support, should make decisions for themselves.
6. May limit someone's rights, doesn't want son to lose rights, protects individual from being taken advantage of, may have positives in terms of safety but concerned about how much this limits individual; they should be treated as people first
7. I don't think G makes daughter feel less worthy as a person but without G she's totally in control of her own life
8. Depends on the person, shouldn't be automatic
9. Pros and cons are on case by case basis

RQ 5. How does the current use of guardianship align or conflict with other US national disability policy goals and initiatives, including the goals of the American with Disabilities Act (ADA) and its community integration mandate and principles of due process under the law?

*Positive Responses to Community Integration Principles:*

1. He can decide if he wants to move out. He's already moved out and got his own apartment. He also went on vacation to CA, with managers. He can vote, get married, and do anything he wants
2. Even during G he always choose his friends and activities. Our job as guardian was to keep him safe and help him grow to where he can make decisions on his own. It's important to understand that because there isn't a definitive line for him between G and SDM. There was no time he would ever feel like he had less rights because they always gave him rights.
3. She picks out her clothing, she's good at picking up clothing, shoes, groceries, doing activities that she'd like to do. Telling you what she'd like to do. She's verbal. I don't always agree with her decisions and I'm sure she doesn't agree with the decisions I'm making. The issue isn't whether you agree with them or not, it's more, is there going to be harm coming from the decision that she makes. Supports her sister making her own decisions
4. She bases her decisions informed by her other kids needs/wants. She tries to integrate daughter into a community. She thinks [Person] can make decisions. Her doctor is good and agrees

5. Daughter has right to vote, purchase gun
6. He votes, goes to community college in integrated classes. It's their right to go to college, to be integrated in the community and have the job that they want and go to school, it's their right to be successful. Nobody should have to settle
7. We voted in November, and she that was very powerful for her
8. For some, guardianship may be the only way to ensure a person's civil rights are upheld
9. Son owns a home, lives with friends
10. A guardian who's a strong advocate is great and can help integrate the PWD into community
11. I hope that the study will end up showing that there are cases where G is truly necessary and it's beneficial.

*Negative Responses to Community Integration Principles:*

1. A lot of folks don't understand the difference between civil rights and legal rights or G
2. Most people do not think she has the capability to make decision.
3. No one should have G Everyone deserves civil rights no matter what level of intelligence. People cannot sign mortgages or get a home under guardianship. They cannot go to the doctors or get surgery without someone else's approval. They cannot live their own life because of guardianship. Guardianship is a civil rights issue
4. She doesn't think one can be fully integrated with guardianship and cannot live a full life with guardianship. She thinks the government should make it easier for people to get out of guardianship
5. It inhibits integration because they always have that person telling them they can't do something or trying to keep them safe
6. They wouldn't allow me to put his name on a debit card. And that was probably one of my biggest problems for the whole situation. I wish I had known beforehand if there was something we could've done from that perspective
7. Somebody could think people in G don't have the ability to think for themselves and they could look down upon them
8. Everybody's civil rights are taken away under G. it wraps back around- the kids maybe wouldn't even know what civil rights are. My daughter, she would be mad if she really understood
9. PWD no longer has legal capacity and the legal capacity is transferred to the guardian
10. Sometimes guardianship is used to prevent people to participate or have community living
11. A person has a right to not be under G
12. A doctor has angered them because he talks to parents rather than son, he expects them to be full POA.

13. We wanted to have POA with him to monitor his financial account since his attendants would have a pass code; we are not on all his accounts or mortgage just the one the attendants have access to and they have ripped him off 3 times.
14. G you kind of take someone's civil rights. You can't enter into a contract. Yes, you can vote but so much of our control is like where do you live? You have no choices to where you live anymore because you can't sign a contract. What do you want to buy? You can't have a credit card. You can't have your own bank account. I think so much of your civil rights are completely ripped away from you under G
15. If people knew he had a guardian in a hospital or someplace I do think it would change how he was treated; I think it would be negative; when doctors come in they start talking to me and they'll ask me questions about him. And I then ask my son the same question, so then they start talking to him. If people knew I was his guardian that they would just talk automatically talk to me
16. If people in the community would know, all rights this person has/doesn't under G then automatically in their head there's this negative connotation, it dramatically lowers their expectations of that individual
17. He was unable to vote because he can't read, she thinks he's unique to many with TBI. Many in the community just thinks he doesn't understand because he's nonverbal but those who take the time, like DR can learn his language
18. I think guardianship can be abused and that it has to be monitored because their civil rights can be taken away. She worries about people that have brain injury and disabilities and have no right or say
19. Attributes his isolation to injury, believes it would be worse if she's wasn't his guardian/advocate
19. G takes away their rights, freedom of choice, invasion of civil/human rights, shouldn't be treated this way just because they have a disability
20. Problems arise if guardian doesn't act in individual's best interest
21. People perceive guardianship to be a threat to an individual's civil rights. It's only a matter of protection as far as she is concerned.

*Neutral Responses to Community Integration Principles:*

1. It can make a person feel small when someone is always speaking for them, then again G can make you bigger
2. Son was plaintiff in case about free museum access for attendants
3. In some cases it could be a way of exerting control but certainly it's not in our case, I don't think her rights are any way diminished.
4. It's in the best interest of the individual and it's not a means of interest of the individual and it's not a means of stripping rights or controlling. I feel like a lot of people are interpreting G as that.

**Professional Experts**

Researchers interviewed twelve professional experts for this study from Illinois (2), Minnesota (1), North Carolina (1), Washington (1), Massachusetts (1), California (2), Georgia (1), New York (2), and Virginia (1). Professional participants include attorneys, law professors, professional guardians, a long-term care professional, and a judge. In addition, the sample includes a professional guardian, and a long-term care professional. The professional participants have an array of previous experiences including drafting guardianship policies and serving on guardianship-based organizations. One participant researches and writes articles about guardianship.

RQ 1. Are people with disabilities receiving fair treatment within the legal system with respect to guardianship?

*Positive Responses:*

1. Generally G try to protect PWD rights and fight for them
2. Legal system provides clients with due process and adequate representation; legal system appropriately assesses client's needs but system may be working poorly for some (theory v practice)
3. Trend toward limited guardianships is good
4. In CA they have limited conservatorships which allow PWD to have rights but support/guardianship in certain domains. In CA conservator and the conservatee get a copy of something called notice of conservatees rights, letting them know they have the rights to have visitors, to get their mail, to vote, to challenge the conservator, to replace the conservatorship, to change things.
5. State laws have been reformed well- to give due process and least intervention necessary but what happens in practice who knows; most state only take away essential rights to wellbeing and safety.

*Negative Responses:*

1. People with disabilities are treated not as individuals, sometimes as stereotypes rather than as individuals with distinct strengths and weaknesses. Older adults face the same stereotypes. However, older adults are more often seen as individuals because people are used to seeing older adults as individuals while people are generally not used to interacting with people with disabilities.
2. Receipt of due process varies. Generally, PWD are not adequately represented in court. If they have counsel, involved or appointed, the counsel usually doesn't represent desires of the PWD, ability to make decisions is not adequately assessed. Is viewed by trial judges and lawyers as a global ability that PWD has or doesn't rather than individualized approach
3. People are generally not adequately represented in court. Council may not adequately represent person's interests, explore alternatives. Council should be educating client about what G means and alternatives, they should build trust. Need to improve assessing of capacity to make decisions- can't correlate bad decisions with incapacity.

4. G has serious constitutional issues: procedural due process, substantive due process and doctrine of least restrictive/drastring means, and equal protection. If we do not reject our current framework/approach (English common law of *parens patriae*), we should at least revert to a presumption of competence and rules of burden of proof and quantity of evidence necessary to overcome the presumption.
5. A person is stigmatized, and the community is less likely to accord the person dignity, where the person has been adjudicated and there is common knowledge of the adjudication. The law should promote dignity; it does not.
6. There's probably a lot of pressure from schools to encourage parents to seek out guardianship whether it's appropriate or not.
7. Courtroom environment is not always best for explaining one's rights and getting PWD to understand their rights and make a decision in their best interest
8. G is death of civil rights; G severely limits one's ability to sign contracts, marry, etc. Due process is limited under G. court and lawyers are not experienced, typically don't understand needs of PWD and typically have low expectations of PWD
9. G takes away PWD rights, independence, and voice
10. Conservatorship is inherently against due process, taking away somebody's rights and imposing the will of somebody else but it is getting better; movement to alternatives like SDM and self-determination, but, conservatorship needs to remain an option. In CA they have limited conservatorships which allow PWD to have rights but support/guardianship in certain domains
11. PWD are not adequately represented in court. In Georgia, a person's court appointed attorney does not need to be an attorney who understands aging issues or disability issues. The evaluations done aren't done by experts in the field of aging or disabilities.
12. PWDs decision making abilities are not adequately assessed, there is no standardized test and the tests they do use assess other things like memory.
13. Majority of people are not represented, people entitled to representation get somewhere between okay and crap, people generally don't have lawyers unless there's an extreme violation of liberty or lots of money
14. People are not adequately assessed, few judges take it seriously, who view PWD as human beings
15. Everybody should be taught about their rights/human rights and if PWD need a different/additional educational opportunities it should be taught as part of special education and then for older people who are out of the educational system I think there has to be robust community education and that can be done through a variety of places, safe based institutions. Know your rights thing, senior centers
16. G completely removes the right of legal capacity. It's a human right and it shouldn't be removed. I think it's a gross violation of due process which is premised only through civil alternative.
17. Often people's ability to make decisions is not adequately assessed;
18. Courts are not reading the law. They always call for limited G in the law, but the number of G in court is not following the law.

19. G creates a category of people who are not considered as legal people. Judges may want to do the right thing, but they don't know enough about disabilities. Judges make determinations about individual's incompetency without ever speaking with person. That's not due process. That's a complete denial of process. Moreover even if an individual is present, the burden is on kind of the person to show that they would be able to act on their own interest the way the laws were established. They're based on kind of a presumption of incompetency
20. G is a violation of civil rights. It's confining as institutionalization. But the label and the requirements of giving up decision making authority is stigmatizing.
21. PWD in G proceedings are not equal under the law. They are not considered people under the law.
22. Civil rights v protection should be least restrictive alternative.
23. Sometimes people receive due process and sometimes not, even if there are good due process requirements they are not always followed

*Neutral Responses:*

1. Society needs to pay special attention to ways that people learn information about their rights. The dissemination of information should be individualized to accommodate various ways that people with disabilities can understand information. If someone has an intellectual disability then another person needs to break down the concept of those rights to the person with the disability as best as possible
2. PWD should be assisted in learning about their rights as youth
3. Need more data of what is actually happening in courts

RQ 2. Is supported decision-making a viable alternative to guardianship? If so, does it lead to better outcomes or are there some negative unintended consequences to using this alternative?

*Positive Responses/Outcomes:*

1. SDM is preferable, maximizes agency and decision making.
2. Community groups and government should establish networks to make guardianship unnecessary and provide more agency to PWD
3. People can make decisions that match their goals/values
4. POA is helpful SDM in terms of finances but not in other arenas- people can still be exploited
5. If G is needed, start with SDM and if SDM proves insufficient proceed toward limited guardianship and finally full guardianship; there should be gradations of support per domain EG may need limited support for general healthcare but full support for complex medical decisions
6. SDM is a more natural solution; progressive, beneficial, works well. PWD feels their value increases and seeks out others for help.

7. Alternatives to G should be used whenever possible. Allows PWI/DD to use circle of support, they help them make personal, financial, legal decisions. SDM is essentially becoming an adult, everybody lives a life of SDM, and you rely on people that know you to help you do what you want to do whether you're an infant or toddler or teenager
8. it's empowering that a person can change their mind in regard to SDM, can revoke the person supporting them
9. SDM is the gold standard for decision-making and other counties have abolished G. SDM makes sense, it's how we live our lives. PWD and older adults shouldn't be viewed any differently. Everybody has the right to a self-determined life. Research says that people who are more in control of their lives have happier and healthier lives. People with SDM are more able to recognize and respond to abuse.
10. SDM is a high aspiration we're working towards. Everyone makes bad decisions, whether or not they have cognitive disability, so we have to let someone make a "wrong" decision, but the outcome weighed with that risk allows greater self-esteem, greater autonomy, and self-control to guide or correct the factors in their life.
11. Getting rid of G has to go along with SDM. SDM can help remove the stigma that's associated with G. Sometimes people need more assistance and other times they need less. It's no difference for PWD. Every human being, with or without disability, has the right to make decision for themselves and more importantly the right to find who can help them make those decisions when needed. It's not about protecting someone. It's about teaching them how to best protect themselves.

*Negative Responses/Outcomes:*

1. SDM offers opportunity to abuse/exploit an individual as there is no neutral entity checking the SDM. SDM is unclear as to ramifications and beyond criminal laws this is a huge concern. Strategies to prevent negative outcomes would be for more people involved - not just 2 family members or 2 community members. There should be vetting of people and assurance that there is no conflict of interest between the supports, the individual, by an independent evaluator.
2. Generally SDM is viable alternative but concern that not enough protections in finances; important use in terms of medical decision making.
3. SDM is not a good form of G there's high risk - people may not be able to prevent PWD from harm; negatives of SDM can be addressed through assigning a team leader, lots of training, and team operates a clear, flexible plan
4. POA and RP are not good alternatives
5. Everybody can be taken advantage of/abused (SDM doesn't prevent abuse)

*Neutral Responses/Outcomes:*

1. Still learning about SDM, the ability to rescind SDM is important,
2. Training is essential so that support doesn't push individual into anything
3. Any SDM has to have some safeguard still. CRPD requires that there'll be safeguards and that PWD be protected from abuse and exploitation. The more

people involved the less likely they are to be abused but they're certainly is the potential for abuse in this as any system.

4. SDM is Positive overall, some dangers. Could be difficult for parents to adjust from making to facilitating the decisions; Problems with decisions about social/sexual contact.

RQ 3. Are people with disabilities who may need decision-making assistance and their families being provided with sufficient information about the guardianship process and possible alternatives to make informed and appropriate decisions?

*Positive Responses:*

1. Schools and social service providers are important sources of information for youth; hospitals and health care providers could provide information to those with TBI, mental health needs.
2. People are generally aware that G comes in limited or full.
3. Self-advocacy movement in this country has been very active. One of the most effective ways of PWD depending on their disabilities and their organization affiliations learned sometimes best with their peers. So self-advocacy is important

*Negative Responses:*

1. Process is not adequately explained, there is not enough public education, some individuals receive bad/wrong information that push them into G
2. Need to start education on self-determination in public schools
3. Not sure how much all parties really know what they need to do, what options are out there
4. Information about rights and guardianship can be misleading, there's a lot of focus on rights deprived under G when some of those rights guardians are designed to protect, some are even given document listing rights to be deprived which is scary
5. Information provided is inadequate as people don't know about it and there is a strong resistance to SDM.
6. PWD and older adults are given little to no information about their options. When options are given, it's in a legal setting but is uncomfortable for a person. A lawyer may not know how to present this information.
7. Not enough information is given to people about what options they have, options that are alternatives to G.
8. Could do a better job of explaining alternatives but this falls on the person's attorney.

*Neutral Responses:*

1. Not sure about information dissemination.
2. Personally does a good job of providing information to client but this may not be true everywhere and information can be given but not necessarily processed/discussed by individual and family.
3. Varies from state to state, case by case; probably not adequate yet.

RQ 4. How does guardianship impact people with disabilities and their families? Does guardianship help improve outcomes of health, safety, and protection for people?

*Positive Impact Responses:*

1. Positive of G is that it's harder to prey on people.
2. G improves the mental health of people around the PWD but not for the PWD
3. G can rectify/protect against financial abuse. Even a full guardian cannot force certain meds etc.
4. G is appropriate when client puts themselves at risk or is being exploited/abused; has a positive impact on clients' and families' health and safety.
5. G as partnered decision making is good, acting upon someone's best interests can be empowering.
6. Sometimes doctors won't help unless there is a guardian. Not many situations where guardian is needed but helps them make decisions.
7. G is called for with somebody in vegetative state and I think maybe five percent of people who really have lost any ability to or never had any ability whatsoever to communicate.
8. G is useful where the person's decision making powers are affected by advanced stages of dementia and where the person's ability to care for themselves and to provide for their own safety, SDM is not going to accomplish the same safety as a G But G should be limited and the individual is engaged and involved in decision making to the greatest extent.
9. G can assist through difficult times, make sure needs are met, and has court authority, cuts off from exploiters, abusers, provided appropriate housing, adequate healthcare, public benefits obtained.
10. Third parties (doctor, healthcare provider, assisted living facility, bank, etc.) who need to deal with personal circumstances may very well welcome the individual knowing there is a competent guardian helping the individual.
11. Lots of situations where it's warranted but needs to truly be with LRA for both types, needs to be uniquely tailored; need better documentation of person's needs
12. Medical decision-making-generally positive or neutral outcomes

*Negative Impact Responses:*

1. In some families G creates hostility if they don't want the G In some cases, the family comes together in positive way for joint decision making but it varies by family
2. Full G relied on the notion that people are incompetent;
3. G can also be very negative, example of 3 cases where person lost will to live after forced into assistive living
4. Process of G humiliates PWD, the person loses their personhood/rights, being in court is stressful
5. Consider the matter of autonomy and dignity in death as analogues for G

6. People under G have lost their voice. G strips the natural family unit relationships and family members may feel as if G is an additional burden.
7. G always has potential for abuse.
8. Disadvantages: people's decision-making rights are taken away from them and it doesn't make sense to take rights away to help them. We should tell them what we can do and help them rather than take them away. It deprives someone of their personhood, dehumanizing.
9. Families can use G as a weapon against each other rather than thinking of the best interest, think of their own best interest
10. Disadvantages: too many personal rights are removed and delegated to someone else, removes personhood, guardian does not appreciate the limit of their authority. Process of being adjudicated by the court, saying they are incapacitated is demeaning and embarrassing, mental health issues can become public record, the legal fact and realization they cannot make any decisions they want can negatively impact their self-esteem and self-respect.
11. Limited guardianship hasn't worked: 1) when judges have the option of limited guardianship, the research has shown that there's few judges actually use it. Because they don't quite understand the difference between primary and limited and they don't totally understand how PWD live their lives; 2) even with limited guardianship, we're still creating this category of people who are dignified as incompetent and without really giving them anything in return. It's not teaching that person how to eventually make decisions and how to support a person and becoming independent to the best of their ability. Why do we want a system that will continue to perpetuate a status of some people who will always be the subject of someone else's decision making? I think that it's really abhorrent to our whole system of legal person. Guardianship is a long outdated mode of categorizing people that doesn't really offer either protection or support that is designed to.
12. When guardians are appointed for someone with an intellectual disability at the age of 18, they are denied the opportunity to learn how to make decisions of the critical years of their lives. It's in those teen years and early 20s when all individuals kind of branch out on their own and learn how to make decision.
13. Can't a good guardian do the same thing that they're doing without a court order of guardianship?
14. Guardianship limits person's ability to grow; limiting; parents want control over morality of sex; can have the tendency to make people more dependent

*Neutral Responses:*

1. G has provided positive outcomes at times, but positive outcomes are also possible without G
2. Need more exploration into ensuring no conflicts of interest in the decision-making process on the part of the SDM team

RQ 5. How does the current use of guardianship align or conflict with other US national disability policy goals and initiatives, including the goals of the American with Disabilities Act (ADA) and its community integration mandate and principles of due process under the law?

*Positive Responses to Community Integration Principles:*

1. G can be a positive tool to help someone integrate into community by providing one to be independent and have some advocate on their behalf.
2. G can improve a person's integration into community, the existence of a guardian indicates to community members that there's someone they can deal with
3. G enhances clients' integration with community because they provide support for the things that may prevent integration EG an inability to take care of financial needs; health issues; etc.
4. It is the guardian's responsibility to ensure all due process is afforded to the individual. Good guardian is going to ensure there is integration into the community.

*Negative Responses to Community Integration Principles:*

1. With wrong guardian, G is bad because the guardian may push for institutionalization
2. G takes away a lot of civil rights and civil liberties. Full guardianship assumes an individual lacks capacity to enjoy basic rights under Constitution and civil rights. Not enough due process given when an individual's rights are taken away; those rights can only be taken away when absolutely necessary.
3. G negates civil rights, person deprived from exercising their rights (EG vote, marriage, religion, travel)
4. G is highly correlated with social isolation from community, can strain personal relationships
5. G should be more creative- large emphasis on creative decision making. Guardians should really get to know and understand a client's goals and work to achieve them while balancing best interest and concerns about potential harm.
6. Guardian controls the individual so they may place restrictions to isolate the individual, may or may not act on the individual's best interest.
7. Denies person rights to get married, vote, decide on living arrangements; can be isolating because a service provider would look to the guardian not the person to answer questions.
8. I think it's a gross violation of the ADA and the overall mandate and it is certainly a gross violation of the human right to dignity. Those of us who believe in the Universal Declaration of Human Rights and the CRPD Article 12, vary as to whether there are ever situations where guardianship is called for.
9. PWD are often not respected. Recalls study in which doctors never look at PWD and directed all of the information only to the professionals in the room or the parents. To be consistent with protecting civil and human rights of PWD we have to get rid of G and start with the presumption that everyone is competent.

*Neutral Responses to Community Integration Principles:*

1. Emphasizing dignity and autonomy for PWD will go a long way in fixing problems with G and how people with disabilities are treated generally