

# Annual Performance Report

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# **INTRODUCTION**

Quality Trust for Individuals with Disabilities (“Quality Trust”) is pleased and proud to submit this Annual Report for the period from September 2014-August 2015.

Quality Trust is an independent, nonprofit advocacy organization dedicated to ensuring that people have the supports and services they need to live full and meaningful lives in the places and ways they choose. Our mission is to act as an independent catalyst for change, partnering with people, families, advocates, professionals, and providers to create a community where everyone is respected and valued, belongs and contributes, and shapes their own present and future. To that end, we have supported thousands of people and trained thousands of individuals, families, attorneys, advocates, guardians, practitioners, and providers on diverse policy and practice topics including guardianship and Supported Decision-Making.

In September of 2014, we were honored to receive Cooperative Agreement Number 90DM0001 to establish the National Resource Center for Supported Decision-Making (“National Resource Center”). Our project partners include the Burton Blatt Institute of Syracuse University (BBI), The Kansas University Life Span Institute (KU), The American Bar Association Commission on Law and Aging (ABA), the Autistic Self Advocacy Network (ASAN), Family Voices (FV), and Parent to Parent USA (P2P).<sup>1</sup>

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<sup>1</sup> In the past year, we have also collaborated with several local, state, national, and international organizations including (but not limited to) Justice in Aging; the National Consumer Law Center; the National Association of State Directors of Developmental Disabilities Services (NASDDDS); the National Association of States United for Aging and Disabilities (NASUAD); the National Association of Area Agencies on Aging (N4A); the

In partnership with older adults, people with disabilities, attorneys and judges, health care and financial professionals and providers, the National Resource Center conducts groundbreaking research, creates educational programs, and develops multidisciplinary best practices with the goal of advancing policy and practice to establish Supported Decision-Making as a recognized, viable alternative to guardianship, a means of increasing self-determination, and a way to improve life outcomes.

## **ACCOMPLISHMENTS**

### **Summary**

In our first year of existence, the National Resource Center has touched the lives of thousands of people—across the United States and as far away as Ethiopia—including older adults, people with disabilities, families, attorneys, advocates, professionals, and providers. We have launched a website, had articles published and accepted for publication in national journals, spoken and been invited to speak at conferences around the country, presented a multi-part webinar series, created and implemented a state grant program, worked to develop and improve policy and practice, and collaborated with existing and new partners.

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National Legal Resource Center (NLRC); District of Columbia Public Schools (DCPS); the American Association of Retired Persons (AARP); Title IIIB legal providers; the National Guardianship Association (NGA); the Association of University Centers on Disabilities (AUCD); WINGS workgroups in Wisconsin, Washington State and Washington DC; Project Action!; the Canadian Association for Community Living (CACL); APSE; and TASH.

## **SupportedDecisionMaking.Org**

In January of 2015, the National Resource Center launched its website, [www.SupportedDecisionMaking.Org](http://www.SupportedDecisionMaking.Org). The website serves as the National Resource Center's information, training and technical assistance hub, functioning as a "one-stop" resource for our diverse community stakeholders, including older adults, people with intellectual and developmental disabilities ("IDD"), families, guardians, advocates, researchers, practitioners, members of the legal community, and policy makers.

The website was "field tested" by self-advocates and other stakeholders and received positive reviews for its content and accessibility. Through August 2015 (approximately eight months after launch), the website has been visited **10,577** times with **26,047** "pages" viewed and our Facebook page has garnered **345** followers in addition to the **1,050** followers of the Jenny Hatch Justice Project page (where we also distribute National Resource Center information). A summary report on website and Facebook page usage is included in the Appendix.

SupportedDecisionMaking.Org provides accessible, useful information, technical assistance, and educational materials aimed at multiple audiences and designed to increase knowledge about, and use of, Supported Decision-Making. In order to make the concept and use of Supported Decision-Making more accessible and acceptable across multiple audiences and disciplines, the National Resource Center has coined the phrase "Everyone has the Right to Make Choices" to show that Supported Decision-Making increases and enables self-determination and individual choice for people of all ages and abilities. That phrase welcomes

all visitors to the website and sets the tone for its content.

The “Front Page” of the website includes an ever-updating list of new content (such as journal articles, blog entries, and training opportunities) as well as an introductory message and videos. Front Page material has included video and audio recordings of National Resource Center staff presenting and conducting trainings; preliminary results from research into Supported Decision-Making best practices; blog posts; scholarly articles written by National Resource Center staff; and a calendar of upcoming events featuring National Resource Center partners.

The website is organized into several areas, each of which is designed to introduce and address a different approach to or way of accessing information about Supported Decision-Making. These include:

#### Stories of Supported Decision-Making

This section is designed to teach people about the impact guardianship and Supported Decision-Making has on the everyday lives of people. In it, we tell the stories of people who use Supported Decision-Making and of work done by Quality Trust and the National Resource Center to advance “The Right to Make Choices.”

Using video, audio, documents, news articles, and links to official and court documents, this section this section includes stories about people like Jenny Hatch and Ryan King who (represented by Quality Trust) seek the right to use Supported Decision-Making instead of being subjected to permanent, plenary guardianship.

In addition, and as detailed further below, this section contains information we have gathered through a national survey of individuals who use Supported Decision-Making.

### In Your State

Home to the National Resource Center's 50-state review of guardianship law and policy, this section allows people to use an interactive map (or a list of states) to view existing laws and policies in each state. The In Your State section will grow each year and is designed to be an interactive, educational tool where people, families, and professionals can learn about (and submit) laws, policies, and practices that impact guardianship and Supported Decision-Making.

This section includes a summary and link to guardianship laws in every state as well as a summary of a person facing a guardianship petition's right to be represented by an attorney.

In addition to basic guardianship laws, we have defined three key domains of participation where supported decision-making can play a key role to review: (1) Education, (2) Health, and (3) Economic. For this past year, we selected a topic to consider under each domain: (1) Special Education Transfer of Rights; (2) Person Centered Planning; and (3) The right to enter into contracts. For each of the reviews we will provide summaries of relevant laws or policies in each state, with a link to the relevant statute or policy guidance. In addition, we indicate whether guardianship (or in some cases, Supported Decision-Making) is explicitly identified and/or whether it is impacted significantly.

In the future, we intend to identify and review additional topics under each domain and/or conduct deeper policy analyses of each issue already reviewed to examine patterns,



trends, and inconsistencies, as well as innovative or forward thinking policies.

### Library

The Library section is divided into two separate areas: (1) A keyword-searchable “Research Library” containing scholarly articles and other national and international materials aimed at professionals and people conducting research; and (2) A “Resource Library” providing useful, “how-to” and other educational materials regarding specific issues (e.g. education, guardianship, health care, life planning) aimed at specific audiences (e.g. older adults, parents of children with disabilities, students, people transitioning into adulthood).

Recent additions to the Research library include journal articles written by National Resource Center staff. Resource Library additions include accessible, “hands on” material and toolkits designed to help individuals and families implement Supported Decision-Making.

These Libraries will grow over time as the National Resource Center receives, creates, and learns about new research and resource material. Visitors may submit new material to the library (and we have already received inquiries from scholars wishing to do so).

### Education

Home to the National Resource Center’s interactive training material, this section currently hosts the following training modules:

- Archived Webinar Series: The Next Generation of Freedom and Self Determination: Moving Supported Decision-Making from Theory to Practice

Part I: Supported Decision-Making and Youth in Transition

Part II: Supported Decision-Making in Medicaid, Home and Community  
Based-Services Final Rule

Part III: Supported Decision-Making and the ABLE Act

- Educational Program: “Introduction to Guardianship and Alternatives”
- Educational Program: “Supported Decision-making: EVERYONE Has the Right to Make Choices.”
- Archived Webinar: eQuality: The Struggle for Web Accessibility by Persons with Cognitive Disabilities
- Archived Webinar Series: Supported Decision-Making: Past, Present, and Future

Part I: Introduction to Supported Decision-Making

Part II: Lessons Learned from the Canadian Experience: Supported  
Decision Making Models

Part III: Supported Decision-Making: The Next Level of Policy  
Development

Other available educational materials include:

- Archived Webinar: The *Olmstead* Supreme Court Decision: The Opportunity Integration Imperative
- Archived Webinar: The Rights and Respect Sarah Taub National Core Indicators Webinar

Our three-part webinar series in April, May, and June of 2015 was a particular success. The series focused on moving Supported Decision-Making from theory to practice. In each of the three parts, national experts opined on the “next steps” needed to increase knowledge of, access to, and implementation of Supported Decision-Making in the educational, health care, and financial fields, respectively. **461** people took part in our live webinars, an average of **153** people per webinar. An additional **907** people accessed archived copies of the webinars from our website. We believe that the large number of people accessing the archived materials is indicative of positive “word of mouth” for our work.

Follow-up evaluation surveys sent to participants yielded strongly positive sentiments about the content and presentation of our webinar series, including:

- 97% of the participants that completed the survey stated that the Knowledge of Presenters was very good or excellent (64% rated excellent, 33% very good)
- 84% of the participants that completed the survey stated that the Clarity of Instructions for participation was very good or excellent (59% rated excellent, 25% very good, 13% good);
- 88% of the participants that completed the survey stated that the overall Quality of Presentation was very good or excellent (47% rated excellent, 41% very good, 9% good);
- 78% of the participants that completed the survey stated that the Materials Provided to Support the Webinar were very good or excellent (39% rated excellent, 39% very good, 23% good);

- 94% of the participants that completed the survey stated that their Knowledge of the subject had increased as a result of this training (30% Considerable amount, 61% Moderate amount, 3% Limited amount);
- 92% of the participants that completed the survey found the information presented was useful (71% Very useful, 21% Somewhat useful); and
- 88% of the participants that completed the survey stated that they would participate in future trainings using this format

### Supported Decision-Making Interactive!

Supported Decision-Making Interactive! is the National Resource Center's listserv dedicated to discussion and debate about guardianship, Supported Decision-Making and other topics relevant to our stakeholders. The listserv allows people to interact with older adults, people with IDD, family members, advocates, and national experts on self-determination to increase knowledge about and use of Supported Decision-Making. As August 2015, **145** people have joined the listserv.

## **Journal Articles**

The National Resource Center and its partners had several articles published in national journals this year. These include:

Published in *Inclusion*, 2015, Vol 3, No. 1 (copies provided with Semi-Annual Report):

- *"The Right to Make Choices": The National Resource Center for Supported*

*Decision-Making.*” Written by Peter Blanck, chairman of the Burton Blatt Institute, a National Resource Center partner, and Jonathan Martinis, project director of the National Resource Center, the article describes the negative effects of overly broad and unnecessarily restrictive guardianship arrangements; the potential benefits of Supported Decision-Making; recent developments in research and practice in Supported Decision-Making; and the National Resource Center’s goals “to increase awareness and advance the practice of Supported Decision-Making.”

- “*Supported Decision-Making in Practice.*” Written by Tina M. Campanella, CEO of Quality Trust, the article focuses on ways to access and implement Supported Decision-Making for older adults and people with IDD. The article includes best-practice recommendations for assessments and the role of direct support.
- “*My Story.*” Written by Margaret “Jenny” Hatch, a National Resource Center advisory board member, this article describes her year-long ordeal, where she was forced to live under a plenary guardianship in a segregated group home. After a year of litigation, Jenny (represented by Quality Trust) won the right to use Supported Decision-Making and now lives and works where she wants, has the friends she chooses, and encourages others to do the same.
- “*A Framework for Research and Intervention Design in Supported Decision-Making.*” Written by National Resource Center partners Karrie A. Shogren and Michael L. Wehmeyer of the University of Kansas, this article “proposes a three-

pronged framework for considering the design of assessments and interventions to promote supported decision-making; decision-making abilities, environmental demands for decision-making, and support needs for decision-making.”

Published in the Journal of Vocational Rehabilitation, Volume 42(3):

- *“‘The Right to Make Choices’: How Vocational Rehabilitation Can Help Young Adults With Disabilities Increase Self-Determination and Avoid Guardianship.”*

Written by Jonathan Martinis, project director of the National Resource Center, this article discusses the problems associated with overbroad and undue guardianship, the benefits of self-determination, and how young adults with disabilities can access and utilize Vocational Rehabilitation services and supports to help them develop self-determination skills and avoid guardianship. A copy of this article is attached in the Appendix.

Published in the American Bar Association Commission on Law and Aging, *Bifocal e-journal*, Vol 36, Issue 5 (June 2015)

- “Supported Decision-Making: Protecting Rights Ensuring Choices.” Written by Jonathan Martinis, project director of the National Resource Center, this article introduces Supported Decision-Making to the readership of the ABA Commission’s bimonthly online publication, which reaches hundreds of attorneys,

aging professionals and advocates. A copy of this article is attached in the Appendix.

Two additional publications have been submitted to journals. Copies of each will be submitted with our first reports after publication:

- “Supported Decision-Making: A Synthesis of the Literature to Guide Assessment and Intervention Development,” co-written by Dr. Karrie Shogren and Dr. Michael has been submitted to *Intellectual and Developmental Disabilities*.
- An article discussing state policy reforms that may be necessary in order to promote recognition of Supported Decision-Making by courts, written by Samantha Crane, has been submitted to the *Journal of International Aging Law and Policy*.

## **Presentations, Education, and Training**

In-person and virtual presentations are a primary focus of our work. Simply put, there is no substitute for meeting actual and potential stakeholders and discussing Supported Decision-Making with them, to help them better understand, absorb, and personalize the issue. The National Resource Center has presented to thousands of people in webinars and conferences across the country. We have spoken to older adults, people with disabilities, families, teachers, doctors, attorneys, advocates, judges, professionals, and providers on topics including

guardianship, education, employment, legal representation, medical care, vocational rehabilitation, and guardianship.

In all, National Resource Center partners have made **54** presentations on Supported Decision-Making theory, implementation, policy, and practice in the last year, an average of **over four** presentations per month, with several national presentations already scheduled for next year.

Our presentations this year included:

<b>Date</b>	<b>Audience</b>	<b>Topic</b>
9/14	National Disability Leadership Alliance Organizers Forum	Supported Decision-Making as an alternative to guardianship and as a means of increasing self-determination
9/14	Nebraska Division of Developmental Disabilities	Supported Decision-Making, with an emphasis on practical implementation
10/14	National Guardianship Association	Supported Decision-Making as an alternative to guardianship and used with people under guardianship
10/14	Virginia Department of Behavioral Health and Behavioral Services	Supported Decision-Making, with a focus on Policy and Practice Implications
10/14	Rotary Club of Dulles, Va	Supported Decision-Making, with a focus on independence and self-determination for older adults
10/14	Catholic University of America, Special Education graduate-level class.	Supported Decision-Making in education, with an emphasis on transition planning



10/14	Georgetown University Law Center practicum class	Guardianship, Supported Decision-Making and commitment of people with IDD
10/14	DC Office of the Ombudsman for Public Education	Guardianship, Supported Decision-Making and Transfer of Rights
10/14	National Guardianship Association (NGA)	Connecting Supported Decision-Making with NGA best practice standards.
11/14	DC Superior Court Subcommittee on Mental Habilitation Standards of Practice	Supported Decision-Making as an alternative to guardianship in legal system
11/14	APSE/ANCOR	Supported Decision-Making, with an emphasis on supporting employment
11/14	Howard County, Maryland Autism Society	Supported Decision-Making, with a focus on guardianship, alternatives, and life/financial planning
11/14	Wisconsin Developmental Disabilities Council	Supported Decision-Making, with a focus on alternatives to guardianship
12/14	TASH	(1) Supported Decision-Making as an alternative to guardianship (2) Supported Decision-Making in Vocational Rehabilitation (3) "TASH talk" on Supported Decision-Making and Self-Determination (4) Self Advocacy for Supported Decision-Making.
12/14	USC	Supported Decision-Making and individuals with serious or persistent mental illness
1/15	DC PALS	Guardianship and Supported Decision-Making for children and older adults.

2/15	Washington DC UCEDD	Supported Decision-Making as alternative to guardianship, with a focus on older adults with disabilities
2/15	D.C. East of the River Casehandlers Group	Guardianship and Supported Decision-Making in the legal and service system.
3/15	American Society on Aging	Sustaining community integration and independence using Supported Decision-Making
3/15	Oklahoma Department Of Human Services	Supported Decision-Making as a way to support community inclusion and independence
3/15	Arc of California	Supported Decision-Making as alternative to guardianship, with a focus on people with intellectual disabilities.
3/15	tenBroek Disability Law Symposium	Overview of Supported Decision-Making and work of the National Resource Center
4/15	New York and Mid-Atlantic Consortium for Genetic and Newborn Screening Services	Webinar for doctors and other health-care professionals on using Supported Decision-Making Decision-Making with patients who are transitioning from adolescence to adulthood
4/15	New York State Association of Community and Residential Agencies	Supported Decision-Making as a way to support community integration and independence
4/15	Arc of NY	Supported Decision-Making as an alternative to guardianship and way to increase self-determination
4/15	National Resource Center For Supported Decision-Making	Webinar on using Supported Decision Making for students in special education transition
4/15	ABA Commission on Law and Aging	Introduction to Supported Decision-Making by for attorneys and judges

4/15	D.C. Judicial and Bar Conference	The Right to Make Choices: Developments in Guardianship Law and Supported Decision-Making
5/15	US Department of Justice	Supported Decision-Making and its potential to improve life outcomes
5/15	International Association for the Scientific Study of Intellectual and Developmental Disabilities	Presentation on Supported Decision-Making as an alternative to guardianship and a way to increase self-determination
5/15	D.C. Office of State Superintendent of Education, LEA Institute	Decision-Making Supports for Adult Students with Disabilities
5/15	Wisconsin Developmental Disabilities Council	Training on using Supported Decision-Making in Special Education and Vocational Rehabilitation
5/15	Texas Guardianship Association	Presentation on Supported Decision-Making as an alternative to guardianship
5/15	National Resource Center for Supported Decision Making	Webinar on using Supported Decision-Making in health care, with a focus on HCBS waivers
5/15	Wisconsin State WINGS Workgroup	Presentation on Supported Decision-Making theory and practice
5/15	Open Society	Present on Supported Decision-Making efforts including policy reform, model legislation, and model agreements
6/15	AAIDD	Presentation on Supported Decision-Making and work of the National Resource Center
6/15	Arc of NC	Keynote Address on Supported Decision-Making as an alternative to guardianship and a way to increase self determination

6/15	Georgetown University	Presentation for health care professionals and care coordinators on using Supported Decision Making in end-of-life planning
6/15	Catholic University of America	Presentation for care coordinators on using Supported Decision-Making for at-risk adults
6/15	Washington State WINGS Workgroup	Presentation on Supported Decision-Making as an alternative to guardianship
6/15	National Resource Center for Supported Decision Making	Webinar on using Supported Decision-Making in financial planning, with an emphasis on ABLE accounts
6/15	Association of People Supporting Employment First	Presentation on Supported Decision-Making and the Right to Make Choices
6/15	US Department of Justice Disability Rights Section	Presentation on ways Supported Decision-Making can promote <i>Olmstead</i> enforcement
6/15	Project Action!	Presentation on Supported Decision-Making and the work of the National Resource Center
6/15	White House Forum on LGBT rights	Presentation on how guardianship can impact LGBT community and how Supported Decision-Making can advance LGBT rights and inclusion
7/15	Arc of the United States	Supported Decision-Making and progress in guardianship reform
7/15	National Association of Area Agencies on Aging	Presentation on Supported Decision-Making for Older adults
7/15	National Association of State Directors of Developmental Disabilities Services	Webinar on Supported Decision-Making and the National Core Indicators research

7/15	D.C. Legal Service Community	Legal Advocacy for People with Intellectual Disabilities: An Interactive Discussion of Practice Tips, Ethical Obligations, and Reasonable Accommodations, including Supported Decision-Making
7/15	National Disability Institute	Webinar on Supported Decision-Making and Community Integration
8/15	AAIDD and the Arc	Presentation on Supported Decision-Making and self-determination
8/15	National Association of Qualified Developmental Disabilities Professionals	Working with families to implement Supported Decision-Making
8/15	National Association of Qualified Developmental Disabilities Professionals	Overview of Supported Decision-Making and the work of the National Resource Center

## **Policy and Practice**

Another focus of the National Resource Center’s work is advancing multi-disciplinary policy and practice to increase the use of Supported Decision-Making and other alternatives to guardianship that increase self-determination.

The National Resource Center has collaborated with several partners, across multiple disciplines, in this effort. Our work this year has included:

- Creating and chairing a DC-based workgroup charged to identify the “gaps” in policy and practice that are a barrier to increased use of Supported Decision-Making. Partners on this effort include people with disabilities, older adults,

family members, and representatives of organizations serving older adults and people with disabilities including ASAN, ABA, DC LTC Ombudsman, AARP, DC Department on Disability Services, DC UCEDD, DC P&A, DC Developmental Disabilities Council, and DC Agency on Aging. The workgroup met quarterly and will produce a white paper on its work.

- Working with the National Guardianship Association to develop its position statement on Supported Decision-Making. The NGA adopted our definition of Supported Decision-Making (citing us in the document) and recommended that it and other alternatives be attempted before seeking guardianship.
- Working with the Delaware Protection and Advocacy System to develop and implement Supported Decision-Making goals and objectives, including reforming policy and practice;
- Working with the Autistic Self-Advocacy Network and Children’s Hospital Center to develop a first-of-its-kind hospital policy designed to decrease the over-reliance on guardianship and increase the use of Supported Decision-Making and other less-restrictive alternatives to guardianship. Work on this initiative continues;
- Contributing to the Supported Decision-Making “toolkit” developed by the Autistic Self-Advocacy Network. The “toolkit” has been used as the basis for several trainings by National Resource Center partners;

- Collaborating with Upstate Medical School in Syracuse, NY, on content for a “grand rounds” designed to educate doctors about Supported Decision-Making;
- Discussing and developing policy and practice recommendations with the Maryland Protection and Advocacy System;
- Speaking with experts from Ireland and Canada to learn about best-practices and the elements of successful Supported Decision-Making policies and practice;
- Working with the American Civil Liberties Union to develop Supported Decision-Making policy and practice recommendations;
- Working with the American Bar Association to develop a new tool and practice guide for attorneys who represent people who may be challenged in decision-making. This tool is called PRACTICAL, and includes nine steps for supporting decision-making, along with a checklist and background guide. It will be tested on ABA attorneys and presented at the National Aging and Law Conference in October before widespread distribution.
- Collaborating with DC Superior Court to develop standards of practice for attorneys in guardianship and commitment cases;
- Working with Jefferson County, Missouri, to provide technical assistance on Supported Decision-Making and policy and practice recommendations
- Collaborating with a Texas-based workgroup to develop and implement Supported Decision-Making policy and practice recommendations;

- Working with WINGS groups in Washington State, Wisconsin, and Washington DC to help change guardianship policy and practice in the legal community;
- Working with the Florida Guardian *Ad Litem* project on policy and practice guiding the work of GALs for children with disabilities;
- Collaborating with the Council of Parent Advocates and Attorneys (COPAA) on special education transition policy and practice standards and issues;
- Working with the Rutland, Vermont, Mental Health Services agency on policy and practice guiding their work with adults with intellectual and developmental disabilities;
- Working on the Uniform Law Commission drafting committee to develop recommendations for modifications to the Uniform Guardianship and Protective Proceedings Act to recognize and increase use of Supported Decision-Making, in collaboration with the ABA;
- Working with the District of Columbia Public Schools to increase the use of Supported Decision-Making in transition planning and stop teachers from telling parents they “must” get guardianship over their children.;
- Contributing to the District of Columbia Department on Disability Services’ draft policy on Supported Decision-Making;
- Working with the District of Columbia Public Schools on a new Transfer of Rights brochure informing students and parents of their right to, among other things, use Supported Decision-Making throughout the Special Education



planning process;

- Commenting on proposed regulations of the D.C. Office of State Superintendent of Education to safeguard the decision-making rights of adult students with disabilities and to promote Supported Decision-Making.
- Meeting with the Virginia Department of Behavioral Health and Developmental Services to discuss policy and practice advancements needed to increase self-determination and decrease over-reliance on guardianship. Our recommendations were adopted in the Department's report to the Virginia General Assembly;
- Meeting with the Consumer Financial Protection Board to discuss ways to collaborate on educational programs and policies to protect older adults from financial abuse;
- Working with the U.S. Administration on Community Living in the planning of a program for health care ombudsman staff in the CMS dual eligible Medicare-Medicaid managed care program, in conjunction with the ABA Commission on Law and Aging;
- Providing the "*Onondaga Pathways to Careers*" project (one of only two nationally-funded demonstration projects by the Department of Labor's Office of Disability Employment that promotes career pathways for students with disabilities through training in high-growth industry sectors) with resources to facilitate the use of supported decision-making as appropriate in the course of their higher-education and career pursuits.

## Research

Leading scholars have identified the lack of research into Supported Decision-Making as a barrier to wider acceptance. Therefore, the National Resource Center has set out to sponsor and conduct research to determine whether the use of Supported Decision-Making is correlated with improved life outcomes.

To that end, the National Resource Center, led by partner Michael Wehmeyer of Kansas University, will create, refine and pilot-test a framework for measuring Supported Decision-Making and use the resulting measure to examine the relationships between Supported Decision-Making, legal decision-making status (i.e., having a legally appointed substituted decision-maker [guardian] or not), self-determination, and lifestyle satisfaction for people with disabilities and older Americans. This year's research included:

- A systematic review of the literature on capacity, environmental demands, and supports needed for decision-making, with the purpose of identifying and generating items that can be used to: (a) measure Supported Decision-Making, (b) develop a guide for using the Supported Decision-Making measure that can be used in practice to enable Supported Decision-Making, and (c) examine the relationship between Supported Decision-Making and valued outcomes related to self-determination and quality of life.

The review has been completed. A paper summarizing findings has been completed and submitted for publication to the journal *Intellectual and Developmental Disabilities*.

- Developing a pilot version of the *Supported Decision Making Assessment* (SDMA), which will measure capacity, environmental demands, and needed supports for Supported Decision-Making in people with disabilities and older Americans. The SDMA will contain three theoretical domains for which items will be generated: Capacity, Environmental Demands, and Support Needs. Using the literature review and input from our Advisory Board, we will develop a pool of items relevant for older adults, people with disabilities and the people that support them. We will then use best practices in assessment development to create item content that represents: (a) the breadth of content in each domain, and (b) levels of Supported Decision-Making across each domain, while maintaining best-practice guidelines in the use of grammar, response logic, and reading level. We will then develop theoretical definitions for each domain to define a taxonomy of characteristics of potential items.

Project staff is in the process of identifying items for the three domains. Our intent is to have multiple forms of assessment to fit the needs of each domain. In addition to the aforementioned review of the literature being used to generate items, we conducted a thorough review of existing instruments and assessments pertaining to these domains and are using those to guide our item development. We anticipate the pilot version of the assessment being done by the end of FY 2015 or early in FY 2016.

In future project years, the SDMA will be refined and tested with the goal of developing a scientifically valid tool for defining and measuring Supported Decision-Making. We will then use the SDMA and the associated planning process to examine relationships between and among SDM, self-determination, and quality of life/lifestyle satisfaction.

In addition, the National Resource Center, led by partner the Burton Blatt Institute of Syracuse University, developed a survey to gather information about people using Supported Decision-Making, including current experiences, challenges encountered, best practices, and success stories. Due to continued strong interest in the survey, we have left it live and continue to collect data. So far, there have been 194 respondents. Final data will be analyzed and reported upon after the survey closes. This report focuses on and provides representative examples of comments people have left.

People have told us ways they use Supported Decision-Making - even if they do not call it by that name

- *A lot of times I have many things that I want to do, but I can't figure out what to do first or what is most important. My husband is very helpful and helps me pick what order to do them in. He also helps me make decisions about buying things, and that really helps me to avoid making irresponsible decisions. I feel a lot more organized with his help*
- *Mostly, if I am unsure of myself on a decision, I ask for help making the decision from my fiancé. He gives me his opinion on what I should do or how to do it, and I take it into consideration. I don't follow his advice 100% of the time, but I do in*

*probably 80% of decisions I make. We agree on many things, so hearing him say what I was thinking out loud gives me confidence and validation. I'm a very shy and nervous person, so sometimes I need that validation in order to go forward with something, even if it is something I've decided to do by myself. It makes me feel good to have help.*

- *I have good brain days and bad brain days and a lot of the time people don't understand. I might need help on a bad brain day that I don't need on a good one! And they get mad because they think I should be able to do it every day.*
- *I often ask my partner for help with decisions because I am not confident I can work out whether or not something is a safe or reasonable idea, I feel more secure and confident that I have picked something that is rational and what I want because he helps me consider other options or points of view that are good that I would not think of and might miss out on otherwise*

Supporters are also telling us how less restrictive options to guardianship were identified, considered, and decided:

- *I as parent determined that guardianship and deprivation of legal rights were not appropriate*
- *team discussion*
- *maintaining individual rights with supports was always the goal; guardianship (full or partial) was never considered*

- *Thru case worker, family.*
- *Though research and reading other people's stories*
- *read, participated in conferences, started support group, consulted with legal prof*
- *I did not want my son to be in guardianship after I'm no longer here. I feel my*
- *By giving her choices so she is included in the decision making*

We are also hearing about the impact of Supported Decision-Making and how being supported, rather than in a guardianship, makes people feel:

- *SDM help a person feel empowered and feel more self-confident*
- *I think that this is the best way to go just so long as the individuals have the capacity to engage in conversation re: what they need. I know that, in my own life, I'll seek advice when I need it but that doesn't mean that I want my entire life micromanaged by somebody else. Most people don't. People need friends who see them as peers instead of as brain-dead.*
- *Supported decision making enables the person to be the agent and center of their own decisions. That agency is legally eliminated when the person is declared legally incompetent and placed under guardianship.*
- *As long as people involved are nonjudgmental and compassionate, people are allowed to grow to their full potential.*
- *The individual is allowed to maintain their civil rights, determine what they want to do with their life, where they live, what community activities they participate in,*

*where they attend church, who they choose to be friends with, and allow them integration into their community as able*

- *Guardianship is an outdated practice that strips people of their rights and autonomy! It is not needed! Making support offered to friends and family more formalized with written agreements is also unnecessary! Please don't do it!*
- *Confidence, self-esteem, decisiveness and education for the person with a disability and their family/supporters or workers*
- *My son knows he has a major part in making his own choices and at the same time knows there is help if needed.*
- *The individual's guardian often takes away chances to be independent and take more risks.*
- *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. If once they are hired and it isn't working out he lets me know and we talk about it and if need be they are terminated. I will not place him in a group home as I want to ensure his rights are not violated in any way shape or form. What makes sense to him is to live at home.*

Finally, respondents are telling us what lessons can and should be learned:

- *People with DD should be considered competent*
- *Treat people how you would want to be treated if you were in a similar situation.*
- *That Supported Decision-Making is a "least restrictive" option for consideration by all individuals with disabilities and allows the individual the right to determine where they live, work, attend church, what activities to participate in, how to spend their income, who to be friends with, and who to seek guidance from. By not putting a formal "guardianship" in place allows an individual to maintain their civil rights as given to all others without disabilities. Having a disability should NOT guarantee an immediate loss of an individual's civil rights through a guardianship!*
- *Doesn't have to be an either/or situation. People (all of us!) look to others for info, advice, and perspective when we make decisions. Person can have a guardian for those rare times when the person 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.*
- *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; individual rights of people with disabilities are taken for granted by system, courts, medical personnel and need to defer to people first then their supporters*



- *When you prefer supported decision making you generalize the expectation of competence rather than the opposite.*
- *There should be alternatives to guardianship that do not deem the individual totally incompetent and allow for individuals to do some self-determination.*
- *There is a lack of relevant information to all parties involved.*
- *when supported and when their style and methods of communication about themselves and their goals - individuals who are otherwise not allowed to participate in decisions can, indeed, make decisions for themselves*
- *we need education for lawyers, family members individuals with disabilities about pros and cons of options when someone has need for specific supports in decision making. We need legislation that recognizes such agreements that go beyond the power of attorney and includes a person's "circle of support."*
- *That there should be protections that aren't all or nothing.*
- *SDM (in practice) take more time than agency directed services (in practice) but the results are far better for the person and 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 in practice is almost nonexistent.*

Furthermore, National Resource Center partners ASAN and Quality Trust collaborated on a survey asking people with intellectual and developmental disabilities about their financial

decision-making methods and needs. The survey, which was done in conjunction with a financial service provider, asked people with I/DD about their experiences managing their money, the type of support they need or want to do so, and the financial decision-making methods and situations that make them the most and least happy. For the over 170 people who participated in the survey, the top two reasons for happiness in their financial decision-making were (1) Receiving help making decisions from someone they trust; and (2) Having some level of control or independence in financial decision making.

The data gathered through our research will allow us, in future project years, to develop a guide describing characteristics of successful Supported Decision-Making relationships and those most likely to cause challenges. It is anticipated that this will also allow us to identify and disseminate recommendations for expectations and best practices for "supporters," documentation and reporting requirements, monitoring and a complaint investigation and resolution system. We will incorporate those standards into best practice training and education materials encouraging the use of "successful" Supported Decision-Making characteristics and discouraging "challenging" decision-making methods in all life areas, across the lifespan.

## **CHALLENGES**

As with any new project, there were some “start-up” challenges, including difficulty scheduling meetings for our Blue Ribbon Panel.

We have also met some challenges in planning and creating content for our annual symposium. As the state of the art and knowledge of Supported Decision-Making has

progressed, we have decided to focus more on practical applications for Supported Decision-Making. In essence, our first symposium focused on “why” one should use Supported Decision-Making. We believe that point has, largely, been proven. Therefore, we have chosen to focus on the “hows” of Supported Decision-Making, to move from theory to application.

As such, we took some extra time to focus the topics and identify presenters for the symposium. We anticipate bringing together leading experts to collaborate with our working groups, helping us not only to educate people about the current state-of-the-art in Supported Decision-Making practice, but set goals for the near, middle, and far term future.

Because we wanted to be sure that our symposium provided the most value to the greatest number of people, and truly helped us shape our future work, we experienced some delay in scheduling the symposium and developing annual goals for the working groups. However, both delays have been overcome. The symposium will be held in November of 2015 and the work groups will move forward from that date.

Finally, an External Evaluator has been identified and we are in the process of finalizing an agreement. Work plan goals for year one are to establish a framework for ongoing evaluation and conducting an initial evaluation of activities by the end of the project year. Our plan is to implement work with the evaluator to review year one activities and establish the framework for ongoing evaluation in year two and beyond. This delay has not impacted other activities and we do not anticipate it will cause any other substantial difficulty in completing our work.

# **PROGRESS TOWARD MEASURABLE OUTCOMES**

## Measurable Outcomes

Hold first meetings of Blue Ribbon Panel

Establish charters for working groups.

Hold initial conference to share initial findings and results

Gather information about current experiences, challenges encountered, best practices, and success stories related to SDM.

Conduct state-by-state policy analyses of SDM laws, policies, and practices

Review existing literature to identify existing tools of or related to SDM, self-determination, and lifestyle satisfaction and measures that examine the three domains of SDM (capacity, environmental demands, needed supports).

Develop a plan for the Supported Decision Making Assessment (SDMA) and build the tool.

## Progress

**Complete**

**Substantial Progress made.** Work Groups and leaders are identified. Internal plans for work by groups are complete.

**Substantial Progress made.** Conference will be held in November, 2015

**Substantial Progress made**  
Qualitative data posted to website  
Survey still live due to high interest

**Substantial Progress Made**  
Reviews complete. Last subject area being posted to website

**Complete.** The literature review was completed. A paper summarizing and analyzing findings has been submitted to the journal *Intellectual and Developmental Disabilities*

**Substantial Progress Made**  
The tool is under construction. It is anticipated that the pilot version will be completed by the end of FY 2015 or early FY 2016

Conduct a pilot test of the SDMA.

**Progress made.** The pilot version of the tool will be completed by the end of September, 2015, with testing beginning shortly thereafter

Collaborate with the ABA and NLRC to amend the Uniform Guardianship

**Progress made.** National Resource Center has been named to the and Protective Proceedings Act drafting and advisory team charged to review and recommend changes to the UGA. The drafting committee met in April and will meet again in October. In addition, the National Resource Center has done presentations for ABA committees and personnel involved in the drafting process

Provide technical assistance to varied audiences Regarding the adoption of policies related to SDM

**Goal Met and Work Ongoing**  
As shown above, National Resource Center has provided assistance to multiple agencies and organizations, across several disciplines and areas of the country, to improve decision-making policy and practice

Conduct training to varied audiences regarding best practices in SDM implementation.

**Goal Met and Work Ongoing.**  
As shown, above, the National Resource Center has conducted training to thousands of people in local, state, and national webinars and conferences.

Provide small state grants to innovative applicants with plans to increase local implementation of SDM.

**Goal Met and Work Ongoing.**

Applications for funding were received from organizations across the country. Five grants were awarded and grantees have begun work.

Adapt the JHJP website to create the NRC-SDM web portal. Post "best practices" and "success stories"

**Complete.** The website was launched. It is regularly updated with new content.

Host/provide links to examples of SDM policies nationally and internationally.

**Complete.** The website's Research and Resource libraries provide links and examples of SDM policies. The website is regularly reviewed and updated

Build a section on SDM on the National Gateway to Self-Determination website

**Complete.** The section is located at:

<http://www.ngsd.org/home/supported-decision-making>

Host webinar series on SDM related topics.

**Complete.** Webinars were presented in April, May, and June 2015. Over 1,000 people registered. The webinars are archived on the NRC-SDM site.

Establish evaluation framework for ongoing internal and external project evaluation.

**Some progress made.** As noted above, we have identified an External Evaluator. We will work with the evaluator to establish a framework and review year 1 activities and progress as well as establish a review process for year 2 and beyond.

Conduct initial evaluation of the project to

**Some progress made.** As noted above, we have identified an External Evaluator. We will work with the evaluator to establish a framework and review year 1 activities and progress as well as establish a review process for year 2 and beyond.

## **PRODUCTS**

During the time period covered by this report, the National Resource Center and its partners have created multiple products These have included:

- (a) [www.SupportedDecisionMaking.Org](http://www.SupportedDecisionMaking.Org) (print out of front page of the website and usage report included in Appendix). As described, above, included in the website are education and training materials, blogs, a research and resource library, a state-based guide to guardianship laws, and a dedicated listserv.
- (b) [www.facebook.com/nrcsdm](http://www.facebook.com/nrcsdm) The National Resource Center's Facebook page (print out of first page included in the Appendix).
- (c) Usage Report for [www.SupportedDecisionMaking.Org](http://www.SupportedDecisionMaking.Org) and the NRC-SDM Facebook page as of August, 2015 (copy included in Appendix)
- (d) A brochure describing Supported Decision-Making in user-friendly, accessible language (copy included in Appendix)
- (e) Two journal publications (copies included in Appendix)
- (f) Multiple training modules (representative samples included in Appendix).

(g) Model form: A D.C. springing power of attorney form memorializing Supported Decision-Making arrangements within the existing D.C. statutory framework.