Survey on Supported Decision-making in Practice

FINAL REPORT

Submitted By:

The National Resource Center for Supported Decision-Making

This project is funded by the Administration on Intellectual and Developmental Disabilities, Administration for Community Living, Grant # HHS-2014-ACL-AIDD-DM-0084

March 31, 2016

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

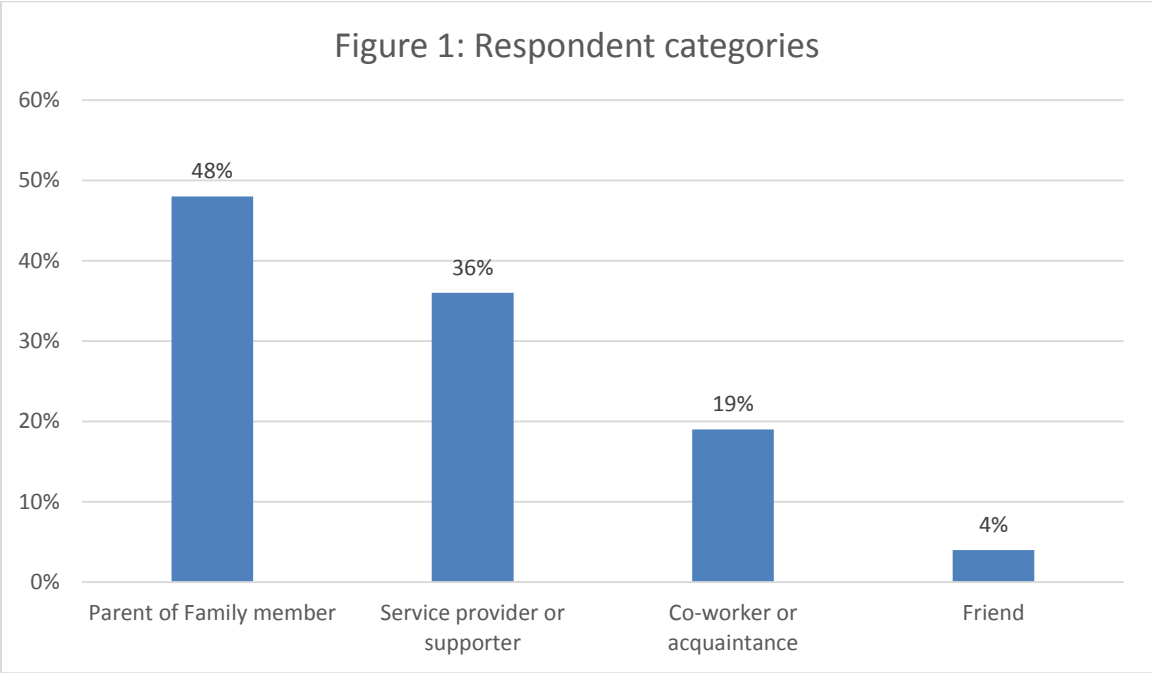
In order to identify a sample of 200 or more participants nationally, the project team recruited participants through the following multiple channels:

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

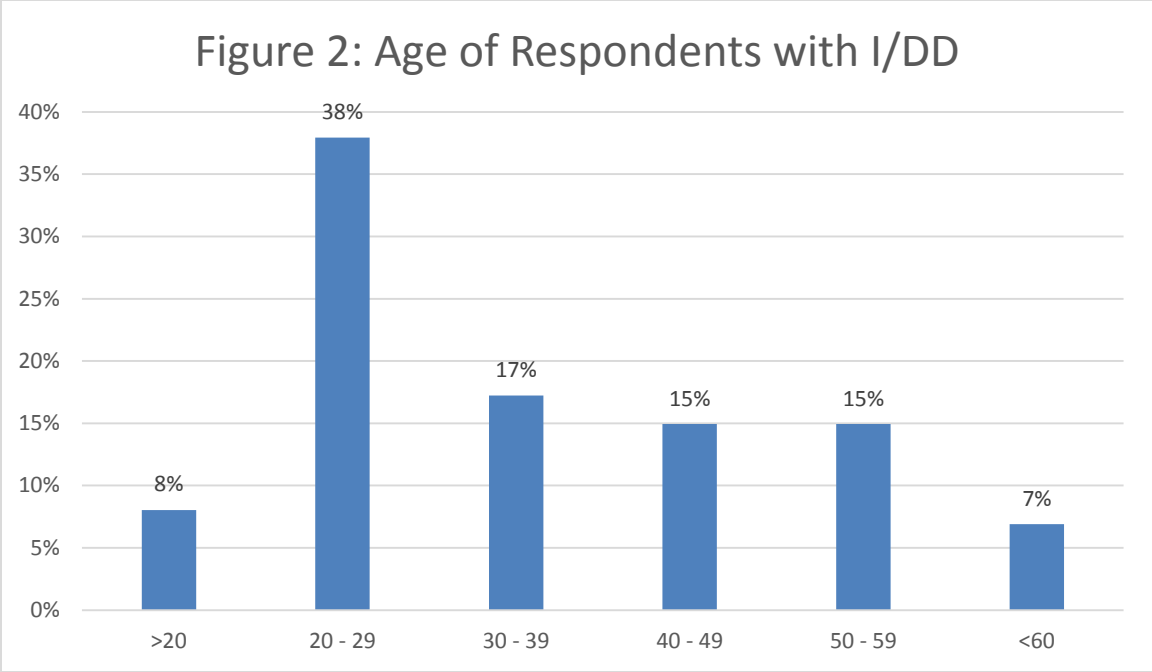
Description of Samples

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

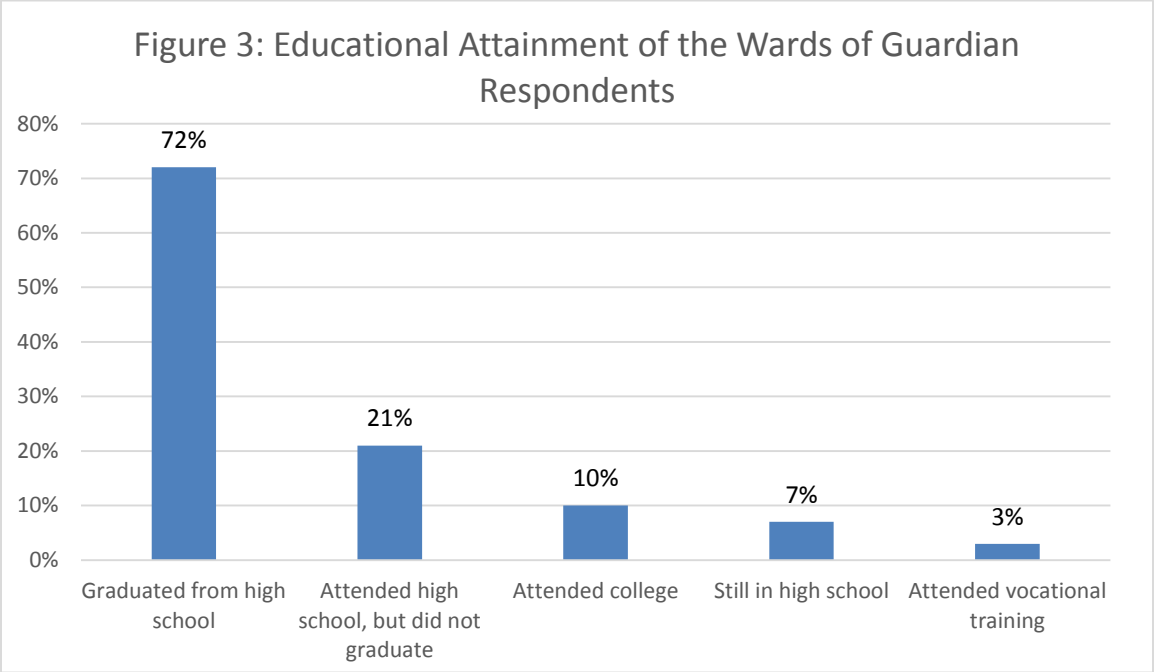
Survey Questions Directed to Guardians

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."

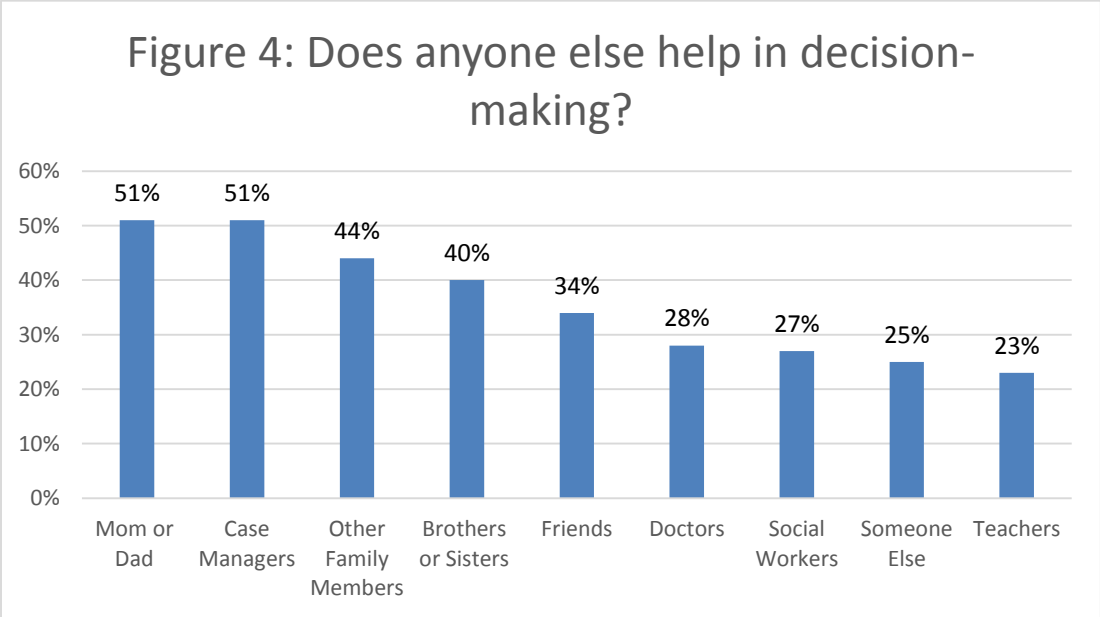
Decision-making under Guardianship

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

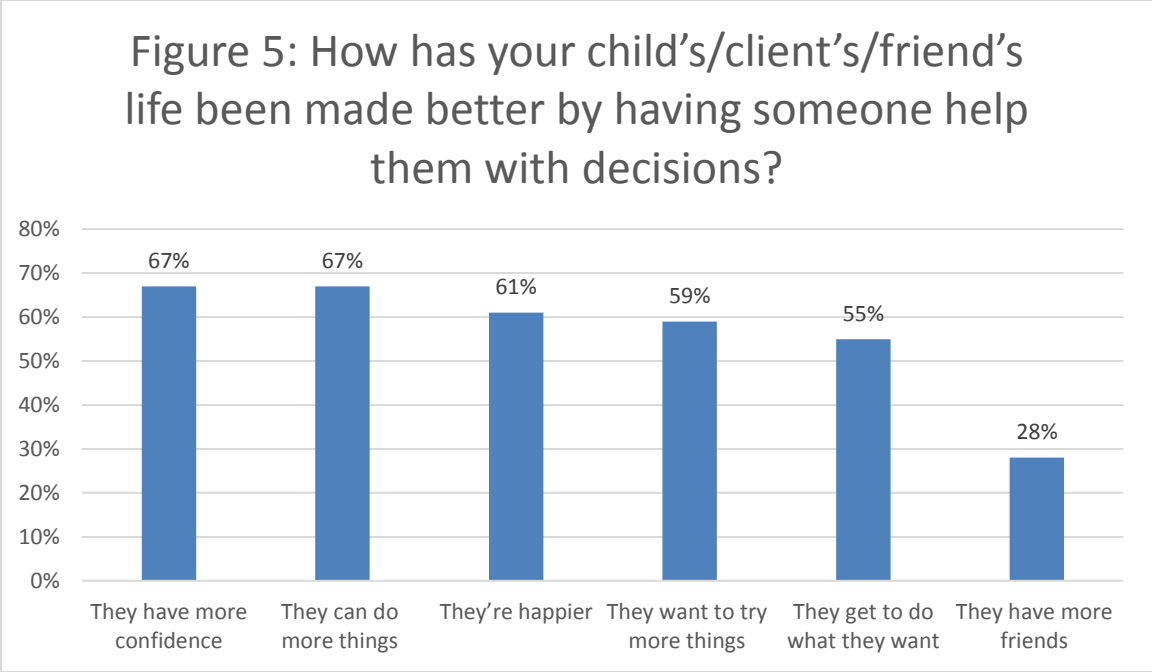
A number of items on the survey were directed only to those respondents who were non-guardians. These questions explored the impact that SDM has had on the life of the individual with I/DD. Other items asked how the choice to use SDM came about, who is part of the decision-making process, and how that 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.

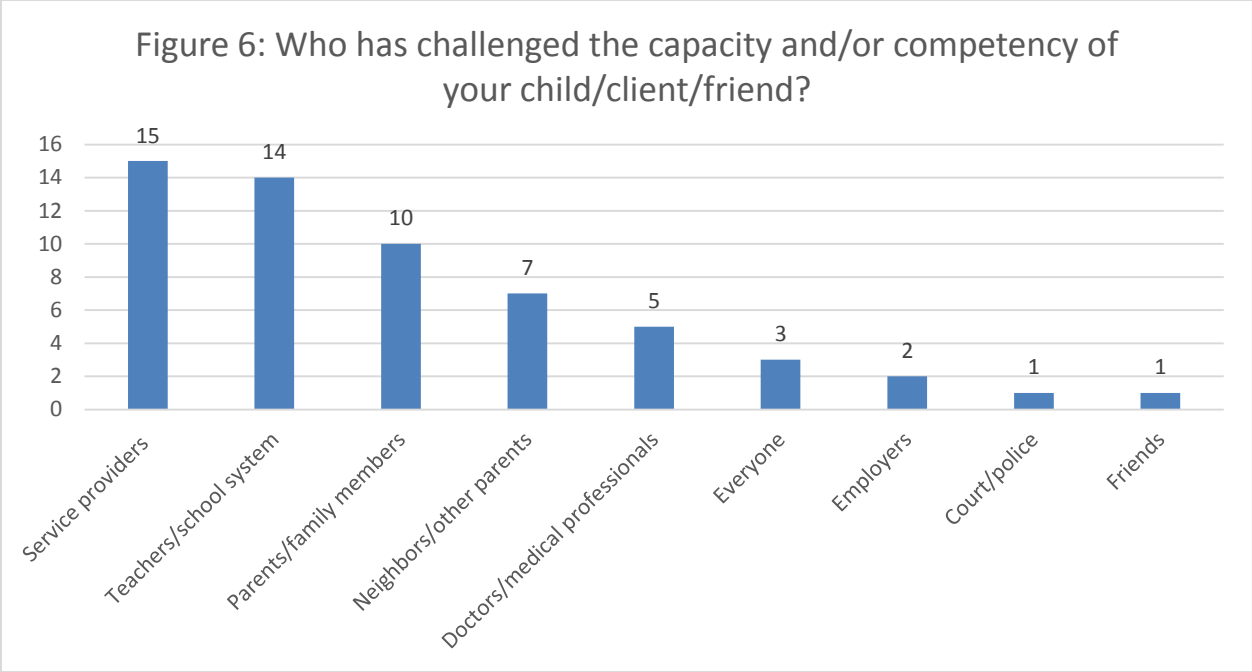
Non-guardians were also asked, "Do you think it has made your child's/client's/friend's life better to have someone help them make decisions? Their responses are below. See Figure 5.



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."

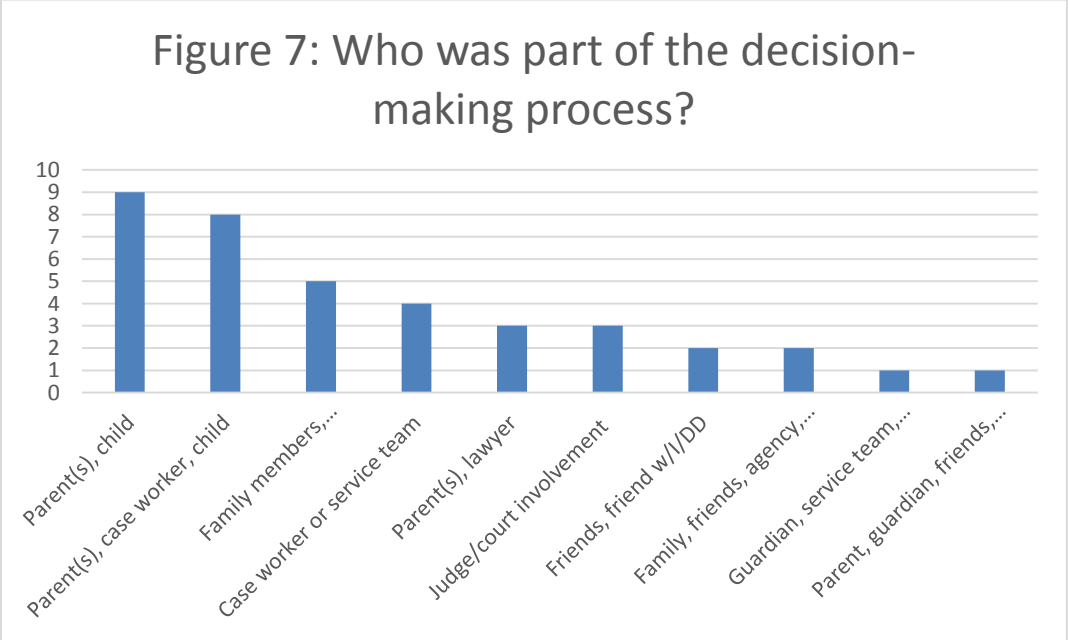
Non-guardians were also asked, "How were less restrictive options to guardianship identified, considered, and decided?" The following is a representative selection of their responses:

- "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.

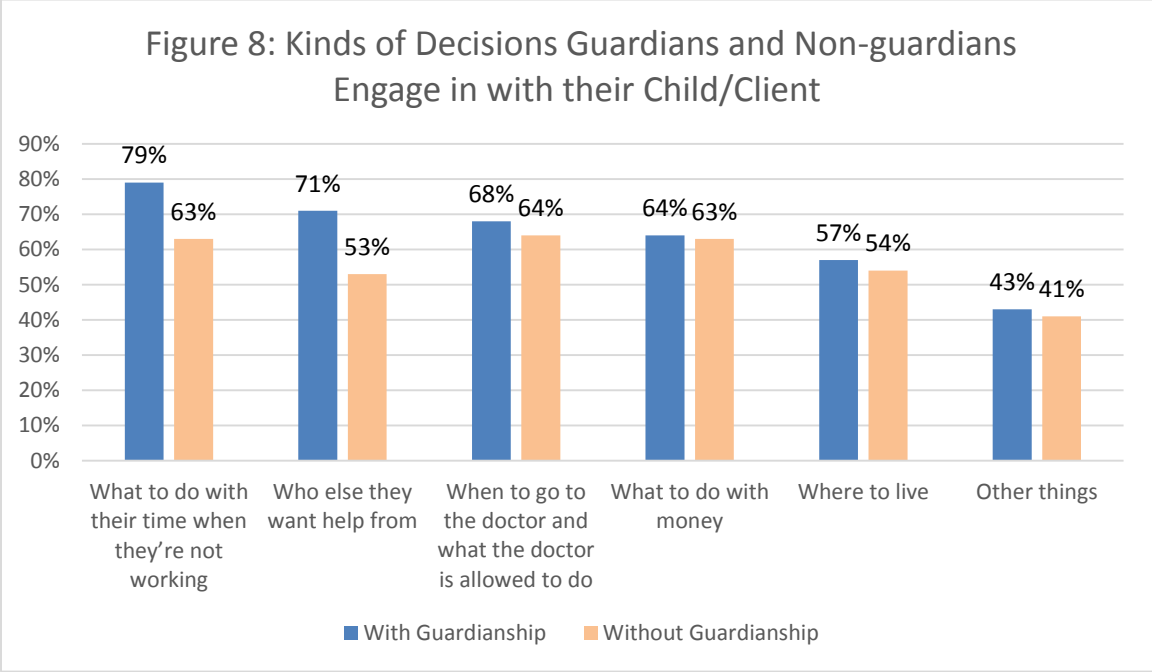
Non-guardians were also asked, "*What do you think is the impact of supported decision-making relative to a more restricted role in decision-making through guardianship?*" The following is a representative selection of their responses to this question:

- "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

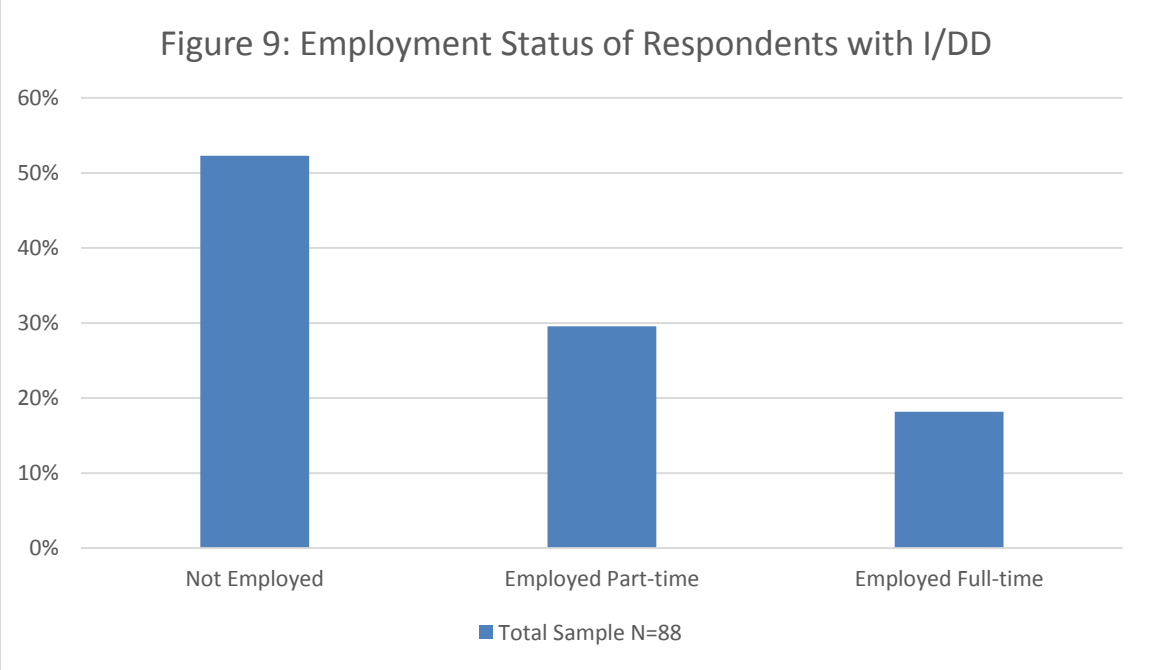
Of the 90 respondents with I/DD, 71% (76) were individuals without a guardian. Of the 76 respondents without guardians, 64% (49) reported having someone who helps them make decisions and 36% (27) reported they did not. However, of the 36% who did not have someone to help them make decisions, 31% (8)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

Individuals with Guardians

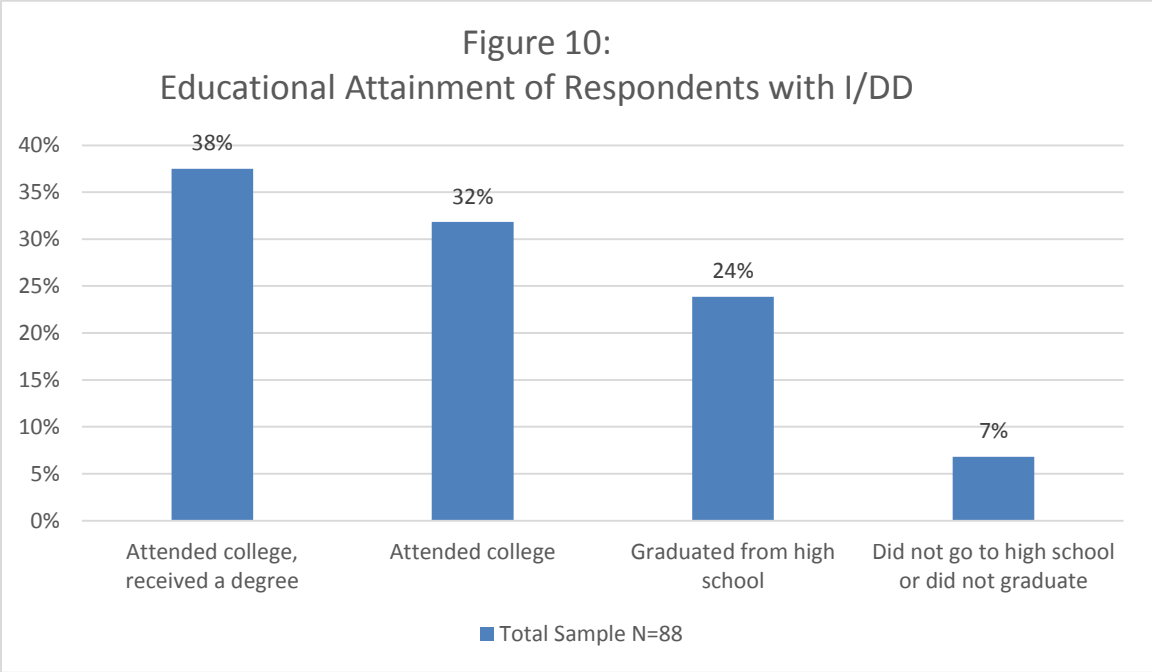
Of the 90 respondents with I/DD, 14 were individuals with guardians. Among those with guardians, 6 had guardians who were parents, 6 had guardians who were siblings or other family members, 1 had a guardian who was a friend, and 1 had a guardian who was a teacher. Four of the respondents reported that 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.



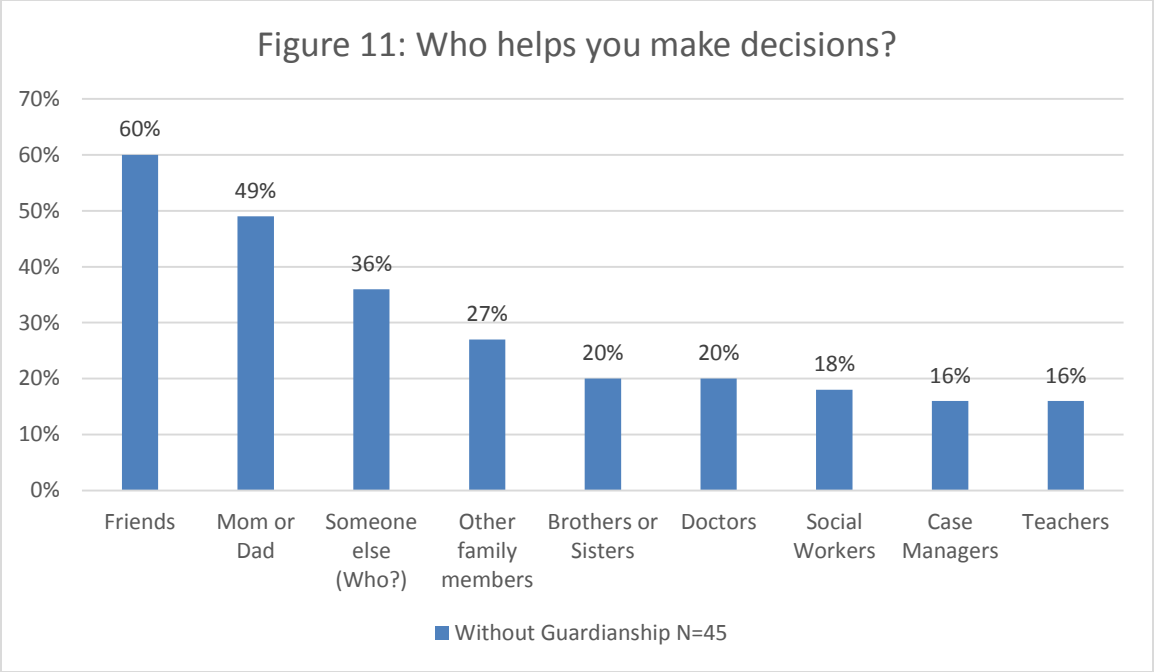
With regard to educational status, 38% (33) reported that they had attended college and received a degree; 32% (28) reported that they had attended college, but had not received a degree; 24% (28) reported that they had attended high school and graduated; and 7% (6) reported that had not graduated from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



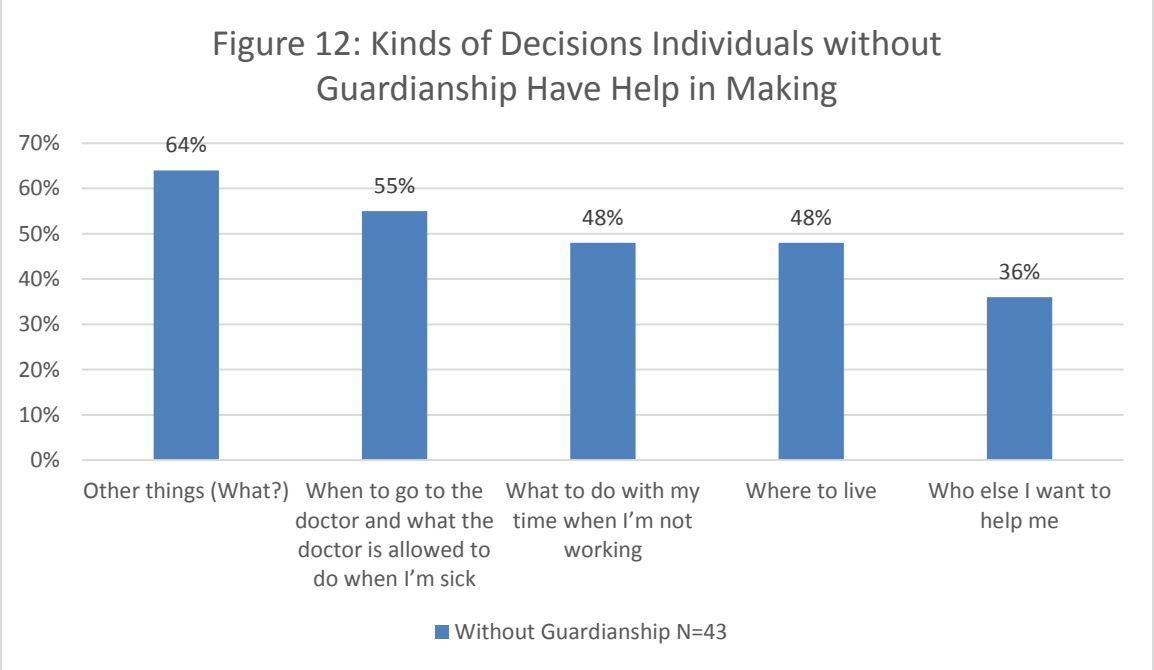
Questions Directed to Participants with I/DD, both with and without Guardians

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.



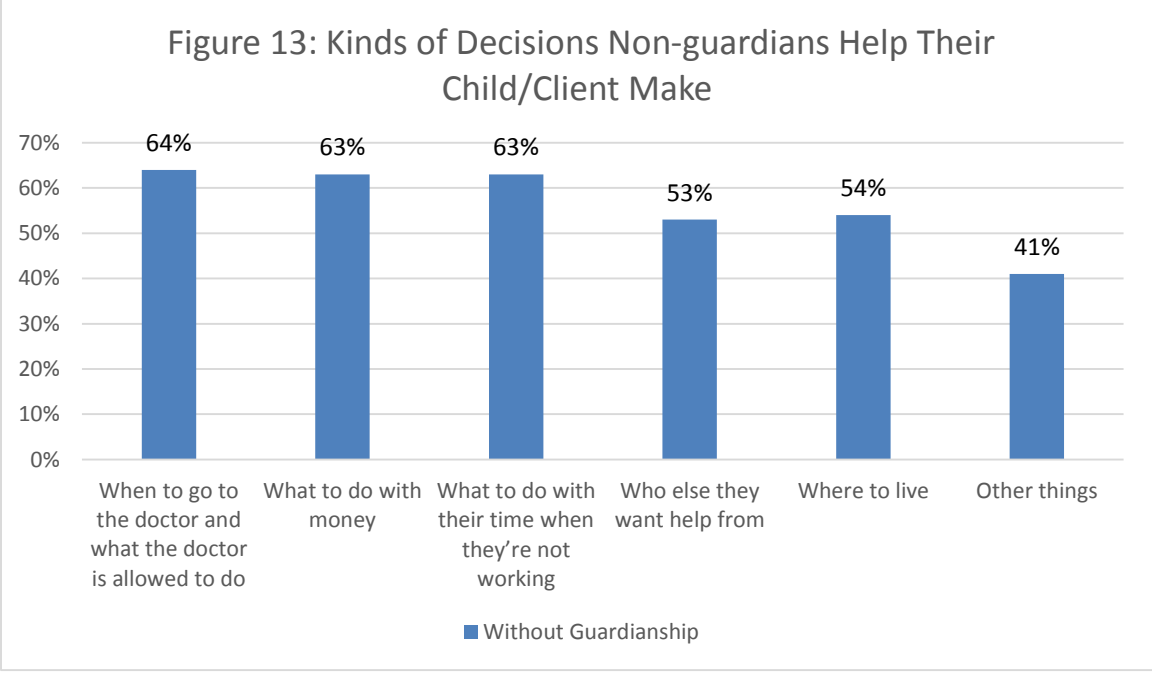
We also asked individuals without guardians, "*What kind of decisions do they help you make?*" They responded as follows (see Figure 12 below):



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

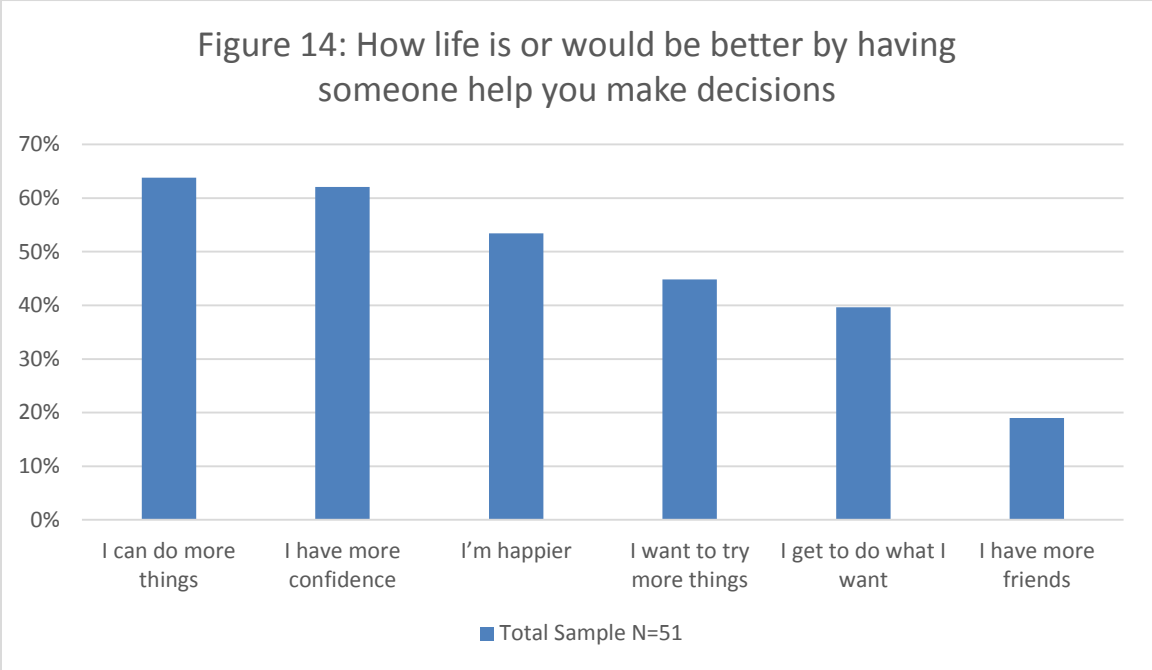
- Living independently
- Activities
- Sports/Exercise
- Friends
- Clothes
- Food
- Work
- Relationships
- General advise
- Education
- Time management, planning, and organizing
- Career choices
- Social situations
- Everyday Living
- Financial decisions

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.

References

Abery, B.H. & Ticha, R., Smith, J.G., Welshons, K., & Berlin, S. (2013). Validation of the Self-Determination and Control Opportunity and Response Evaluation Scale (SD-CORES). manuscript submitted for publication.

Agency for Health Research and Quality. (2001). *Translating research into practice (TRIP)-II* (AHRQ Publication No. 01-P017). Washington, DC: Agency for Health Research and Quality.

Alavi, M., & Leidner, D.E. (2001). Review: Knowledge management and knowledge management systems: Conceptual foundations and research issues. *MIS Quarterly, 25*(1), 107-136.

Algozzine, B., Browder, D., Karvonen, M. R., Test, D. W., & Wood, W. M. (2001). *Effects of self-determination interventions on individuals with disabilities.* Review of Educational Research, 71, 219-278.

Americans with Disabilities Act of 1990 (ADA*), Pub.L. 101–336,* 104 Stat. 327 (July 26, 1990), as amended by *Pub.L. 110–325,* 122 Stat. 3553 (Sept. 25, 2008).

Bach, Michael. (2014). Supported Decision-Making: Evolution of an idea and Canadian Experience [PDF document]. Retrieved March 26, 2014 from bbi.syr.edu/news_events/news/2014/03/Bach.ppt

Bailey, R., Wilner, P., Dymond S. (2011). A visual aid to decision-making for people with intellectual disabilities. Research in Developmental Disabilities, 32(1), 37-46.

Baron, J., & Brown, R. V. (Eds.). (1991). *Teaching decision making to adolescents*. Hillsdale, NJ, England: Lawrence Erlbaum Associates, Inc.

Bersani, H., & Lyman, L. M. (2009). Governmental policies and programs for people with disabilities. In Drum, C. D., Krahn, G. L., & Bersani, H. (Eds.), *Disability and Health* (pp. 79-104). Washington DC: American Public Health Association.

Beyth-Marom, R., Fischhoff, B., Quadrel, M. J., & Furby, L. (1991). Teaching decision making to adolescents: A critical review. In J. Baron & R. V. Brown (Eds.), *Teaching decision making to adolescents* (pp. 19-59). Hillsdale, NJ, England: Lawrence Erlbaum Associates, Inc.

Bamberger, M., Rugh, J., & Mabry, L. (2006). *Real World Evaluation: Working Under Budget, Time, Data, and Political Constraints*. Thousand Oaks: Saga Publications, Inc.

Blanck P., & Martinis, J. G. (2015). The Right to Make Choices: The National Resource Center for Supported Decision-Making. *Inclusion* (3)1, 24-33.

Bollen, K. A. (1986). Sample Size and Bentler and Bonett's Nonnormed Fit Index. *Psychometrika*, 51(1), 375-377

Braddock, D., R. Hemp, M. C. Rizzolo, L. Haffer, E. S. Tanis, and J. Wu. (2011). *The State of the States in Developmental Disabilities 2011.* Washington, DC: American Association on Intellectual and Developmental Disabilities.

Braddock, D., & Rizzolo, M. K. (2013, Feb. 27). *Intellectual and Developmental Disabilities Services in the U.S.: 2013*. AAIDD Webinar. Retrieved January 9, 2014 from: http://www.stateofthestates.org/

Bransford, J., Stipek, D., Vye, N., Gomez, L. and. Lam, D. (eds.) (2009). *The role of research in educational improvement*. Cambridge, MA: Harvard Education Press.

Campanella, T. (2015). Supported decision-making in practice. *Inclusion, 3*(1), 35-39.

Canadian Institutes of Health Research (2011). *More About Knowledge Translation at CIHR.* Retrieved April 25, 2012, from http://www.cihr-irsc.gc.ca/e/39033.html.

CBS This Morning (2013, Nov. 13). Jenny Hatch: Disabled young woman helps others gain independence. Retrieved January 24, 2014 from: http://www.cbsnews.com/videos/jenny-hatch-disabled-young-woman-helps-others-gain-independence

Cheung, G. W., & Rensvold, R. B. (2002). Evaluating goodness-of-fit indexes for testing measurement invariance. *Structural Equation Modeling, 9*(2), 233-255.

Chamaz, K. (2000). Grounded theory: Objectivist and constructivist methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (2nd ed.). Thousand Oaks, CA: Sage.

Cobb, B., Lehmann, J., Newman-Gonchar, R., & Alwell, M. (2009). Self-determination for students with disabilities: A narrative metasynthesis. *Career Development for Exceptional Individuals*, 32(1), 108-114.

Corrigan, P.W. (2005). *On the Stigma of Mental Illness: Practical Strategies for Research and Social Change.* American Psychological Association: Washington DC.

Council on Quality and Leadership (2012). Towson, MD: The Council on Quality and Leadership.

Cousins, J.B., & Earl, L. (1992). *The Case for Participatory Evaluation: Educational Evaluation and Policy Analysis*, *14*(4), 397-418.

Creswell, J. W. (2012). *Qualitative Inquiry and Research Design: Choosing Among Five Approaches* (3rd ed.). Thousand Oaks, CA: Sage.

Deci, E. (1975). *Intrinsic motivation*. New York: Plenum Press.

Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The satisfaction with life scale. *Journal of Personality Assessment, 49*(1), 71-75.

Dillman, D. A., Smyth, J. D., & Christian, L. M. (2009). *Internet, Mail, and Mixed-Mode Surveys: The Tailored Design Method* (3rd ed.). New York: Wiley.

Dinerstein, R. D. (2012). Implementing legal capacity under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The difficult road from guardianship to supported decision-making. *Human Rights Brief 19*(2), 1-5.

Disability Rights North Carolina. (2015). Guardianship. Retrieved April 25, 2015 from http://www.disabilityrightsnc.org/guardianship

Everson, J., & Zhang, D. (2000). Person-centered planning: Characteristics, inhibitors, and supports. *Education and Training in Mental Retardation and Developmental Disabilities*, 35(1), 36-43.

Faul, F., Erdfelder, E., Lang, A.-G., & Buchner, A. (2007). G* Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods, 39*(2), 175-191.

Fervaha, G., Graff-Guerrero, A., Zakzanis, K. K., Foussias, G., Agid, O., & Remington, G. (2013). Incentive motivation deficits in schizophrenia reflect effort computation impairments during cost-benefit decision-making. *Journal of Psychiatric Research, 47*, 1590-1596. doi: http://dx.doi.org/10.1016/j.jpsychires.2013.08.003

Fixsen, D.L., Blase, K.A., Horner, R., & Sugai, G. (2009). Intensive technical assistance. Scaling-up Brief, 2. State Implementation & Scaling-up of Evidence-based Practices. Retrieved July 21, 2011, from http://eric.ed.gov/PDFS/ED507441.pdf

Florin, P., Mitchell, R., & Stevenson, J. (1993). Identifying training and technical assistance needs in community coalitions: A developmental approach. *Health Education Research*, *8*(3), 417-432.

Furby, L., & Beyth Marom, R. (1992). Risk taking in adolescence: A decision-making perspective. *Developmental Review, 12*(1), 1-44.

Gardner, J. F., Carran, D. T., & Taylor, S. J. (2005). Attainment of personal outcomes by people with developmental disabilities. *Mental Retardation, 43*(3), 157-174.

Gay, G. (2000). Culturally responsive teaching: Theory, research, & practice. New York: Teachers College Press.

Gay, G. (2002). Preparing for culturally responsive teaching. Journal of Teacher Education, 53, 106-116.

Gibbons, M. (2008). Why is knowledge translation important? Grounding the conversation. *FOCUS Technical Brief, 21*. Retrieved July 21, 2011, from http://www.ncddr.org/kt/products/focus/focus21/Focus21.pdf

Glen, K. B. (2015). Supported Decision-Making and the Human Right of Legal Capacity. *Inclusion 3*(1), 2-16.

Graham, I. D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in translation: Time for a map? *The Journal of Continuing Education in the Health Professions, 26,* 13-24.

Granger, B. & Glen, W. (2001) *Developing an Effective Dissemination Plan*. National Center for the Dissemination of Disability Research. January. Retrieved from http://www.ncddr.org/du/products/dissplan.html

Harbour CK, Malik PK. 2010. History of Intellectual Disability. In: JH Stone, M Blouin, editors. International Encyclopedia of Rehabilitation. Available online: http://cirrie.buffalo.edu/encyclopedia/en/article/143/

Hatch, J. (2015). My story. *Inclusion, 3*(1), 34.

Hatch, J. Crane, S. A., & Martinis, J. G. (in press). *Inclusion.*

Hickson, L., & Khemka, I. (2013). Problem solving and decision making. In M. L. Wehmeyer (Ed.), *The Oxford Handbook of positive psychology and disability* (pp. 198-225): Oxford University Press, New York, NY.

Hox, J. J. & Maas, C. J. M. (2004). Multilevel analysis: Techniques and applications. Mahweh, N.J.: Larence Erlbaum Associates.

James & Watts 2014 Implementation of SDM in Canada (pg.3)

Jameson, M.J., Riesen, T., Polychonis, S., Trader, B., Mizner, S., Martinis, J., & Hoyle, D. (under review). Alternatives to guardianship: supported decision-making and individuals with disabilities. Manuscript submitted to *Research and Practice for Persons with Severe Disabilities.*

Kahn, L., Hurth, J., Diefendorf, M., Kasprzak, C., Lucas, A., & Ringwalt, S. (2009). NECTAC technical assistance model for long-term systems change. Chapel Hill: The University of North Carolina, FPG Child Development Institute, National Early Childhood Technical Assistance Center. Retrieved July 21, 2011, from http://www.nectac.org/~pdfs/pubs/tamodel.pdf

Khemka, I., Hickson, L., & Reynolds, G. (2005). Evaluation of a decision-making curriculum designed to empower women with mental retardation to resist abuse. *American Journal of Mental Retardation, 110*(3), 193-204.

Kline, R. B. (1998). *Principles and Practice of Structural Equation Modeling*. New York: The Guilford Press.

Kohn, N. A., & Blumenthal, J. (2014). A critical assessment of supported decision-making for persons aging with intellectual disabilities. *Health and Disability Journal, 7*(1), S40-S43.

Kohn, N. A., Blumenthal, J., & Campbell, A. (2013). Supported decision-making: A viable alternative to guardianship? *Penn State Law Review, 117*(4), 1111-1157.

Krug, A., Cabanis, M., Pyka, M., Pauly, K., Kellermann, T., Walter, H., . . . Kircher, T. (2014). Attenuated prefrontal activation during decision-making under uncertainty in schizophrenia: A multi-center fMRI study. *Schizophrenia Research, 152*(1), 176-183. doi: http://dx.doi.org/10.1016/j.schres.2013.11.007

Lachapelle, Y., Wehmeyer, M.L., Haelewyck, M.C., Courbois, Y., Keith, K.D., Schalock, R., Verdugo, M.A., & Walsh, P.N. (2005). The relationship between quality of life and self-determination: An international study. *Journal of Intellectual Disability Research, 49,* 740-744.

Lane, J. P., & Flagg, J. L. (2010). Translating three states of knowledge—discovery, invention, and innovation. *Implementation Science, 5*(9), 1-15.

Lane, J. P., & Rogers, J. D. (2011). Engaging national organizations for knowledge translation: Comparative case studies in knowledge value mapping. *Implementation Science, 6*(106), 1-13.

Little, T. D. (1997). Mean and covariance structures (macs) analyses of cross-cultural data: Practical and theoretical issues. *Multivariate Behavioral Research*, 32(1) 53-76.

Little, T. D. (2013). *Longitudinal structural equation modeling*. New York: Guilford Press.

Little, T. D., Bovaird, J. A., & Slegers, D. W. (2006). Methods for the analysis of change. *Handbook of personality development*, 181-211.

Little, T. D., Card, N. A., Bovaird, J. A., Preacher, K., & Crandall, C. S. (2007). Structural equation modeling of mediation and moderation with contextual factors. In T. D. Little, J. A. Bovaird, & N. A. Card (Eds.), *Modeling contextual effects in longitudinal studies* (pp. 207-230). Mahwah, NJ: LEA.

Little, T. D., Lindenberger, U., & Nesselroade, J. R. (Producer). (1999). On selecting indicators for multivariate measurement and modeling with latent variables: When "good" indicators are bad and "bad" indicators are good. [doi:10.1037/1082-989X.4.2.192]

Lotan, G. & Ells, C. (2010). Adults with Intellectual and Developmental Disabilities and Participation in Decision Making: Ethical Considerations for Professional-Client Practice. Intellectual and Developmental Disabilities, 48(2), 112-125.

MacCallum, R. C., Browne, M. W., & Cai, L. (2006). Testing differences between nested covariance structure models: Power analysis and null hypotheses. *Psychological methods, 11*(1), 19.

Martinis, J.G. (n.d.). *One person, many choices: Using special education transition services to increase self-direction and decision-making and decrease overbroad or undue guardianship*. Unpublished manuscript. Retrieved January 24, 2014 from: http://jennyhatchjusticeproject.org/docs/publications/jhjp_publications_draft_article_guardianship.pdf

McGibbon, S., Nadler, S. A., Vogelman, C. (2014). SSA Represenative Payee: Survey of State Guardianship Laws and Court Practices. Administrative Conference of the United States. Retrieved December 24, 2014 from https://www.acus.gov/sites/default/files/documents/SSA%2520Rep%2520Payee_State%2520Laws%2520and%2520Court%2520Practices_FINAL.pdf

McGrath, P.J., Lingley-Pottie, P., Johnson Emberly, D., Thurston,C., & McLean, C. (2009). Integrated knowledge translation in mental health: Family help as an example. *Journal of the Canadian Academy of Child and Adolescent Psychiatry, 18*(1), 30-37.

Mestre, L.S. (2004). Culturally relevant instruction for Latinos. *Academic Exchange*, *8*(4), 46-50.

Millar, D. S. (2014). Addition to transition assessment resources: A template for determining the use of guardianship alternatives for students who have intellectual disability. *Education and Training in Autism and Developmental Disabilities*, 49(1), 171-188.

Nota, L., Ferrrari, L., Soresi, S., & Wehmeyer, M.L. (2007). Self-determination, social abilities, and the quality of life of people with intellectual disabilities. *Journal of Intellectual Disability Research, 51*, 850-865.

Nuss, 2015; Testimony of Laura L. Nuss, Director, The Department on Disability Services FY 2014–FY 2015 Performance Hearing The Committee on Health and Human Services Honorable Chairperson Yvette Alexander Friday, February 20, 2015 http://dds.dc.gov/sites/default/files/dc/sites/dds/release_content/attachments/FY2014%20DDS%20Performance%20Testimmony%20%202%2020%202015.pdf)

Neely-Barnes, S. L. (2005). Consumer choice in developmental disability services: Assessing the impact on quality of life indicators. Thesis submitted to the University of Washington. http://hdl.handle.net/1773/8135

Nutley, S., Walter, I., & Davies, H. (2003). From knowing to doing: A framework for understanding the evidence-into-practice agenda. *Evaluation*, *9*(2), 125-148.

O'Day, B. L, & Killeen, M. B. (2002). Research on the lives of persons with disabilities: The emerging importance of qualitative research methodologies. *Journal of Disability Policy Studies, 13*(1), 9-15.

Office of the Public Advocate 2014

Olmstead v. L.C. ex rel. Zimring, 527 U.S. 581 (1999).

Ordoñez, M and Serrat, O. (2010). *Disseminating knowledge products*. Washington, DC: Asian Development Bank. Retrieved from http://digitalcommons.ilr.cornell.edu/intl/179/.Wackwitz, J. (2010).

Patient Protection and Affordable Care Act (Obamacare), *Pub.L. 111–148,* 124 Stat. 119 (Mar. 23, 2010).

Patton, M.Q. (2008). Utilization-focused evaluation, 4th edition. Thousand Oaks, CA: Sage.

Pepper, C. (prepared statement) (1987). U.S. Subcommittee on Health & Long Term Care of the House Select Comm. On Aging, 100th Cong. *Abuses in guardianship of the elderly and infirm: A national disgrace*. H.R. Rpt. 100-639, 21.

Powers, L.E., Geenen, S., Powers, J., Pommier-Satya, S., Turner, A., Dalton, L.D, et al. (2012). My life: Effects of a longitudinal, randomized study of self-determination enhancement on the transition outcomes of youth in foster care and special education. *Children & Youth Services Review, 34*(11), pp. 2179–2187.

Preacher, K. J. (2011). Multilevel SEM strategies for evaluating mediation in three-level data. *Multivariate Behavioral Research, 46*(4), 691-731.

Preacher, K. J., & Hayes, A. F. (2004). SPSS and SAS procedures for estimating indirect effects in simple mediation models. *Behavior Research Methods, Instruments, & Computers, 36*(4), 717-731.

Preacher, K. J., & Kelley, K. (2011). Effect size measures for mediation models: quantitative strategies for communicating indirect effects. *Psychological Methods, 16*(2), 93.

Preacher, K. J., Zhang, Z., & Zyphur, M. J. (2011). Alternative methods for assessing mediation in multilevel data: The advantages of multilevel SEM. *Structural Equation Modeling, 18*(2), 161-182.

Preacher, K. J., Zyphur, M. J., & Zhang, Z. (2010). A general multilevel SEM framework for assessing multilevel mediation. *Psychological Methods, 15*(3), 209.

Quality Trust for Individuals with Disabilities. (2013). Supported decision-making: An agenda for Action. Retrieved from http://jennyhatchjusticeproject.org/node/264

Rehabilitation Act of 1973, *Pub.L. 93–112,* 87 Stat. 355 (Sept. 26, 1973) (as amended).

Reynolds, S.L. (2002). Guardianship primavera: A first look at factors associated with having a legal guardian using a nationally representative sample of community-dwelling adults. *Aging & Mental Health, 6*(2), pp. 109-120.

Riessman, C. K. (1993). *Narrative Analysis.* Thousand Oaks, CA: Sage.

Rossi, P., Lipsey, M., & Freeman, H. (2004). *Evaluation: A Systematic Approach 7th Edition.* Thousand Oaks: Sage Publications, Inc.

Roux, D.J., Rogers, K.H., Biggs, H.C., Ashton, P., & Sergeant, A. (2006). Bridging the science-management divide: Moving from unidirectional knowledge transfer to knowledge

interfacing and sharing. *Ecology and Society*, *11*(1), 4-23.

Saaltink, R., MacKinnon, G., Owen, F., Tardif-Williams, C. (2012). Protection, participation and protection through participation: young people with intellectual disabilities and decision making in the family context. Journal of Intellectual Disability Research, 56(2), 1076-1086.

Salzman, L. (2010). Rethinking guradianship (again): Substituted decision making as a violation of the integration mandate of title II of the Americans with Disabilities Act, University of *Colorado Law Review, 81*, pp. 157-245.

Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., & Parmenter, T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. *Mental Retardation, 40*(6), 457-470.

Schalock, R. L., Gardner, J. F., & Bradley, V. J. (2007). *Quality of life for people with intellectual and other developmental disabilities: Applications across individuals, organizations, communities and systems*. Washington, DC: American Association on Intellectual and Developmental Disabilities.

Schmidt, W.C., Jr. (1995). *Guardianship: Court of last resort for the elderly and disabled*. Durham, NC: Carolina Academic Press

Selinger, M. (2004). The role of local instructors in making global e-learning programmes culturally and pedagogically relevant. In A. Brown & N. Davis (Eds.), *World Yearbook 2004*: *Digital technology, communications, and education* (pp. 211-224). London: RoutledgeFalmer.

Shogren, K. A., Lopez, S. J., Wehmeyer, M. L., Little, T. D., & Pressgrove, C. L. (2006). The role of positive psychology constructs in predicting life satisfaction in adolescents with and without cognitive disabilities: An exploratory study. *The Journal of Positive Psychology, 1*(1), 37-52.

Shogren, K. A., Luckasson, R., & Schalock, R. L. (in press). The definition of context and its application in the field of intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities.*

Shogren, K.A., & Wehmeyer, M. L. (2015). A framework for research and intervention design in Supported decision making. *Inclusion*, 3(1), 17-23.

Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Rifenbark, G. G., & Little, T. D. (in press).

Relationships between self-determination and postschool outcomes for youth with disabilities. *Journal of Special Education*.

Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Forber-Pratt, A., Little, T., & Lopez, S. (in press). *Causal Agency Theory: Reconceptualizing a Functional Model of Self-Determination.* Final Submission Version.

Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Soukup, J. H., Little, T. D., Garner, N., & Lawrence, M. (2008). Understanding the construct of self-determination: Examining the relationship between The Arc's Self-Determination Scale and the AIR Self-Determination Scale. *Assessment for Effective Intervention, 33*, 94-107.

Shogren, K. A., Wehmeyer, M. L., Reese, R. M., & O'Hara, D. (2006). Promoting self determination in health and medical care: A critical component of addressing health disparities in people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 3,* 105-113.

Shrout, P. E., & Bolger, N. (2002). Mediation in experimental and nonexperimental studies: new procedures and recommendations. *Psychological methods,* 7(4), 422.

Singh, H. (2003). Building effective blended learning programs. *Educational Technology, 43*(6), 51-54.

Stancliffe, R. J. (2001). Living with support in the community: Predictors of choice and self-determination. *Mental Retardation and Developmental Disabilities Research Reviews,*7(2), 91-98.

Stancliffe, R. J., & Parmenter, T. R. (1999). The Choice Questionnaire: A scale to assess choices exercised by adults with intellectual disability. *Journal of Intellectual and Developmental Disability, 24*(2), 107-132.

Stein, B. D., Kogan, J. N., Mihalyo, M. J., Schuster, J., Deegan, P. E., Sorbero, M. J., & Drake, R. E. (2013). Use of a computerized medication shared decision making tool in community mental health settings: Impact on psychotropic medication adherence. *Community Mental Health Journal, 49*, 185-192.

Sudsawad, P. (2007). *Knowledge translation: Introduction to models, strategies and measures.* Austin, TX: Southwest Educational Development Laboratory, National Center for the Dissemination of Disability Research.

Summers, J. A., Hoffman, L., Marquis, J., Turnbull, A., Poston, D., & Nelson, L. L. (2005). Measuring the quality of family-professional partnerships in special education services.

Exceptional Children, 72(1), 65-81.

Suto, W. M., Claire, W. C., Holland, A. J., & Watson, P.C. (2005). Capacity to make financial decisions among people with mild intellectual disabilities. Journal of Intellectual Disability Research, 49(3), 199-209.

Teaster, P. B., Wood, E. F.,Lawrence, S. A., & Schmidt, W. C. (2007). Wards of the state: A national study of public guardianship. *Stetson Law Review, 193.*

Thompson, J.R., Bryant, B., Campbell, E.M., Craig,, E.M., Hughes, C., Rotholz, D., Schalock, R.L., Silverman, W., Tasse, M.J., & Wehmeyer, M.L. (2004). *Supports Intensity Scale: Standardization and users manual.* Washington, DC: American Association on Mental Retardation.

Thompson, J.R., Bryant, B., Schalock, R.L., Shogren, K.A., Tasse, M.J., Wehmeyer, M.L. Campbell, E.M., Craig,, E.M., Hughes, C., Rotholz, D., & Silverman, W (in press).

Thompson, J. R., Bradley, V. J., Buntinx, W. H. E., Schalock, R. L., Shogren, K., Snell, M. E., et al. (2009). Conceptualizing supports and the support needs of people with intellectual disability. *Intellectual and Developmental Disabilities*, 47(1), 135-146.

Tingus, S. J., Berland, B. J., Myklebust, J., & Sherwood, A. (2004). *NIDRR Long-Range Planning Update for KDU.* Paper presented at the Knowledge Dissemination and Utilization Projects Meeting: Translating Disability Research into Practice, Pentagon City, VA.

Uekert, B.K. & Van Duizend, R. (2011). Adult Guardianships: A "Best Guess" National Estimate and the Momentum for Reform. In *Future Trends in State Courts 2011*. Williamsburg, VA: National Center for State Courts. Retrieved January 24, 2014 from: http://www.eldersandcourts.org/Guardianship/Guardianship-Basics/~/media/Microsites/Files/cec/AdultGuardianships.ashx

Valentine, J. C., & McHugh, C. M. (2007). The effects of attrition on baseline comparability in randomized experiments in education: A meta-analysis. *Psychological Methods, 12*(3), 268.

Wackwitz, J. (2010). Knowledge for a Better Life: Ensuring Research benefits People with Disabilites. *SEDL Letter.* XXI (2), pp 8-9. Retrieved from http://www.sedl.org/pubs/sedl-letter/v22n02/SEDLLetter_v22n02.pdf

Wehmeyer, M. L. (1995). *The Arc's Self-Determination Scale: Procedural guidelines*. Arlington, TX: The Arc National Headquarters.

Wehmeyer, M. L. (1996). A self-report measure of self-determination for adolescents with cognitive disabilities. *Education and Training in Mental Retardation and Developmental Disabilities, 31*, 282 - 293.

Wehmeyer, M. L. & Kelchner, K. (1995). *The Arc's Self-Determination Scale*. Arlington, TX: The Arc National Headquarters.

Wehmeyer, M.L., Kelchner, K., & Richards, S. (1996). Essential characteristics of self-determined behavior of individuals with mental retardation. American Journal on Mental Retardation, 100(6), 632-642.

Wehmeyer, M.L. (2005). Self-determination and individuals with severe disabilities: Reexamining meanings and misinterpretations. *Research and Practice for Persons with Severe Disabilities, 30,* 113-120.

Wehmeyer, M.L., Abery, B., Mithaug, D.E., & Stancliffe, R. J. (2003). *Theory in self-determination: Foundations for educational practice.* Springfield, IL: Charles C Thomas Publisher, LTD.

Wehmeyer, M.L., Agran, M., Hughes, C., Martin, J., Mithaug, D.E., & Palmer, S. (2007). *Promoting self-determination in students with intellectual and developmental disabilities.* New York: Guilford Press.

Wehmeyer, M. L., & Bolding, N. (1999). Self-determination across living and working environments: A matched-samples study of adults with mental retardation. *Mental Retardation, 37*, 353-363.

Wehmeyer, M. L., & Bolding, N. (2001). Enhanced self-determination of adults with mental retardation as an outcome of moving to community-based work or living environments. *Journal of Intellectual Disability Research, 45*, 371-383.

Wehmeyer, M. L., & Kelchner, K. (1995). *The Arc's Self-Determination Scale: Adolescent Version*. Arlington, TX: The Arc of the United States.

Wehmeyer, M. L., & Palmer, S. B. (2003). Adult outcomes for students with cognitive disabilities three-years after high school: The impact of self-determination.

Wehmeyer, M.L., Palmer, S., Agran, M., Mithaug, D., & Martin, J. (2000). Promoting causal agency: The self-determined learning model of instruction. *Exceptional Children*, 66(4), 439-453.

Wehmeyer, M. L., Palmer, S. B., Shogren, K., Williams-Diehm, K., & Soukup, J. H. (2013). Establishing a Causal Relationship Between Intervention to Promote Self-Determination and Enhanced Student Self-Determination. *The Journal of Special Education, 46*(4), 195-210.

Wehmeyer, M. L., & Schwartz, M. (1998). The relationship between self-determination and quality of life for adults with mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities, 33*, 3-12.

Wehmeyer, M. L., Shogren, K. A., Palmer, S. B., Williams-Diehm, K. L., Little, T. D., & Boulton, A. (2012). The impact of the self-determined learning model of instruction on student self-determination. *Exceptional Children, 78*(2), 135-153.

West, S. G., Finch, J. F. & Curran, P. J. (1995). *Structural equation models with non-normal variables: Problems and remedies.* In R. Hoyle (Ed.), Structural equation modeling: Concepts, issues, and applications. Thousand Oaks, CA: Sage.

Wiliner, P., Bailey, R., Parry, R., & Dymond, S. (2010). Performance in temporal discounting tasks by people with intellectual disabilities reveals difficulties in decision-making and impulse control. *American Journal on Intellectual and Developmental Disabilities, 115*, 157-171. doi: http://dx.doi.org/10.1352/1944-7558-115.2.157

Winick, B. (1995). The side effects of incompetency labeling and the implications for mental health law. *Psychology, Public Policy &Law, 1*(1), pp. 6-42.

World Health Organization. (2007). *International classificaiton of functioning, disability and health: Children and youth version*. Geneva: Author.

Wright, J. (2010). Guardianship for your own good: Improving the well-being of respondents and wards in the USA. *International journal of law and psychiatry*, *33*(5-6), 350-368. http://dx.doi.org/10.1016/j.ijlp.2010.09.007

Wright, J. (2004). Protecting who from what, and why, and how?: A proposal for an integrative approach to adult protective proceedings. *The Elder Law Journal, 12*(1), pp. 53-118.

Yannacci, J., Roberts, K. & Ganju, V. (2006). Principles from Adult Learning Theory, Evidence-Based Teaching, and Visual Marketing: What are the Implications for Toolkit Development? 21 September 2008 <http://www.nri-inc.org/reports_pubs/2006/EBPAdultLearnTheory2006.pdf

Burton Blatt Institute
SYRACUSE UNIVERSITY

Survey of Supported Decision-Making in Practice

Consent Form – Parent/Service Provider/Supporter

You are invited to participate in a research survey about supported decision-making as used by people with intellectual or developmental disabilities or someone who uses supported decision-making, and the people that support and work with them. If you choose to participate, you will see an online survey that should take approximately 10-15 minutes of your time. If you prefer to take the phone by survey or paper, you can contact our survey administrator and she will help you (see below for all contact information).

Your participation in this survey is strictly voluntary. You can choose not to participate at any time without any penalty. This survey is anonymous. We will not ask you for your name or identifying information.

Whenever one works with email or the internet there is always the risk of compromising privacy, confidentiality, and/or anonymity. Your confidentiality will be maintained to the degree permitted by the technology being used. It is important for you to understand that no guarantees can be made regarding the interception of data sent via the internet by third parties.

At the end of the survey, you will be given the opportunity to provide your name and contact information in case you wish to participate in future research. If you choose to do so, you will click on a link that takes you to a separate page to enter that information and there will be no tie between your survey responses and contact information.

If you want to take this survey by phone or have a paper copy mailed to you, contact Celestia Ohrazda at cohrazda@law.syr.edu. If you have questions about the study, contact Dr. Meera Adya at the Burton Blatt Institute at 315-443-2863 or madya@syr.edu. If you have questions or problems about participating in this study that you don't want to ask Dr. Adya, contact the Syracuse University Institutional Review Board at 315-443-3013 or orip@syr.edu.

By clicking the "next" button, you are also indicating that you are age 18 years or older.

NEXT

COLLECTING STORIES OF SUPPORTED DECISION-MAKING

Thank you! Before we start the survey, we need to ask you your age and if you want to start.
Are you 18 years old or older?

- ❍ Yes
- ❍ No

Are you a parent, friend, supporter, service provider, or someone else who knows or works with a person with I/DD or someone who uses supported decision-making?

- ❍ Yes
- ❍ No

Survey for parent, friend, supporter, service provider, or someone else who knows or works with a person with I/DD or someone who uses supported decision-making

Which of the following best describes you?

- ❍ A Parent or Family Member of a Person with I/DD or someone who uses supported decision-making
- ❍ A Friend of a Person with I/DD or someone who uses supported decision-making
- ❍ A Service Provider, or Supporter of a Person with I/DD or someone who uses supported decision-making
- ❍ Someone else who knows or works with a person with I/DD or someone who uses supported decision-making

How old are you? _____

What is your sex?

- ❍ Male
- ❍ Female

What is your Marital Status?

- ❍ Single
- ❍ Cohabitating
- ❍ Married
- ❍ Separated
- ❍ Divorced
- ❍ Widowed

What is the highest degree or level of school you have completed?

- ❍ Less than 9th grade
- ❍ 9th to 12th grade, no diploma
- ❍ High school graduate or GED
- ❍ Some college, no degree
- ❍ Associate degree
- ❍ Bachelor's degree
- ❍ Master's degree
- ❍ Professional degree (e.g., JD, MD)
- ❍ Doctorate degree

Do you have a job?

- ❍ Yes, Full-time
- ❍ Yes, Part-time
- ❍ No

Answer If Which of the following best describes you? A Parent or Family Member of a Person with I/DD or someone who uses supported decision-making Is Selected
Are you a parent?

- ❍ Yes
- ❍ No

Answer If Which of the following best describes you? A Parent or Family Member of a Person with I I/DD or someone who uses supported decision-making Is Selected
Do you have any other children with disabilities?

- ❍ Yes
- ❍ No

Answer If Which of the following best describes you? A Parent or Family Member of a Person with I I/DD or someone who uses supported decision-making Is Selected
Do you have any other children without disabilities?

- ❍ Yes
- ❍ No

Are you a guardian for someone?

- ❍ Yes
- ❍ No

Answer If Are you a guardian for someone? Male Is Selected

How old is the person you are a guardian for?

Answer If Is the person you are a guardian for male or female? Male Is Selected

Is the person you are a guardian for male or female?

- ❍ Male
- ❍ Female

Answer If Are you a guardian for someone? Yes Is Selected

Did the person you are a guardian for go to high school?

- ❍ Still in high school
- ❍ Graduate from high school
- ❍ Attended high school - did not graduate

Answer If Are you a guardian for someone? Yes Is Selected And Did the person you are a guardian for go to high school? Still in high school Is Not Selected

Did the person you are a guardian for attend higher education?

- ❍ Yes, College
- ❍ Yes, Vocational Training
- ❍ No
- ❍ Other. Please specify: _____

Answer If Did the person you are a guardian for go to high school? Still in high school Is Not Selected And Did the person you are a guardian for attend high eduction? No Is Not Selected

Does the person you are a guardian for have a college degree?

- ❍ Yes
- ❍ No

Answer If Are you a guardian for someone? Yes Is Selected

Does the person you are a guardian for have a job?

- ❍ Yes, Full-time
- ❍ Yes, Part-time
- ❍ No

Answer If Are you a guardian for someone? Yes Is Selected And Does the person you are a guardian for have a job? No Is Not Selected

What kind of job is it?

Answer If Are you a guardian for someone? Yes Is Selected

Did you want to be a guardian?

- ❍ Yes
- ❍ No

Answer If Are you a guardian for someone? Yes Is Selected And Which of the following best describes you? A Service Provider, or Supporter of a Person with I/DD or someone who uses supported decision-making Is Selected

How many people do you provide guardianship for? __

Answer If Are you a guardian for someone? No Is Selected

Do you help your child/client/friend make decisions (would you consider yourself a “supported decision-maker)?

- ❍ Yes
- ❍ No

Answer If Are you a guardian for someone? Yes Is Selected

Did your child/client want a guardian?

- ❍ Yes
- ❍ No

Answer If Are you a guardian for someone? Yes Is Selected

Who told you about guardians?

- ❑ Mom or Dad
- ❑ Brothers or Sisters
- ❑ Other family members
- ❑ Friends
- ❑ Teachers
- ❑ Doctors
- ❑ Social Workers
- ❑ Case Managers
- ❑ Someone else (Who?) _____

Answer If Are you a guardian for someone? No Is Selected

Does anyone else help your child/client/friend make decisions?

- ❑ Mom or Dad
- ❑ Brothers or Sisters
- ❑ Other family members
- ❑ Friends
- ❑ Teachers
- ❑ Doctors
- ❑ Social Workers
- ❑ Case Managers
- ❑ Someone else (Who?) _____

Answer If Are you a guardian for someone? Yes Is Selected

Did you have to go to court or see a judge to get a guardian?

- ❍ Yes
- ❍ No

Answer If Are you a guardian for someone? Yes Is Selected

Does your child/client like having a guardian?

- ❍ Yes
- ❍ No

Answer If Are you a guardian for someone? Yes Is Selected

Do you make all or some of your child's/client's decisions?

- ❍ All
- ❍ Some

Answer If Are you a guardian for someone? Yes Is Selected

Do you ask your child/client what they want and try to do only that for them?

- ❍ Yes
- ❍ No

Answer If Are you a guardian for someone? Yes Is Selected

What kind of decisions does your child/client help you make?

- ❑ Where to live
- ❑ What to do with my money
- ❑ What to do with my time when I'm not working
- ❑ When to go to the doctor and what the doctor is allowed to do when I'm sick
- ❑ Who else I want to help me
- ❑ Other things (What?) _____

Answer If Are you a guardian for someone? No Is Selected

What kind of decisions do you help your child/client make?

- ❑ Where to live
- ❑ What to do with my money
- ❑ What to do with my time when I'm not working
- ❑ When to go to the doctor and what the doctor is allowed to do when I'm sick
- ❑ Who else I want to help me
- ❑ Other things (What?) _____

Answer If Are you a guardian for someone? No Is Selected

Do you think it has made your child's/client's/friend's life better to have someone help them make decisions?

- ❑ They have more confidence
- ❑ They can do more things
- ❑ They're happier
- ❑ They have more friends
- ❑ They get to do what they want
- ❑ They want to try more things

Answer If Are you a guardian for someone? No Is Selected

Has anyone ever challenged your child's/client's/friend's capacity and/or competency?

- ❍ Yes
- ❍ No

Answer If Are you a guardian for someone? No Is Selected And Does your child/client want to make some of their own decisions? Yes Is Selected

Who challenged your child's/client's/friend's capacity and/or competency?

Answer If Are you a guardian for someone? No Is Selected And Does your child/client want to make some of their own decisions? Yes Is Selected

Was there a legal process involved?

- ❍ Yes
- ❍ No

Answer If Are you a guardian for someone? No Is Selected And Does your child/client want to make some of their own decisions? Yes Is Selected And Who challenged your child's/client's/friend's capacity and/or competency? Yes Is Selected

Was the legal process ending a previous decision to have a guardian and exploration of less restrictive options or new/first time guardianship hearing?

- ❍ Previous
- ❍ First time

Answer If Are you a guardian for someone? No Is Selected

How were less restrictive options to guardianship identified, considered, and decided?

Answer If Are you a guardian for someone? No Is Selected

Who was part of decision making process?

Answer If Are you a guardian for someone? No Is Selected

When supported decision-making was put in place, who decided who would be supporters and was a formal agreement negotiated?

Answer If Are you a guardian for someone? No Is Selected

What do you think is the impact of supported decision-making relative to a more restricted role in decision making through guardianship?

Do you think there are any lessons learned that are generalize-able for policy, practice in courts and/or service delivery systems?

Thank you!

Dear Participant,
If you are interested in information about any future research activities, please provide us with your preferred email address or phone number. Please note that this does not mean you have to participate in future research. Your email or phone number will be used only to let you know about new research activities. We will store your name and email or phone number in a safe and separate place from your survey answers. Please enter your preferred email address or phone number in the space below:

Email or phone:_____

Answer If Thank you! Before we start the survey, we need to ask you your age and if you want to start. Are... No Is Selected

Thank you for your interest in our work! This survey is for adults only, but we may have another one in the future for you.

Survey of SDM in Practice – Consent Form 2 – Parent/Service Provider/Supporter

Survey of Supported Decision-Making in Practice

Consent Form - Individual

- You are invited to **participate** in (be a part of) **a research survey** (list of questions you answer) to tell others about how you make decisions and how you use help to make decisions.

- You are being asked to participate in this evaluation because you make decisions.

- This form has **information about participating** in this survey.

- If you understand everything on this form and would like to participate, you need to **click a button to continue**.

- You can **choose** to participate or not.

Who is in charge of this survey?

Meera Adya, Ph.D., J.D.
Director of Research
Burton Blatt Institute
Syracuse University

What is the survey for?

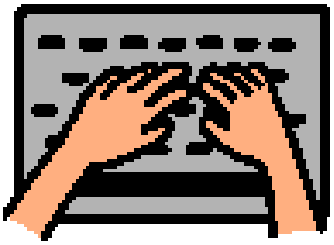
To learn:

- How you **make decisions**
- How **people help you** make decisions

What will happen if you decide to participate in the survey?

You will **see a list of questions** on the screen.

You can **click buttons** to tell us your answers.



If you don’t want to answer questions on your computer, you can ask us to call you.

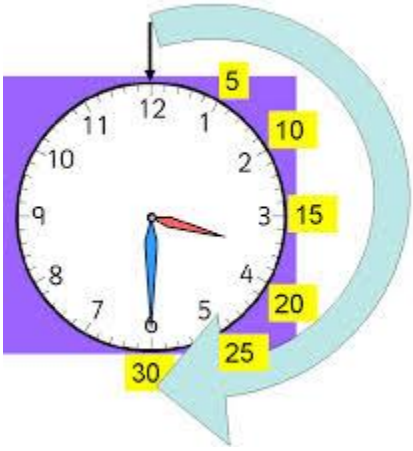
Or you can ask us to send you papers.

Some of these questions will be:

1. How old are you?
2. Does someone help you make decisions?

You can **skip questions** or **stop** whenever you want.

May last up to half an hour



No right or wrong answers

Can anything bad happen to you from participating in the survey?

Meera does not expect anything bad to happen to you from participating in the survey. Remember:

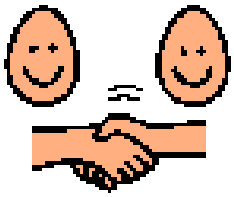
- You get to choose to answer questions.
- You can stop any time.

Everything you say will be **private,** or anonymous.

But, sometimes people steal information from a computer. We will lock our computer information, but when you send the answers by computer someone may see it. We promise to do our best to stop them.

We will not ask you your name or who you are. And we will not tell others who you are or that you took our survey.

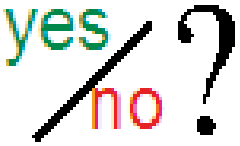
What will you get from participating in the evaluation?



You might **like** sharing your experiences

You may **feel good about helping us learn** more about how you make decisions and how others help you.

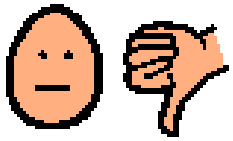
What will happen if you decide NOT to participate?



Nothing!

No one will be upset if you choose not to participate, including Meera, the other members of the research project, or your family or staff

It is **your right** to decide



If you **do not want to participate** or if you **want to stop** participating during the interview, you can say:

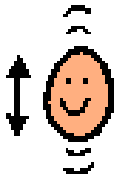
- *I don't want to keep going.*
- *I would rather not participate.*
- *This won't work for me.*
- *I don't want to answer that question.*

What will happen after the information is collected?

- Meera will look at all of the information she has collected and write a summary of findings.
- Meera will share findings with others.

What should you do now?

- Think things over
- Talk to a friend or family member, if you want to
- When you are ready, decide if you want to participate



If you would like to participate

Do you understand everything on this form?
Do you have any questions?

If you have questions or problems about participating in this study that you don't want to ask Meera, contact:

Institutional Review Board (IRB)
Syracuse University
315-443-3013
orip@syr.edu

If you have questions about the study, contact:

Dr. Meera Adya
Burton Blatt Institute
Syracuse University
315-443-2863
madya@syr.edu

- You may stop your participation in this study at any time, without anything bad happening.
- Please print and keep a copy of this form for your records.
- By clicking the "next" button, you are also indicating that you are age 18 years or older.

NEXT

Survey for person with I/DD or someone who uses supported decision-making

How old are you? _

Are you a man or a woman?
- ❍ Man
- ❍ Woman

Did you go to high school?
- ❍ Yes
- ❍ No

Answer If Did you go to high school? Yes Is Selected

Did you go to college?
- ❍ Yes
- ❍ No

Answer If Did you go to college? Yes Is Selected

Do you have a college degree?
- ❍ Yes
- ❍ No

Do you have a job?
- ❍ Yes
- ❍ No

Answer If Do you have a job? Yes Is Selected

Is your job full-time or part-time?
- ❍ Full-time
- ❍ Part-time

Do you have a Mom?
- ❍ Yes
- ❍ No

Do you have a Dad?
- ❍ Yes
- ❍ No

Do you have any brothers or sisters?
❍ Yes
❍ No

Answer If Do you have any brothers or sisters? Yes Is Selected
How many brothers or sisters do you have?

Are you married?
❍ Yes
❍ No

Do you have a guardian?
❍ Yes
❍ No

Answer If Do you have a guardian? Yes Is Selected
Who is your guardian?
❑ Mom or Dad
❑ Brothers or Sisters
❑ Other family members
❑ Friends
❑ Teachers
❑ Doctors
❑ Social Workers
❑ Case Managers
❑ Someone else (Who?) _____

Answer If Do you have a guardian? Yes Is Selected
Did you want a guardian?
❍ Yes
❍ No

Answer If Do you have a guardian? Yes Is Selected

Who told you about guardians?

- ❑ Mom or Dad
- ❑ Brothers or Sisters
- ❑ Other family members
- ❑ Friends
- ❑ Teachers
- ❑ Doctors
- ❑ Social Workers
- ❑ Case Managers
- ❑ Someone else (Who?) _____

Answer If Do you have a guardian? Yes Is Selected

Did you have to go to court or see a judge to get a guardian?

- ❍ Yes
- ❍ No

Answer If Do you have a guardian? Yes Is Selected

Do you like having a guardian?

- ❍ Yes
- ❍ No

Answer If Do you have a guardian? Yes Is Selected

Does your guardian make all or some of your decisions for you?

- ❍ All
- ❍ Some

Answer If Do you have a guardian? Yes Is Selected

Does your guardian ask you what you want and try to do that for you?

- ❍ Yes
- ❍ No

Answer If Do you have a guardian? Yes Is Selected

What kind of decisions does your guardian help you make?

- ❑ Where to live
- ❑ What to do with my money
- ❑ What to do with my time when I'm not working
- ❑ When to go to the doctor and what the doctor is allowed to do when I'm sick
- ❑ Who else I want to help me
- ❑ Other things (What?) _____

Answer If Do you have a guardian? Yes Is Selected

Does you want to make some or all of your own decisions?

❍ Yes
❍ No

Answer If Did you want a guardian? No Is Selected

Do you have someone help you make decisions?

❍ Yes
❍ No

Answer If Did you want a guardian? Yes Is Selected

Do you have someone help you make decisions other than your guardian?

❍ Yes
❍ No

Answer If Do you have a guardian? No Is Selected And Do you have someone help you make decisions? No Is Selected

Do you wish you had someone to help you make decisions?

❍ Yes
❍ No

Answer If Do you have a guardian? Yes Is Selected And Do you have someone help you make decisions other than your guardian? No Is Selected

Do you wish you had someone to help you make decisions other than your guardian?

❍ Yes
❍ No

Answer If Do you have someone help you make decisions? Yes Is Selected Or Do you have someone help you make decisions other than your guardian? Yes Is Selected

Who helps you make decisions?

❑ Mom or Dad
❑ Brothers or Sisters
❑ Other family members
❑ Friends
❑ Teachers
❑ Doctors
❑ Social Workers
❑ Case Managers
❑ Someone else (Who?) _____

Answer If Do you have someone help you make decisions? Yes Is Selected Or Do you have someone help you make decisions other than your guardian? Yes Is Selected

What kind of decisions do they help you make?

- ❑ Where to live
- ❑ What to do with my money
- ❑ What to do with my time when I'm not working
- ❑ When to go to the doctor and what the doctor is allowed to do when I'm sick
- ❑ Who else I want to help me
- ❑ Other things (What?) _____

Answer If Do you have someone help you make decisions? Yes Is Selected Or Do you have someone help you make decisions other than your guardian? Yes Is Selected

Do you think it has made your life better to have someone help you make decisions?

- ❑ I have more confidence
- ❑ I can do more things
- ❑ I'm happier
- ❑ I have more friends
- ❑ I get to do what I want
- ❑ I want to try more things

Answer If Did you wish you had someone to help you make decisions? Yes Is Selected Or Did you wish you had someone to help you make decisions other than your guardian? Yes Is Selected

Who do you wish would help you make decisions?

- ❑ Mom or Dad
- ❑ Brothers or Sisters
- ❑ Other family members
- ❑ Friends
- ❑ Teachers
- ❑ Doctors
- ❑ Social Workers
- ❑ Case Managers
- ❑ Someone else (Who?) _____

Answer If Did you wish you had someone to help you make decisions? Yes Is Selected Or Did you wish you had someone to help you make decisions other than your guardian? Yes Is Selected

What kind of decisions do you wish they would help you make?

- ❑ Where to live
- ❑ What to do with my money
- ❑ What to do with my time when I'm not working
- ❑ When to go to the doctor and what the doctor is allowed to do when I'm sick
- ❑ Who else I want to help me
- ❑ Other things (What/) _____

Answer If Did you wish you had someone to help you make decisions? Yes Is Selected Or Did you wish you had someone to help you make decisions other than your guardian? Yes Is Selected

Do you think it would made your life better to have someone help you make decisions?

- ❑ I would have more confidence
- ❑ I could do more things
- ❑ I would be happier
- ❑ I would have more friends
- ❑ I would get to do what I want
- ❑ I would want to try more things

Do you want to tell us anything else about how you make decisions and how it makes you feel?

_____

_____

_____

_____

Thank you!

Dear Participant,

If you are interested in information about any future research activities, please provide us with your preferred email address or phone number. Please note that this does not mean you have to participate in future research. Your email or phone number will be used only to let you know about new research activities. We will store your name and email or phone number in a safe and separate place from your survey answers. Please enter your preferred email address or phone number in the space below:

Email or phone:_____