

## **State Grant Report**

### **Disability Rights Maine**

Disability Rights Maine (“DRM”) is Maine’s Protection and Advocacy agency for individuals with disabilities. Our mission is to advance and enforce the rights of individuals with disabilities. We enhance and promote the equality, self-determination, independence, productivity, integration, and inclusion of people with disabilities through education, strategic advocacy, and legal intervention.

DRM provides individuals with information about their rights and services, represents individuals at meetings and hearings, and provides free legal services to individuals and groups. The organization works for systemic change and provides training on individual rights and developing advocacy skills. We provide expert information and referral services for individuals with needs outside the scope of our priorities.

On June 1, 2015, DRM applied for and received a State Grant from the National Resource Center for Supported Decision-Making to fund an initiative to:

- (1) Identify and advocate for implementation of state laws, policies, and practices that increase the use of Supported Decision-Making by older adults and people with intellectual and developmental disabilities (I/DD) across the life course; and
- (2) Collect and disseminate information to document the positive impacts of Supported Decision-Making in Maine and, at least annually, issue a report documenting success stories, challenges, and any changes that have been made to increase the use of Supported Decision-Making.

DRM created a strategic plan with measurable outcomes to meet the goal objectives of this grant. Through the implementation of this strategic plan and funding from the National Resource Center for Supported Decision-Making, we believe that we have successfully achieved the first phase in a multi-step plan to legitimize Supported Decision-Making as its own process and as a viable alternative to guardianship in Maine. Through a major campaign of outreach, we have reached hundreds of individuals including individuals with disabilities, family members, and service providers across all counties ranging the entire length of the State. By way of outreach, training, and legal representation, we have established Supported Decision-Making as a real and tangible option for individuals in Maine experiencing limitations in decision-making and seek a renewal of the project to continue to provide support to the people of Maine in eradicating unnecessary and overbroad guardianships.

### **Goals and Measurable Outcomes**

When DRM applied for the State Grant, Supported Decision-Making was virtually unknown across populations and disciplines in Maine. For individuals experiencing limitations in

decision-making, guardianship was the only option offered to the families and services seeking to support their loved ones and clients. Guardianship as the only option seemed to be echoed in Maine Probate law, Medicaid regulation, and State created materials for transitioning youth with disabilities. For these reasons, most individuals with disabilities are not ever given an opportunity for decision-making or the type of dignity of risk that educates responsible decision-making. In response, we identified that the first phase of promoting civil equality in legal capacity for individuals with disabilities had to be a major campaign of outreach to teach Maine citizens about Supported Decision-Making as a viable alternative to guardianship.

### *Maine's Supported Decision-Making Coalition*

Critical in supporting any system-wide change and paradigm shift is engaging the individuals which will be affected and all supporting organizations and stakeholders. To this end, DRM founded and facilitates Maine's Supported Decision-Making Coalition ("Coalition"); a partnership of aging adults, individuals with disabilities, and agencies representing and supporting individuals with disabilities whose collective goal is to educate the public on and promote Supported Decision-Making as a legitimate and appropriate alternative to guardianship. As part of its membership, each Partner agreed, at minimum, to attend and participate in Coalition meetings; to assist with distribution of Supported Decision-Making materials; promote Supported Decision-Making on their organization's website; and assist us in identifying adults and youth under or at risk of guardianship who would thrive under Supported Decision-Making.

At the time of the application, DRM had engaged nine community leaders representing and supporting individuals with disabilities as partners in the Coalition. Since that time, the Coalition has grown to include more individuals with disabilities, statewide service review agencies, and agencies providing services to individuals with disabilities. As a critical addition to the Coalition, DRM engaged representatives from the Department of Health and Human Services' ("DHHS") Office of Aging and Disability Services ("OADS") and Office of Child and Family Services ("OCFS") and the Department of Education ("DOE") to represent the State and participate as a partner in the Coalition.

Across the grant period, the Coalition participated in three day-long strategic planning meetings and Coalition members maintained contact via email and social media:

On July 17, 2015, the Coalition convened for the first time to assess priorities and review the work plan DRM submitted in consideration of the State Grant. In the first half of the day, Coalition members observed presentations by Lydia Paquette, DRM Staff Attorney, on Supported Decision-Making in Maine and Robert Fleischner, Assistant Director at the Center for Public Representation, on the Center for Public Representation's Supported Decision-Making pilot project. In the second half of the day, Coalition members broke into three small work groups to create strategic plans for materials development, legislative and policy research, and training and outreach.

On December 14, 2015, the Coalition hosted a joint meeting with the Developmental Disabilities Advisory Council (“Advisory Council”), an organization of approximately 15 individuals with developmental disabilities who review and provide input into DRM’s priorities. The first half of the meeting was spent discussing and practicing effective ways to communicate the benefits of Supported Decision-Making. The Coalition and the Advisory Council worked together to invite local Maine legislators to participate in the second half of the meeting which comprised of an educational luncheon on the merits of Supported Decision-Making as an alternative to guardianship.

On February 19, 2016, the Coalition met again to assess progress and determine next steps in the strategic plans devised during the July meeting. In the first half of the day, the Coalition heard presentation from Clint McKay, the Arc of Indiana, on Indiana’s progress as a State Grant recipient and Julia Otis, TrueLink Financial, on the TrueLink Card and other accessible financial management tools. In the second half of the day, Coalition members broke again into three small work groups to create strategic plans for continued outreach and training, legislative and policy research, and consideration of a Supported Decision-Making pilot project.

*The Website ([www.supportmydecision.org](http://www.supportmydecision.org))*

In this digital age, a fully accessible and informational website is necessary and instrumental for any major systems change. To that end, DRM put the majority of the funds provided from the State Grant into creating and maintaining an accessible website to house resources and information about Supported Decision-Making generally and the Coalition’s website in Maine. This website was successfully launched on November 1, 2016.

The website is broken into five separate tabs: Home, Community, Tools, About, and Contact. The Home screen features a metaphor called “The Vending Machine Problem” which DRM created and has found to be successful in describing what it feels like to be a person with difficulty in decision-making.

#### The Vending Machine Problem:

*Imagine for a moment that you are standing in front of a vending machine full of food. You're hungry and you know you have some change in your pocket, but you don't know how to count it. How do you decide what to do?*

*You could start putting money in the machine and pressing buttons until something falls out. You could also just give all your money to someone else and hope they buy you something. Neither option is likely to get you what you want.*

*Putting money in the machine and pressing buttons is what it's like to live without support when you need assistance in decision-making. It doesn't mean you don't know what you want or you can't make informed decision. It simply means you lack the support you need.*

*Giving your money and decision-making authority to someone else is guardianship. You lose any ability to participate in the decision-making process, including choosing what decisions need to be made.*

*If you can think of any alternative besides putting your money in the machine and giving your money to someone else, you've chosen Supported Decision-Making. You've kept yourself as a critical part of the decision-making process and you've asked for the support you need to make a decision. Support can come in all forms and can be tailored your needs and your specific circumstances.*

The Home tab additionally features a video featuring self-advocates discussing guardianship and Supported Decision-Making; a Q&A about Supported Decision-Making and Guardianship; important calendar events related to Supported Decision-Making; and news stories featuring Supported Decision-Making.

The Community tab features community members, individuals with and without disabilities alike, and a short quote on their feelings about Supported Decision-Making and guardianship. The website has space to house as many pictures and quotes as needed. DRM additionally has contracted with Margaret Cardoza, a former special education teacher and self-advocate who specializes in testimonials and storytelling, to work with individuals who utilize Supported Decision-Making to develop testimonials for the Community page.

The Tools tab houses all the resources created and utilized by DRM and Maine's Supported Decision-Making Coalition, separated into Templates & Examples, Background & Resources, and Trainings. Our Featured Tool is a Designation of Supported Decision-Making Team template form which individuals can fill out to identify their Supported Decision-Making relationships to third parties. The Tools tab also features and credits resources created by other entities which the Coalition supports, such as the Autistic Self Advocacy Network's (ASAN's) "The Right to Make Choices" toolkit discussing Supported Decision-Making and guardianship.

The About tab identifies the Coalition partners, Coalition meetings, and houses the agendas and notes from those meetings.

Finally, the Contact page allows for an external message to be sent directly to DRM with questions, concerns, or requests for more information about Supported Decision-Making.

To measure the effectiveness of the website, DRM anticipated receiving approximately 500 traffic hits per month. After accounting for repeat viewers, we found that the website currently averages 109 unique viewers per month. However, that number is steadily increasing. We anticipate the number continuing to grow as outreach and training continues. Moreover, we recently developed a rack card which introduced Supported Decision-Making and is expected to drive more traffic to the website for further information. We additionally created social media accounts related to the website to further advertise the website as a hub for information regarding Supported Decision-Making.

### *Materials Development*

Within its application, DRM proposed developing a pamphlet, Supported Decision-Making Team Designation form, and a handbook dedicated to Supported Decision-Making to feature on the website and distribute in outreach. As an update to the traditional tri-fold paper pamphlet, we finalized a colorful laminated rack card which introduces Supported Decision-Making and directs viewers to DRM and the website. (Enclosed with this report, please find a copy of the rack card.) We also finalized a Supported Decision-Making Team Designation form which allows individuals to formalize and designate Supported Decision-Making relationships for third parties to rely on. (Enclosed with this report, please find a copy of the Designation form.) Finally, DRM chose to delay finalizing a Supported Decision-Making handbook and feature the plain language and visual gestural guides produced by ASAN on the website.

To measure the effectiveness of materials development, DRM anticipated distributing over 1,000 of each pamphlet, Designation form, and handbook. Through trainings and outreach, we conservatively estimate distribution of over 1,000 rack cards and Designation forms. Because the rack card, Designation form, and ASAN's guide are featured on the website, these tools are also downloaded and distributed by individuals that view them on the website making an exact accounting currently immeasurable.

DRM additionally provided feedback in State produced materials to include Supported Decision-Making in DHHS OCFS' guide to transition services for youth transitioning to adulthood and DHHS OADS' guide to guardianship and alternatives to guardianship. OCFS has completed and begun distributing its handbook which prominently features Supported Decision-Making as a

viable and appropriate alternative to guardianship for transitioning youth. OADS is still developing their guide and has agreed to maintain contact with DRM for commentary on their draft version.

*Training*

DRM finalized and conducted outreach and trainings across the State for individuals, family members, service providers, and State employees as follows:

Date	Location	Sponsor	Approx # Attendees <sup>1</sup>
June 2, 2015	Augusta, ME	Developmental Disabilities Council	4
October 5, 2015	Augusta, ME	Developmental Disabilities Advisory Council	15
November 4, 2015	Portland, ME	STRIVEU- Self Advocacy class	7
November 11, 2015	Scarborough, ME	Morrison Center	20
November 14, 2015	Brewer, ME	Maine Parent Federation- Transition Fair Panel and Workshop	150
January 11, 2016	Augusta, ME	Acquired Brain Injury Advisory Council	25
March 14, 2016	Portland, ME	Housing Coalition	30

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<sup>1</sup> This is reflective of the number of attendees which were provided information about Supported Decision-Making. More specific data can be generated regarding the category of persons (individuals, service providers, family members, etc.) and whether they attended trainings if needed.

March 16, 2016	Augusta, ME	Developmental Services Oversight and Advisory Board	15
March 30, 2016	Scarborough, ME	Pine Tree Society- Parents Roundtable	20
April 6, 2016	Presque Isle, ME	Department of Education- Transition Conference	50
April 11, 2016	Augusta, ME	MaineCite- webinar	35 <sup>2</sup>
April 12, 2016	Belfast, ME	Department of Education- Transition Conference	50
April 19, 2016	Damariscotta, ME	Mobius	5
April 27, 2016	Portland, ME	Department of Education- Transition Conference	100
May 20, 2016	Augusta, ME	CCSM- Hope Conference	200

DRM additionally prioritized developing training for clinicians and psychologists as these professions often produce the sole recommendation and evidence used at hearing to place individuals under guardianship. On May 13, 2016, we conducted a Supported Decision-Making training for the Director of Psychology and psychologists working at MaineGeneral's Edmund Ervin Pediatric Center at both their Augusta and Waterville locations. DRM has also scheduled a co-training with Dr. Rick Ellis for October 14, 2016 to provide training with continuing education credits to psychologists and other clinicians on evaluating for Supported Decision-Making.

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<sup>2</sup> Approximately 35 individuals attended the live broadcast of the webinar. There is no way to calculate how many individuals watched the webinar together and/or downloaded the archived version, however from feedback surveys we understand that it has been widely viewed and linked.

DRM has finalized training for court appointed attorneys, guardian ad litem, and court appointed visitors and is currently applying for continuing legal education credit to accompany the training. We also scheduled quarterly trainings sponsored by DHHS for State employees and providers of Developmental Services. Finally, we have included introductory slides on Supported Decision-Making in our corresponding and regularly scheduled trainings on the Rights of Individuals with Developmental Services, Rights of Recipients of Mental Health Services, and Rights of Individuals Receiving Special Education.

### *Individual Testimonials*

In its application, DRM anticipated identifying five individuals and five organizations supporting individuals willing to provide testimonials on guardianship and Supported Decision-Making. Within the grant year, we taped and produced an approximately seven minute video featuring six self-advocates speaking about their personal experiences with guardianship and Supported Decision-Making. The video is included as a critical part of training, on the website, and is currently featured on the home page of the National Resource Center on Supported Decision-Making's website. We have taped and are in the process of editing three short following up videos which document an individual who terminated guardianship and two separate Supported Decision-Making teams. Additionally, the website's Community tab currently maintains individual pictures and corresponding quotes of Maine community members.

It is of the utmost importance that this movement is guided by and reflective of the individuals which it seeks to liberate from unnecessary and overbroad guardianships. As aforementioned, DRM has contracted with Ms. Cardoza, a self-advocate with expertise in special education and storytelling, who will soon be featured on the website telling her own harrowing experience with guardianship and institutionalization. Ms. Cardoza will use her time with DRM to reach out to individuals with disabilities and help them to develop their stories for future testimonials, trainings, and outreach.

### *Legislative and Policy Research*

The current legal standard for incapacity in Maine is "any person who is impaired by reason of mental illness, mental deficiency, physical illness or disability, chronic use of drugs, chronic intoxication, or other cause except minority to the extent that he lacks sufficient understanding or capacity to make or communicate responsible decisions concerning his person." 18-A M.R.S.A.

§ 5-402 et seq. However, Maine's legislature is currently considering adopting a version of the Uniform Probate Code (UPC) which would change these standards considerably.

On December 14, 2015, the Coalition and Advisory Council hosted a joint meeting inviting legislators to come and learn more about Supported Decision-Making over lunch with members of both organizations. On January 28, 2016, DRM was invited to speak on Supported Decision-Making during a work session in which the Judiciary Committee considered the adoption of the UPC. As a result of the information provided by DRM, a resolve was issued directing “[t]hat the Probate and Trust Law Advisory Commission shall examine the concept of supported decision making, consult with interested parties and make recommendations concerning inclusion of supported decision making in the Probate Code, including any proposed legislation, in a report no later than January 15, 2017 to the joint standing committee of the Legislature having jurisdiction over judiciary matters.”

Moreover, DRM provided comments during the promulgation of State rules which regulate the delivery of Medicaid services to individuals with developmental disabilities to include consideration of Supported Decision-Making in all areas of skill building.

### *Individual Representation*<sup>3</sup>

DRM continues to be at the forefront of legal representation to prevent and terminate unnecessary and overbroad guardianship orders that limit individuals' ability to make decisions and thrive independently in the community. For example, in 2001, DRM successfully represented individuals with mental health and developmental disabilities in the U.S. District Court to challenge a Maine constitutional amendment that prevented persons “under guardianship for reasons of mental illness” from voting. DRM is dedicated to and continues to provide technical assistance and direct representation to individuals seeking to terminate their guardianship. The following describes just a few case scenarios DRM has advocated on, or is currently advocating on, which use Supported Decision-Making as an alternative to guardianship:

- *DRM was contacted by an adult male with autism who had questions about guardianship. DRM Attorney responded and attended the Client's individual support team meeting. The Client explained that he felt like sometimes made poor choices and he wished there was someone who would help him think through his decisions. He thought that he might want to have a guardian. During the meeting, DRM Attorney talked to the Client about what*

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<sup>3</sup> Some identifying client information has been changed to protect confidentiality.

*guardianship was and the array of alternatives to guardianship that exist. The Client said he wanted to think about it more. DRM Attorney sent the Client a packet of information about guardianship and alternatives.*

*DRM Attorney met the Client again after he had some time to think. The Client stated that he did not want someone to have the legal authority to force him to do something he didn't want to do, but he still wanted help with making decisions. DRM Attorney talked to the Client about directives, powers of attorney, Supported Decision-Making, and other alternatives that might be helpful. The Client considered each alternative and thought about how it might apply to different scenarios.*

*The Client decided he wanted to try Supported Decision-Making. DRM Attorney helped the Client think through how Supporters might help him make decisions and drafted a Supported Decision-Making contract for the Client to use. DRM Attorney checked back in after a month and the Client now successfully uses Supported Decision-Making and no longer wants to have a guardian.*

- *DRM was contacted by the mother of an adult female with an intellectual disability. The Client had recently turned 18 and the mother was considering petitioning for guardianship over her. After seeing a DRM training on Supported Decision-Making, the mother requested that DRM Attorney meet with her and the Client to talk more about the Client's specific circumstances.*

*DRM Attorney met with the Client and her mother and talked about the guardianship process and alternatives to it. The Client and her mother both agreed that they engage in a Supported Decision-Making relationship and changing that relationship would not benefit the Client in any way. The Client and her mother met with other members of their family and began developing other supportive relationships which assist the Client to process complicated information and make decisions.*

*DRM Attorney met with the Client and her mother again to talk about these relationships and how the Client would like these relationships to be respected by third parties (bank officials, doctors, service providers, etc.) During this meeting, the mother agreed that petitioning for guardianship was not the answer. DRM Attorney is currently drafting a Supported Decision-Making agreement which reflects the values inherent in the Client's current Supported Decision-Making Team.*

- *During an outreach visit to a children's institution, DRM Attorney met with a female child with a developmental disability. The Client contacted DRM after she turned 18 seeking assistance. She had recently been arrested due to minor property damage and her father had petitioned for and been awarded temporary guardianship.*

*DRM Attorney met with the Client in jail and talked with her about her rights while under temporary guardianship and her right to contest plenary guardianship at the upcoming hearing. DRM Attorney attended the pre-trial conference on behalf of the Client and talked to the Client's father about Supported Decision-Making and alternatives to guardianship. The Client's father agreed that the Client makes better choices when she is acknowledged and guided rather than told what to do. Both the Client and her father agreed Supported Decision-Making would be a better fit for her.*

*DRM Attorney successfully advocated for the Client to be transferred from jail to a hospital where she could receive the right support to meet her needs and clinical assistance to develop a successful Supported Decision-Making Team. While at the hospital, the Client developed a record of good decisions using supports and has located a home to transition to in the community. The Client will be transitioning soon into that placement where she will be able to practice Supported Decision-Making with the support she needs.*

### **Lessons Learned**

Through this first phase of outreach and training, DRM has learned the critical importance of understanding the needs, priorities, and strengths of any given audience. For example, what is important and persuasive to a family member is not the same as what is important and persuasive to the individual. For these reasons, we spent considerable time piloting trainings and listening to feedback from many sources.

By way of example, here is how the differences between individuals and their family members can affect any given outreach visit:

Through training, outreach, and representation, DRM quickly learned that many individuals facing guardianship do not know the basic fundamentals about what guardianship is. Accordingly, they did not know about due process and their rights before, during, and after guardianship proceedings. Because of this, they often did not know how their decisions could lead to guardianship or that they had any ability to contest guardianship.

While autonomy and self-determination are important to individuals facing guardianship, individuals transitioning into adulthood still worried that contesting guardianship will disappoint their parents. This fear often overwhelms the desire for autonomy. Further, by not fully understanding guardianship, they perceive contesting guardianship as contesting their parents' involvement in their lives. Most individuals think guardianship is Supported Decision-Making because they are often told that guardianship is “help” or “assistance” rather than substitute decision-making.

For these reasons, it is critical to spend a long time describing what guardianship is and what rights individuals have before, during, and after guardianship proceedings. It is also important to spend time discussing the difference between support and having decisions made for you. Lastly, it's critical to describe how Supported Decision-Making is a way of keeping family involved and doing the least to change the relationship that they have with their families.

Similarly, DRM quickly learned that families petitioning for guardianship of their adult children are motivated by the fear of potential abuse, neglect, and exploitation of their loved ones and fear of being excluded from the individual's life. There are similar gaps of knowledge about guardianship, however the fear of potential abuse overshadows most arguments related to self-determination and autonomy. They are generally unmotivated, and sometimes offended, by arguments which pose the real dangers of “civil death” because it is perceived as an attack on the families for trying to protect their children.

It makes sense then that no Supported Decision-Making training will be effective with families unless it addresses how abuse, neglect, exploitation, and exclusion of the family will be prevented. Thus, for these trainings, DRM spends considerably more time reviewing the research that discusses how individuals who practice self-determination are more capable of advocating for themselves and seeking support when faced with abuse. Further, under current Maine law, when a guardian dies the guardianship is dissolved. This fact is typically unknown to guardians and can be motivating as a way of planning for the future. In this way, guardianship can feel like a stopgap for a greater problem (the individual's difficulties in decision-making) which will resurface when the families are no longer around to provide support. This can be persuasive as a way of beginning the conversation about alternatives to guardianship, such as a simple release of information or a Supported Decision-Making agreement, which allows the families to remain included in the individual's decision-making.

Having this knowledge about what is important to the audience can affect everything from the handouts which are distributed to the presenter's tone of voice. Much like Supported Decision-Making, the right combination of elements in any training can keep the individual and families informed about the choices they face and give them the peace of mind necessary to make a reasoned decision.

## **Phase II**

DRM is dedicated to the Supported Decision-Making movement and see it as an opportunity for a real and concrete paradigm shift from unnecessary and overbroad guardianships. We believe this first phase has been successful in educating the community on Supported Decision-Making and providing the solution to individuals under the threat of guardianship. As a reflection of our commitment, we have devoted our 2016 annual dinner to Supported Decision-Making and have invited Hon. Kristin Booth Glen as our keynote speaker.

In our second phase, DRM will be prioritizing individual representation of individuals seeking to contest and terminate guardianship in favor of Supported Decision-Making in all 16 Probate courts. We will continue to provide targeted training and outreach to professions and community members who systematically recommend guardianship to families and individuals. Additionally, we have reached out to the State and service providers to create a network of supporters in efforts to establish a pilot project in the coming year.

DRM appreciates this opportunity to work with the National Resource Center for Supported Decision-Making and hopes to continue working together in the coming years in recognition of the right to legal capacity and to bring true equality to Maine.