



Survey on Supported Decision-making in Practice

FINAL REPORT

Submitted By:

The National Resource Center for Supported Decision-Making

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BACKGROUND

The pressing need to develop and implement evidence-based practices to support people in their communities is especially acute because the demand for quality community services for people with intellectual and developmental disabilities (I/DD) is growing. Of the 4.9 million people with I/DD in the U.S. (as of 2011), 72% lived with a family caregiver (Braddock & Rizzolo, 2013) all of whom are aging and will become unable to provide the individual with care and support in the future. People with I/DD are living longer than at any point in the past. These facts put people with I/DD at increased risk for being placed under guardianship by the state (Glen, 2015), potentially restricting their ability to be self-determined, which could lead to diminished quality of life outcomes and reduced community integration and participation (Blanck & Martinis, 2015; Shogren & Wehmyer, 2015).

Since 1995, the estimated number of adults under partial or total (plenary) guardianship in the U.S. has tripled from .5 to 1.5 million (Schmidt, 1995; Reynolds, 2002; Uekert & Van Duizend, 2011). More than 8 million people receiving Social Security or Social Security Income have a representative payee (guardian) to help manage their benefits (Mcibbon, Nadler, & Vogelmann, 2014).

Less restrictive alternatives to guardianship, like Supported Decision-Making (SDM), protect peoples' right to make basic choices about their lives in the community; such as where to live, where to work, what activities to engage in, by enhancing their self-determination: empowering them to be “causal agents...actors in their lives instead of being acted upon” (Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000, p. 440).

While there is no singular definition or model of SDM (Dinerstein, 2012), it generally occurs when people with disabilities use friends, family members, and professionals to help them understand the everyday situations and choices they face, so they may make their own decisions without the “need” for a substitute decision-maker such as a guardian (Blanck & Martinis, 2015; Quality Trust, 2013).

Because SDM is increasingly being advocated for and used in the field, there is a critical need for valid and reliable empirical evidence regarding (1) best practices in SDM,

including effective and challenging “support structures and methods; and (2) whether people who engage in SDM are more autonomous, experience better life satisfaction, and achieve meaningful community living and participation (Kohn, Blumenthal, & Campbell, 2013). To this end, the National Resource Center for Supported Decision-making (NRC-SDM) hosted an online survey to collect stories of SDM successes and challenges from individuals, family members, advocates, and providers across the country.

Survey Instrument

The survey was developed by consulting working with a network of experts and professionals in the area of supported decision-making. Once the survey was in its final form, an application was submitted to Syracuse University’s Institutional Review Board, who conducted an ethics review and provided approval for the project to move forward. (See Appendix I for Survey Instruments.)

Participant Recruitment

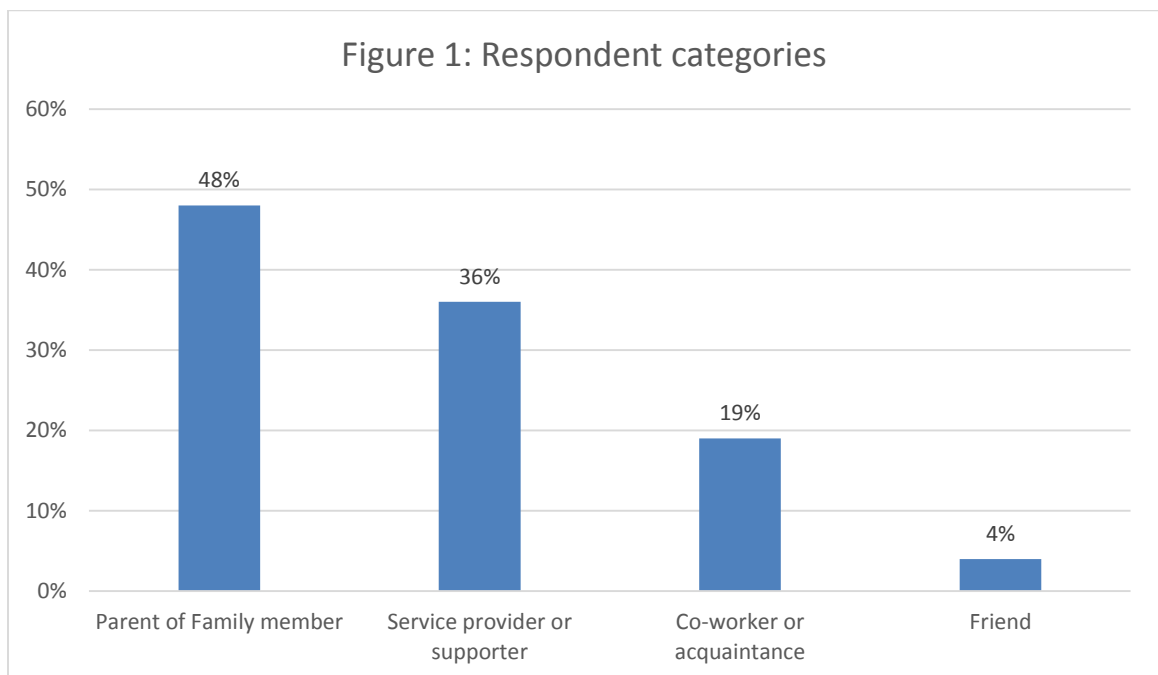
In order to identify a sample of 200 or more participants nationally, the project team recruited participants through the following multiple channels:

1. The Syracuse University Burton Blatt Institute Website
2. The Southeast ADA Center Website
3. The National Resource Center for Supported Decision-making Website
4. The Autistic Self Advocacy Network (ASAN)
5. Parent to Parent USA
6. Family Voices
7. ABA Commission on Law and Aging
8. Facebook Pages Project & Personal
9. Twitter Accounts

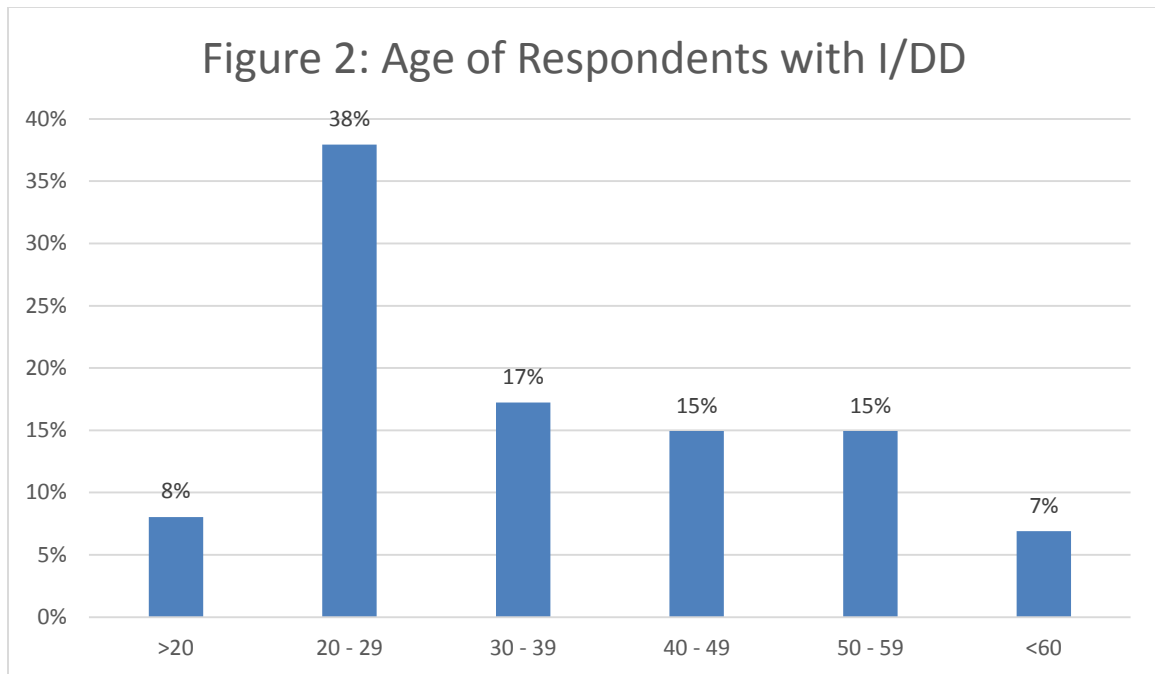
Description of Samples

The study includes a sample of 162 participants who represent a parent, friend, supporter, service provider, or someone else that knows or works with a person with I/DD. The online survey was started by 162 of these respondents, completed by 126 (78% of the sample), and partially completed by 36 (22%).

Of the 162, 48% (78) were parents or a member of the family; 36% (59) were service providers or supporters, 12% (19) were co-workers or acquaintances, and 4% (6) were friends. Thirty six (22%) had guardianship and among parent respondents, 24 had guardianship and 48 did not. See Figure 1 below.



The study includes a second sample of 127 participants with I/DD. The online survey was started by 127 of these respondents, completed by 90 (71% of the sample), and partially completed by 37 (29%). Of the 90 respondents with I/DD that completed the survey, 16% (14) were under guardianship and 84% (76) were not. Thirty five percent (29) were male and 65% (54) were female. They ranged in age from 19 to 67 with the greatest percentage falling in the 21 to 29 category (38%). See Figure 2 below.



Findings

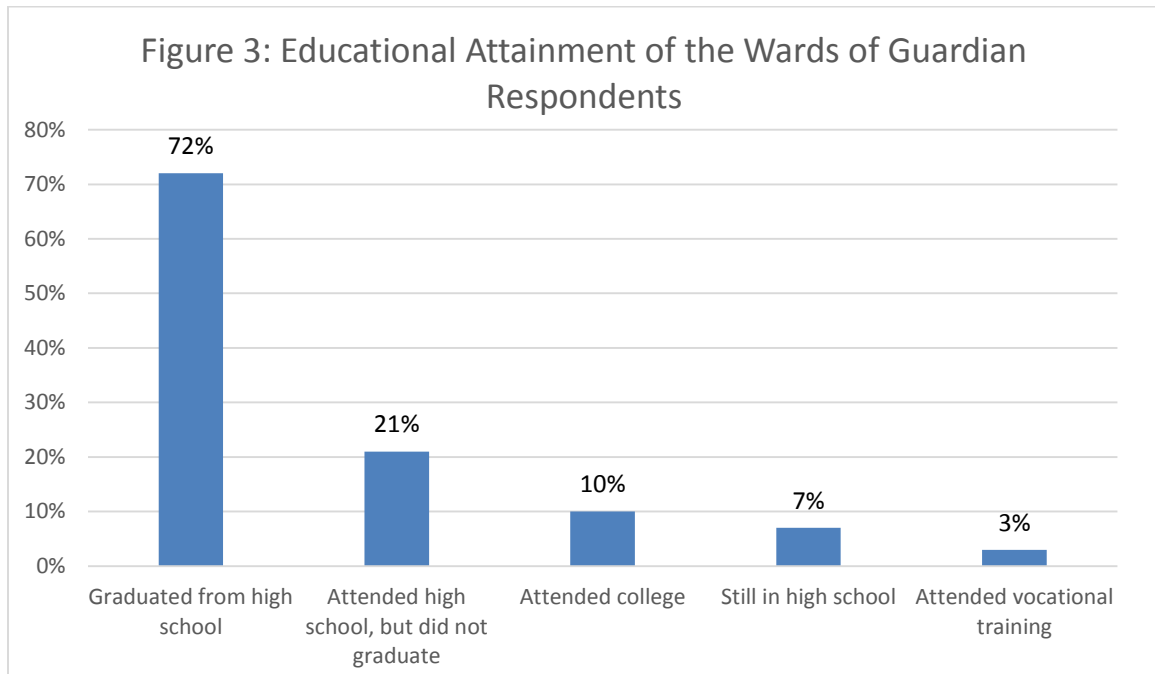
Survey Questions Directed to Guardians

A number of items on the survey were directed only to those respondents who identified themselves as guardians. These questions explored the level of education and employment status of the guardians' wards. Further questions explored satisfaction of both guardian and ward with guardianship and the nature of their decision-making. Of the 162 respondents, 22% (36) were guardians. Among the guardians, 25 respondents were parents or family members, 9 were service providers or supporters, and 2 were friends. The following findings refer only to the responses from those who identified themselves as guardians.

Employment Status and Educational Level of Wards with I/DD

Of the 36 guardians, 31 answered questions regarding their ward's employment status. Thirty two percent (7) reported that their ward is currently working and 77 % (24) reported that their ward was currently unemployed. Twenty nine guardians answered questions regarding the educational attainment of their wards. Seventy two percent (21) reported that their ward had graduated from high school; 21% (6) reported that their ward had attended high school, but did not graduate; and 7% (2) reported that their ward was still

in high school. In addition, 10% of the guardians (3) reported that their ward had attended college and 3% (1) reported that their ward had attended vocational training. See Figure 3 below.



Satisfaction with Guardianship

The majority of guardians reported that they and their wards were satisfied with the guardianship arrangement. In response to the question, “Did you want to be a guardian?” 90% (27) answered, “Yes,” while 10% (3) answered, “No.” And in response to the question, “Did your child/client want a guardian?” 89% (26) answered, “Yes,” while 11% (3) answered, “No.” Similarly, in response to the question, Does your child/client like having a guardian, 93% (26) answered “Yes,” while 7% (2) answered, “No.”

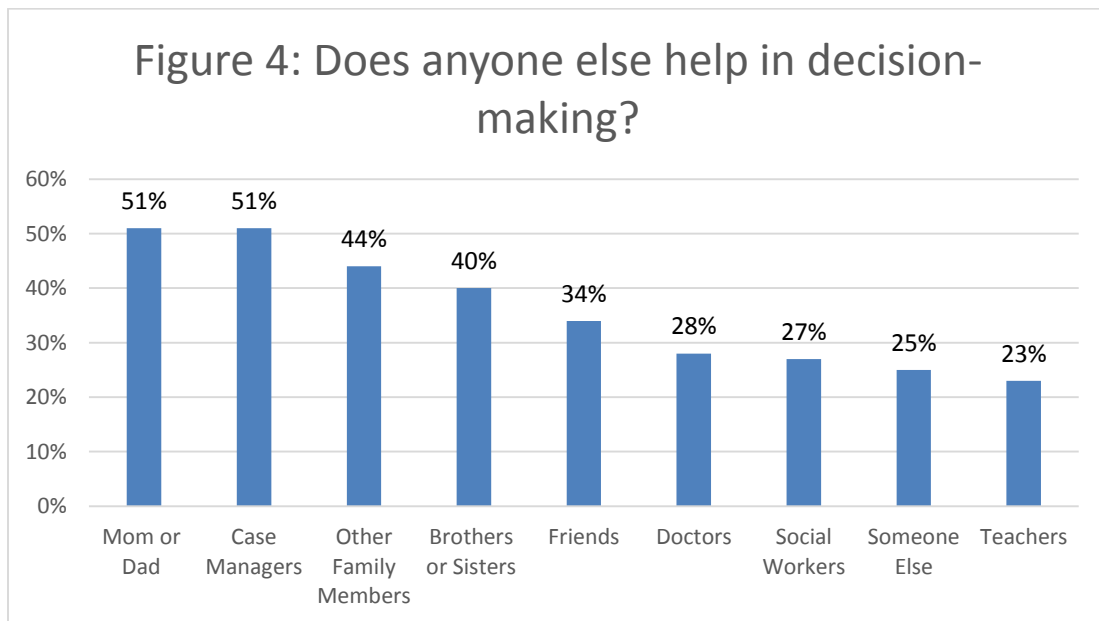
Decision-making under Guardianship

The majority of guardians reported that they do not make all of their ward’s decisions. In response to the question, “Do you make all or some of your child’s/client’s decisions?” 73% (22) replied, “Some,” while 27% (8) replied, “All.” Similarly, 73% (22) reported that they ask their ward what they want and try to do only that for them, while 27% (8) reported that they do not ask their ward what they want.

Questions Directed to Non-guardians

A number of items on the survey were directed only to those respondents who were non-guardians. These questions explored the impact that SDM has had on the life of the individual with I/DD. Other items asked how the choice to use SDM came about, who is part of the decision-making process, and how that was decided. Of the 162 respondents, 78% (126) were non-guardians. Among these non-guardians, 53 were parents or family members, 50 were service providers or supporters, 19 were a co-workers or acquaintances, and 4 were friends. The following findings refer only to the responses from those who identified themselves as non-guardians.

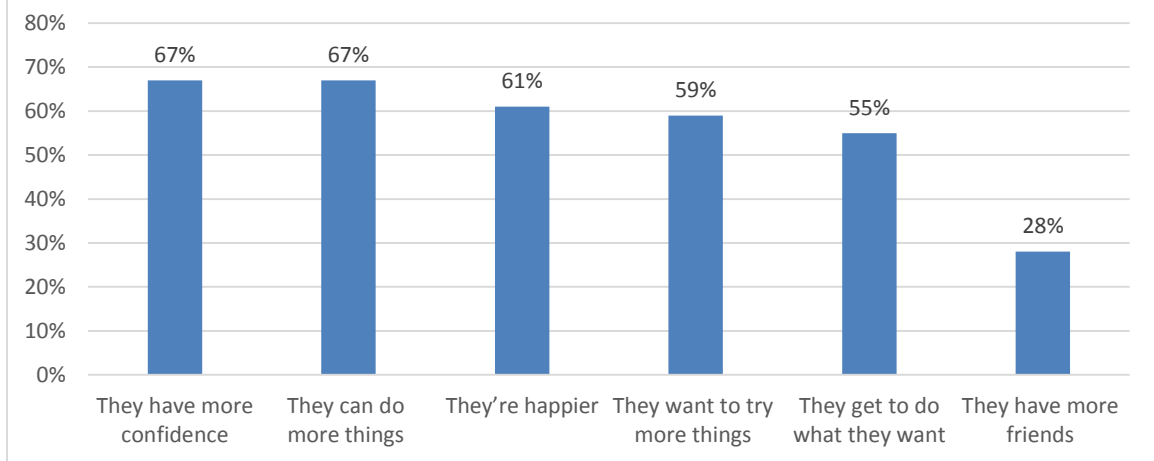
Of the non-guardians in the sample, 87% considered themselves a “supported decision-maker” and 13% did not. However, there may be a number of others taking part in decision-making for each of the respective individuals with I/DD related this study. When asked if anyone else helps their child/client/friend make decisions, the non-guardians responded as follows (see Figure 4 below):



The results indicate that many of the non-guardian respondents are part of their child/client’s larger supported decision-making network containing other supporters.

Non-guardians were also asked, “Do you think it has made your child’s/client’s/friend’s life better to have someone help them make decisions? Their responses are below. See Figure 5.

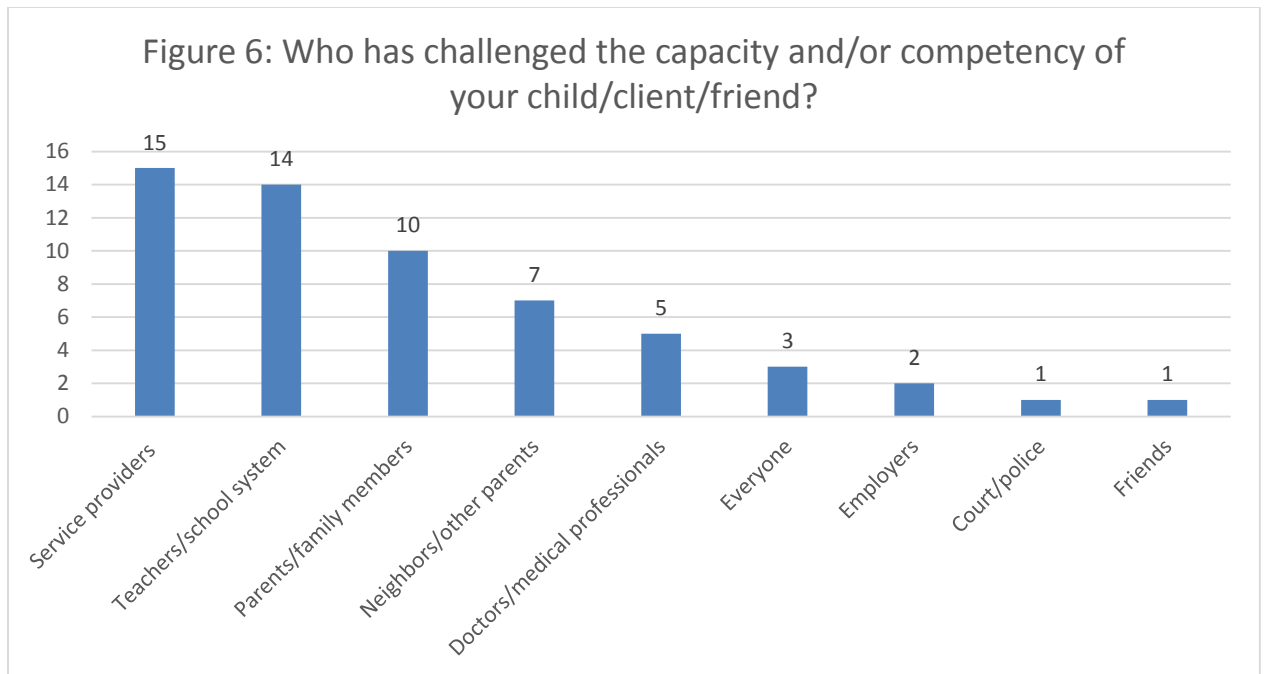
Figure 5: How has your child's/client's/friend's life been made better by having someone help them with decisions?



Responses to this question were overwhelmingly positive with regard to the outcomes of supported decision-making. The majority of non-guardian respondents reported that their child's/client's/friend's life has been made better in the following ways:

- They have more confidence.
- They can do more things in their life.
- They are happier.
- They want to try more things
- They get to do what they want

We also asked non-guardians if anyone had ever challenged their child's/client's/friend's capacity and/or competency. The majority, 58% of respondents answered "Yes" while 42% responded "No." When asked, "Who challenged your child's/client's/friend's capacity and/or competency?" respondents identified individuals in the following categories. See Figure 5 below.



The sources of stigmatization identified by the non-guardian respondents align closely with past research on stigma and individuals with I/DD as well as individuals with psychiatric disabilities (Corrigan, 2005). When asked if there was a legal process involved in response to having their child's/client's/friend's capacity and/or competency challenged, 3 (6%) out of 51 respondents replied, "Yes."

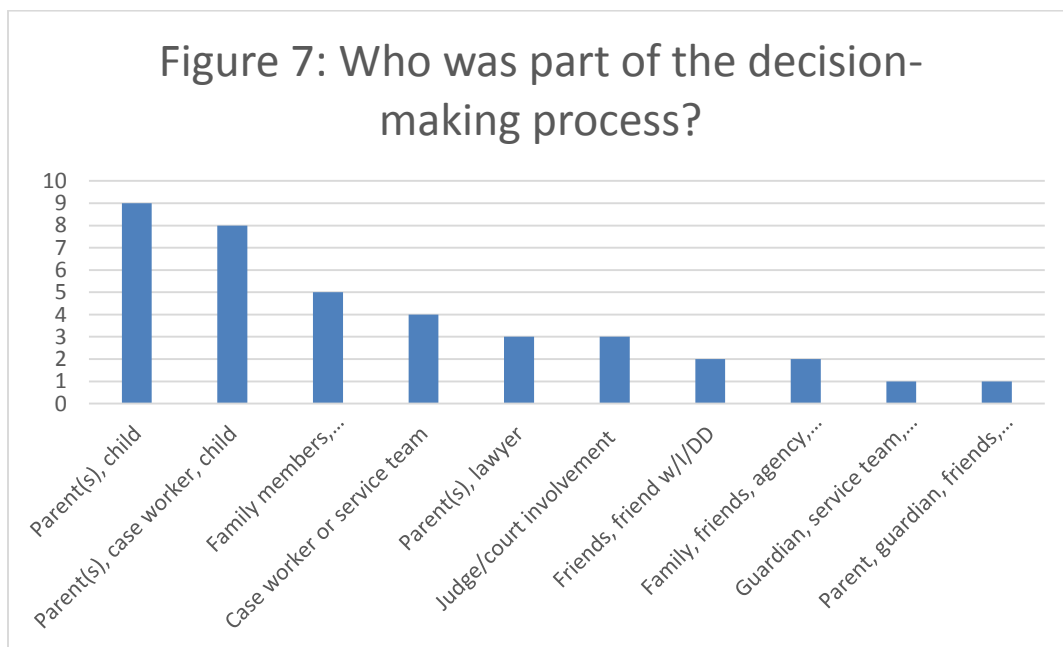
Non-guardians were also asked, "How were less restrictive options to guardianship identified, considered, and decided?" The following is a representative selection of their responses:

- "Through research and reading other people's stories."
- "I read a lot, participated in conferences, started a support group, and consulted a legal professional."
- "Her circle of support weighed out the options and didn't want to take away her rights and free choice."
- "I did not want my son to be in guardianship after I'm no longer here. I feel my son knows when to ask for help. He also knows his limitations."
- "I as parent, I determined that guardianship and the deprivation of legal rights were not appropriate."

- “For us, maintaining individual rights with supports was always the goal; guardianship (full or partial) was never considered.”
- “We have not sought guardianship so as to not limit our son's ability to make his own decisions.”
- “She's always broken barriers so why keep her from that?”

In making a decision to use a less restrictive option than guardianship, non-guardian respondents described a number of approaches. Many conducted their own research, others participated in conferences, joined support groups, and consulted professionals. Others described having never considered guardianship based on their own personal and lived values regarding individual rights.

The survey also asked non-guardians, “*Who was part of the decision-making process?*” Respondents reported the involvement of the following groups of individuals. See Figure 7 below.



We also asked non-guardians, “*When supported decision-making was put in place, who decided who would be supporters and was a formal agreement negotiated?*” Of the 43 responses, 4 (9%) reported negotiating a formal agreement, while 5 (12%) reported having a power a power of attorney in place.

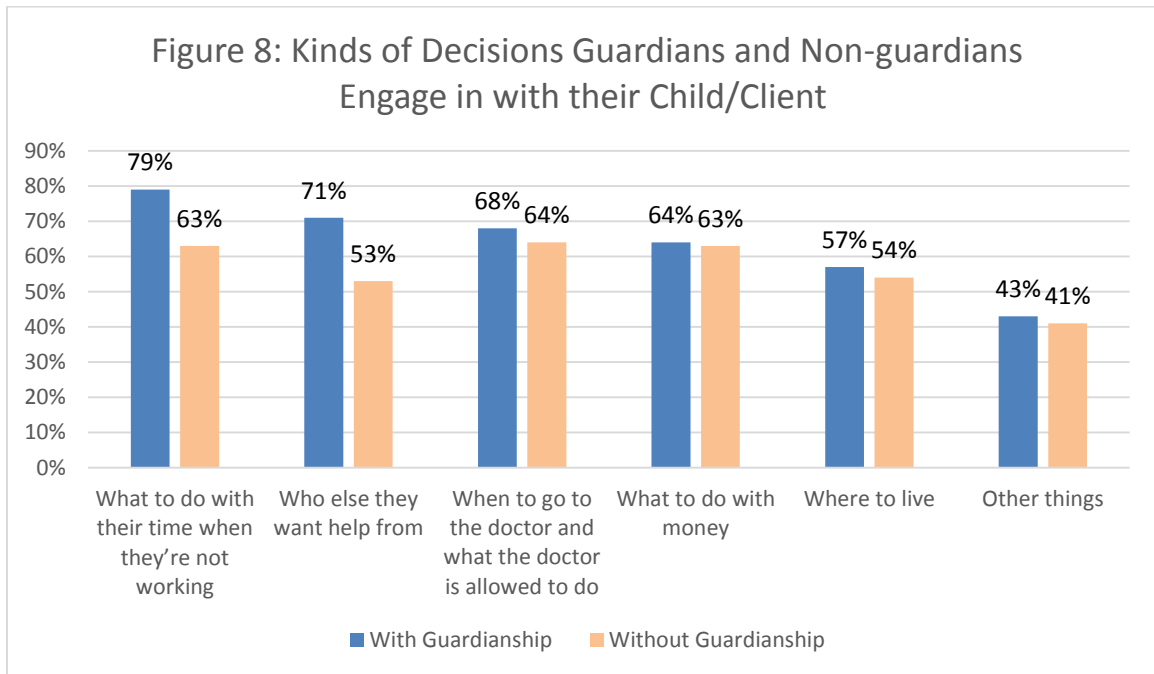
Non-guardians were also asked, “*What do you think is the impact of supported decision-making relative to a more restricted role in decision-making through guardianship?*” The following is a representative selection of their responses to this question:

- “Supported decision-making enables a person to be the agent and center of their own decisions. That agency is legally eliminated when a person is declared legally incompetent and placed under guardianship.”
- “The individual is allowed to maintain their civil rights, determine what to do with their life, where to live, what community activities to participate in, where to attend church, and who to be friends with. Supported decision-making allows for integration into their community as they are able.”
- “Supported decision-making allows for dignity and allows for family members outside the "legal" role to still have influence on adult children.”
- “My son knows he has a major part in making his own choices and at the same time knows there is help if needed.”
- “We do not want to take away our son's rights as to where to live, eat, and recreate. He is involved in EVERY decision that is made about his life. If he has to make his mark on something, I explain what it is and ask him if he wants to sign it. If he declines then he declines. He interviews his staff and HE lets me know who he wants working with him. Once they are hired, if it isn't working out, he lets me know and we talk about it. If need be, they are terminated.”
- “Supported decision-making helps a person feel empowered and more self-confident.”
- “It allows the individual to make an informed decision with guidance and support.”
- “It helps individuals achieve better control over their lives, learn what risks to take and what to avoid, and participate as an equal in society.”
- “When people with significant disabilities are taught to be independent, their opportunities and goals are maximized. They are more autonomous and have improved confidence and self-esteem.”

Questions Directed to Both Guardians and Non-guardians

The 95 supporters without guardianship in the sample were asked “What kind of decisions do you help your child/client make?” and the 25 respondents who are guardians,

were asked, “What kind of decisions does your child/client help you make?” They responded as shown in the table below. See Figure 8 below.



The responses of guardians and non-guardians were quite similar except in two categories: “What to do with their time when they’re not working” and “Who else they want help from.” In this sample, there were a greater percentage of guardians than non-guardians engaged with decisions regarding the involvement of other supporters and activities outside of work.

For the category labeled “other things” guardian respondents reported discussing the following topics:

- Activities
- Sports
- Friends
- Clothes
- Food
- Work
- Vacation
- Education

- Time management, planning, and organizing
- Clubs
- Transportation
- Cleaning and hygiene
- Housemates

For the same category, non-guardian respondents mentioned the topics listed above, but included the following topics as well:

- Legal issues
- Understanding terminology
- Community resources
- Hiring staff, a life coach, or an attorney
- Understanding and communicating financial and medical decisions
- Decisions regarding a small business
- Alternative resources for life style changes
- Determining risk and safety
- Independence
- Deciding if a day habilitation program is a good choice

It is notable that the topics reported only by the non-guardians with their child/clients are indicative of issues individuals face when they have greater autonomy and independence.

Both guardians and non-guardians were asked, “Do you think there are any lessons learned that are generalizable for policy, practice in courts and/or service delivery systems?” The following is a representative selection of responses to this question from guardian respondents:

- “It is important to be person-centered. It is time consuming and often people do not have the time or do not want to take it. But in making any decision for or with a person with an I/DD, you have to know their history and capabilities in addition to their wants, needs, and goals.”
- “There are opportunities for guardianship which are a good fit and with training the guardian can be sure to include the person on all decisions.”

- “The medical profession, in our experience, say they listen to advocates, but they do not do this in practice. They are trained to listen to the patient. They need a different method of questioning those with communication problems and a pain scale that the patient can understand, even if it is individualized to them. Medics need to be able to assess patients visually and then ask guardians to interpret their observations.”
- “There should be protections that aren’t all or nothing.”
- “Supported decision-making, in practice, takes more time than agency-directed services do, in practice. But the results are far better for the person and are cost-effective for the system. It is the only way service delivery support systems should be offering services. The entire service delivery system needs LOTS of training. This is a paradigm shift from business as usual. It is my impression that there is much talk about SDM, but monitoring and evaluation of SDM is almost nonexistent.”
- “Respect, honor, and use as much empathy as can be mustered for the person in my care. Use all my resources to allow her to live as normal of a life as possible. Never assume there is a limitation of her mind and brain. Always remember there is a living, breathing, feeling, and THINKING individual in her body. NEVER underestimate the intellect of the individual. The output may not be there, but the processes may.”

Non-guardians were also asked, “Do you think there are any lessons learned that are generalizable for policy, practice in courts and/or service delivery systems?” The following is a representative selection of responses to this question from non-guardian respondents:

- “Too often, the education system uses the threat of guardianship to achieve their control. Many individuals and their supporters are ushered towards guardianship because of school personnel who are not knowledgeable.”
- “We need education for lawyers, family members, and individuals with disabilities regarding the options available when someone has a need for specific supports in decision-making. We need legislation that recognizes such agreements that go beyond the power of attorney and include a person's "circle of support.”
- “It’s important to take the time to figure out what a person wants and to also let them learn from bad decisions. It is my son's life, not mine.”
- “Everyone needs to be valued, no matter their level of functioning. Because of his diagnoses, my son is thought to be in his own world. But when things are explained to him, he is capable of letting us know what his choices are.”

- “When a person presents with some disability in his or her intellectual processing—at whatever age—the parent or guardian should be made aware of the legal services and supports that will impact this person the rest of their life.”
- “Guardianship tends to be a default option for people who do not communicate verbally, particularly if they do not have access to a communication device. Educating people about supported decision-making should include consideration of how people can and do communicate.”
- “It doesn’t have to be an either-or situation. People (all of us!) look to others for information, advice, and perspective when we make decisions. A person can have a guardian for those rare times when he is not able to make the decision himself, and still be his own decision-maker (using input and perspective from others) when he is able.”
- “There is a need for more financial support for housing availability, transportation support, and employment options specialized to help people with I/DD be more self sufficient.”

Among both the guardian and non-guardian respondent groups, there was agreement on certain issues in a number of cases:

- The need to educate others regarding the principles of supported-decision making and its effectiveness, especially reaching individuals with disabilities, family members, teachers, school administrators, service and health care providers, lawyers, and judges.
- The importance of developing a true continuum of care among diverse helping professionals based on excellent and unbroken communication.
- The need for more research on supported decision-making in practice.
- The importance of educating parents about the option of supported decision-making before their children with I/DD reach the age of 18.
- The error in assuming that people who do not communicate verbally do not communicate.
- The importance of understanding that styles and methods of communicating that are highly individualistic need to be honored.

Further Description of the Sample of Participants with I/DD

Individuals without Guardians

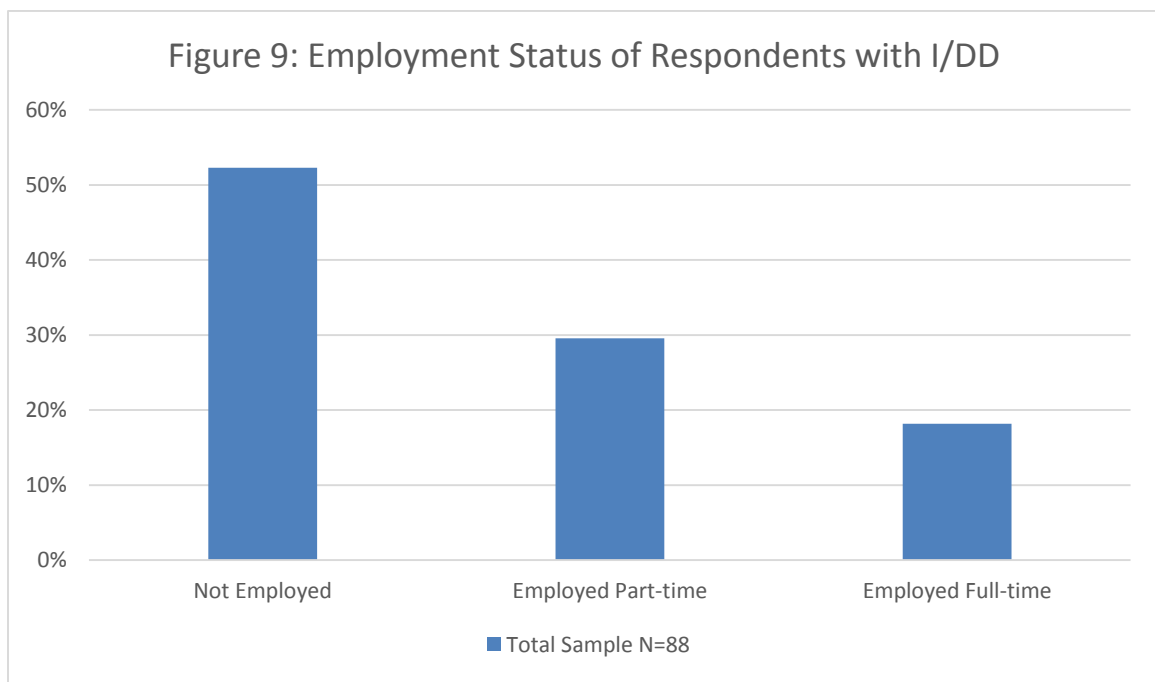
Of the 90 respondents with I/DD, 71% (76) were individuals without a guardian. Of the 76 respondents without guardians, 64% (49) reported having someone who helps them make decisions and 36% (27) reported they did not. However, of the 36% who did not have someone to help them make decisions, 31% (8) reported that they wish they had someone to help them make decisions while 69% (18) reported that they do not.

Individuals with Guardians

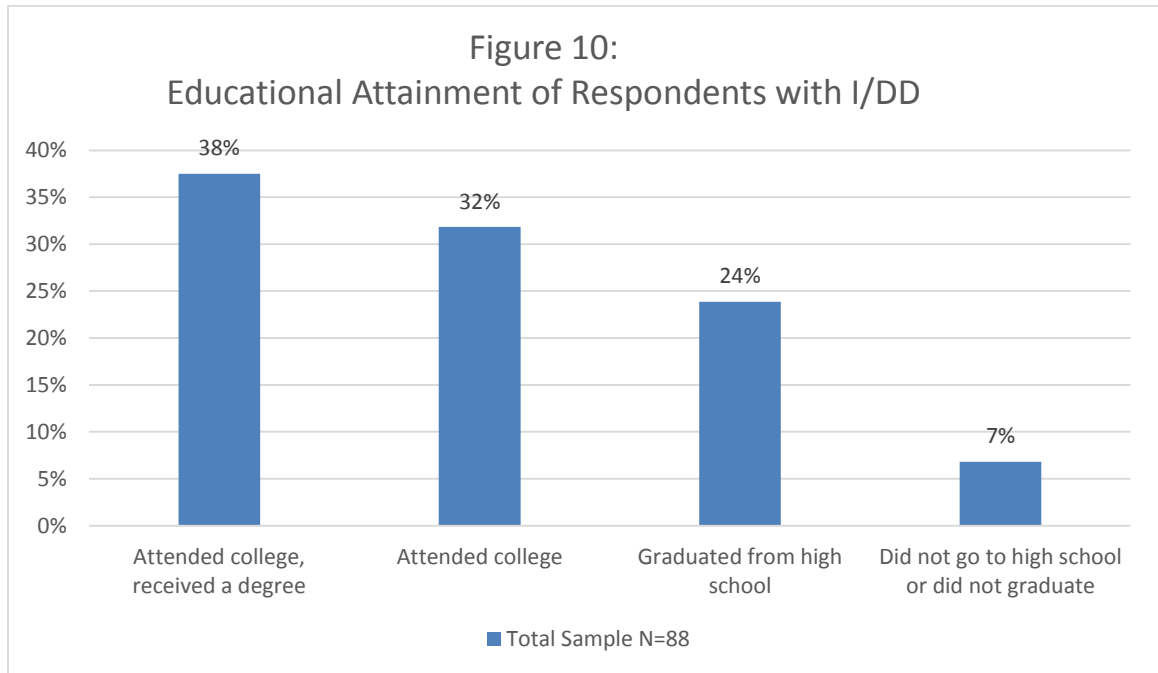
Of the 90 respondents with I/DD, 14 were individuals with guardians. Among those with guardians, 6 had guardians who were parents, 6 had guardians who were siblings or other family members, 1 had a guardian who was a friend, and 1 had a guardian who was a teacher. Four of the respondents reported that the guardianship was court ordered, while 6 reported that they did not have to go to court to obtain a guardian.

Employment Status and Educational Level of Respondents

Of the 90 respondents with I/DD that completed the survey, 88 answered questions regarding their education and employment status. Eighteen percent (16) reported that they are currently working fulltime, 30% (26) reported that that they are currently working part-time, and 52% (46) reported that that they are currently unemployed. See Figure 9 below.



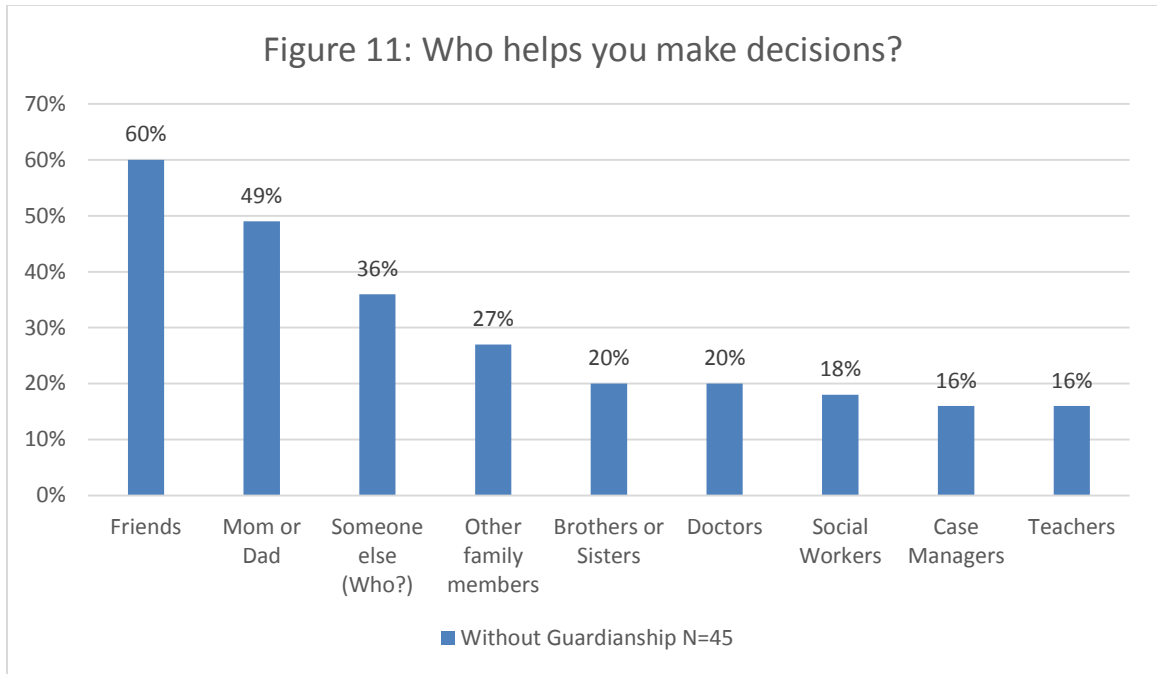
With regard to educational status, 38% (33) reported that they had attended college and received a degree; 32% (28) reported that they had attended college, but had not received a degree; 24% (28) reported that they had attended high school and graduated; and 7% (6) reported that had not graduated from high school. See Figure 10 below.



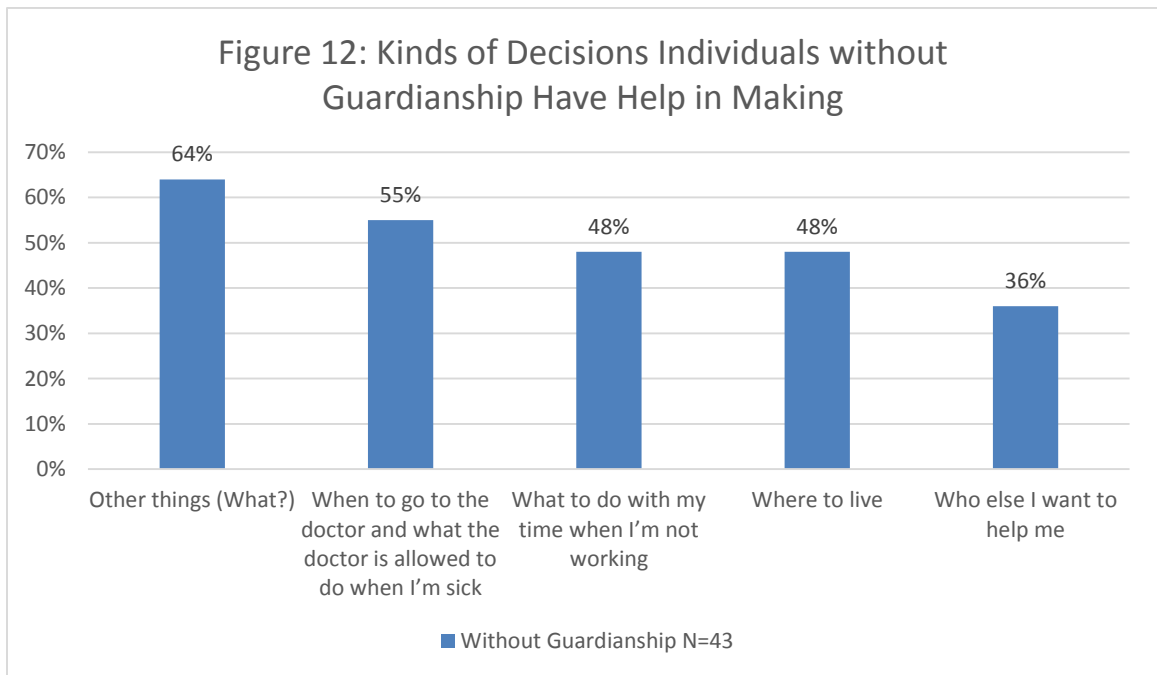
Questions Directed to Participants with I/DD, both with and without Guardians

We asked those with and without guardians if they receive help from someone in making decisions. Six of the 13 individuals with guardianship, and 49 of the 88 individuals without guardianship responded that someone helps them make decisions. This indicates that a significant number of respondents in both groups are involved in decision-making with one or more supporters (46% of individuals with guardianship and 56% without).

We also asked individuals without guardians, “*Who helps you make decisions?*” Notably, the group most often identified was “friends,” followed by “mom or dad” in second place, and “someone else” in third. See Figure 11 below.



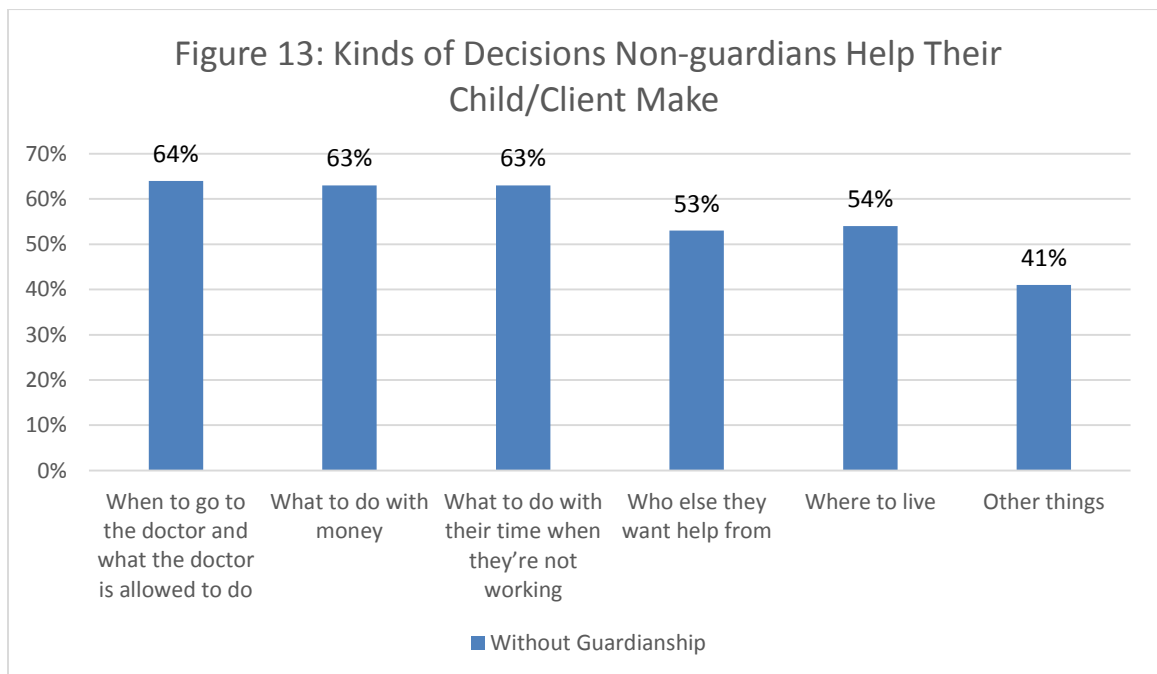
We also asked individuals without guardians, “*What kind of decisions do they help you make?*” They responded as follows (see Figure 12 below):



For the category labeled “other things” 64% (28) of individuals without guardianship reported discussing the following topics:

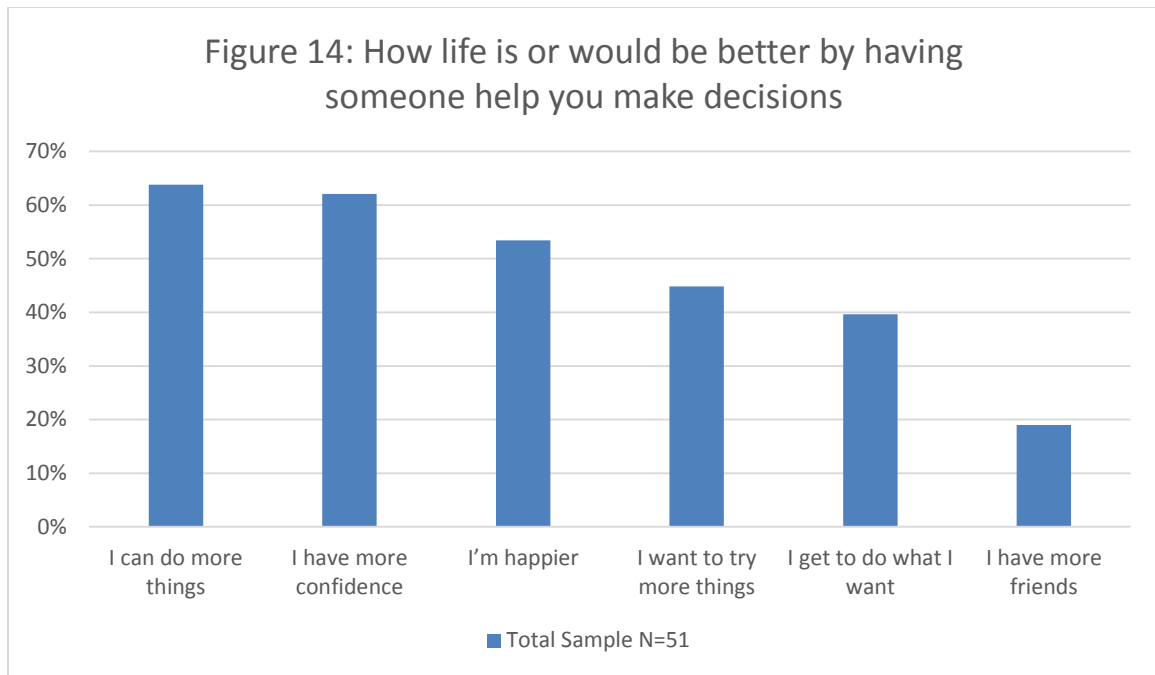
- Living independently
- Activities
- Sports/Exercise
- Friends
- Clothes
- Food
- Work
- Relationships
- General advise
- Education
- Time management, planning, and organizing
- Career choices
- Social situations
- Everyday Living
- Financial decisions

The table above is remarkably similar to the responses by Non-guardians in Figure 8. There we asked, “*What kind of decisions do you help your child/client make?*” We reproduce their responses here for the sake of comparison. See Figure 13 below.



The similarities among the two tables regarding related questions and responses by unrelated groups instills confidence that this study is quite robust.

We also asked those individuals with and without guardians, “*Do you think it (would) make(s) your life better to have someone help you make decisions?*” They responded as follows (See Figure 14 below).



Individuals with I/DD with and without guardianship responded in a positive way regarding the perceived benefits of receiving help in decision-making. The majority of respondents reported that supported decision-making

- Has given them (or would give them) greater confidence
- Has given them (or would give them) the ability to do more things
- Has made them (or would make them) happier.

Summary

The aim of the Survey on Supported Decision-making was to capture the experiences, opinions, and expertise of those individuals on the forefront of enacting supported decision-making in their daily lives. Our participants included parents, family members, service providers, co-workers, and friends. We heard from individuals with I/DD who had guardians and those who did not have guardians. We surveyed both guardians and non-guardian supporters of individuals with I/DD. What follows is a brief summary of some of the survey's more important findings.

1. The majority of non-guardian supporters reported that supported decision-making has made their child's/client's/friend's life better in the following ways:
 - They have more confidence.
 - They can do more things in their life.
 - They are happier.
 - They want to try more things.
 - They get to do what they want.
2. The majority of participants with I/DD, with and without guardianship, reported that supported decision-making:
 - Has given them (or would give them) greater confidence.
 - Has given them (or would give them) the ability to do more things.
 - Has made them (or would make them) happier.
3. Fifty six percent of the participants with I/DD who have guardians and 46% of the participants who do not reported that someone helps them make decisions. This indicates that a significant number of respondents in both groups are involved in decision-making with one or more supporters
4. Participants with I/DD without a guardian identified friends and parents most often as those that help with decisions.
5. Fifty eight percent of non-guardian supporters reported having their child's/client's/friend's capacity or competency challenged. When asked by whom, the individuals identified by most respondents were the following:
 - Service providers

- Teachers/school system
 - Family members
 - Neighbors/other parents
 - Doctors and medical professionals
 - Employers
6. Non-guardians were asked, “When supported decision-making was put in place, was a formal agreement negotiated?” Out of 43 responses, 4 respondents or 9% reported negotiating a formal agreement.
7. Among both the guardian and non-guardian supporter respondent groups, there was agreement on the following issues in a number of cases:
- The need to educate others regarding the principles of supported-decision making and its effectiveness, especially reaching individuals with disabilities, family members, teachers, school administrators, service and health care providers, lawyers, and judges.
 - The importance of developing a true continuum of care among diverse helping professionals based on excellent and unbroken communication.
 - The need for more research on supported decision-making in practice.
 - The importance of educating parents about the option of supported decision-making before their children with I/DD reach the age of 18.
 - The error in assuming that people who do not communicate verbally do not communicate.
 - The importance of understanding that styles and methods of communicating can be highly individualistic and need to be honored.

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