

the Work Group was able to complete a variety of objectives over the year of the contract.

Proposal and Grant Agreement language

Under the proposed state grant program, DDC proposed and agreed to work with its project partners to:

- (1) Identify Delaware 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 those that serve as barriers to doing so; and
- (2) Collect and disseminate information to document the positive impacts of Supported Decision-Making in Delaware 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 in the First State.

A major activity of this project was to focus on increasing the levels of awareness of SDM through use of educational experiences that will be tailored to older adults and people with I/DD at times of transition when guardianship decisions are common (e.g., transition from the Department Of Education (DOE) services to adult services). In addition, educational experiences will be tailored to increase the levels of awareness of SDM in other targeted populations including:

- those directly involved in a person’s SDM,
- those providing supportive services,
- professionals and others providing care,
- legislators, and
- general public

Subaward Match

The match for this Subaward of \$5,000.00 included funds from the DDDS for production of the Supported Decision-Making video in the amount of \$3,000.00

and funds from the DDC for the Supported Decision-Making Summit in the amount of \$3,296.00. In addition, each partner agency contributed staff time each month to complete the Scope of Services Outcomes for the duration of this contract.

Deliverables and Outcomes

1. Draft Language of a Bill for Delaware – Prior to the application for this grant, the Working Group had been meeting to discuss our current Guardianship statute and had been contacted by ASAN to discuss their model legislation for SDM. After researching legislation that has been passed and proven effective, worldwide, the Working Group spent time reviewing, in particular, the model legislation that was provided by ASAN, the recent legislation passed in Texas, and legislation that is being used in Canada. We drafted an agreement document that could be used by people when choosing a Supported Decision-Making “helper” so that the barriers when visiting clinicians, banks, etc. would be lessened (attached). S.B. No. 230 was introduced in the Delaware Senate on April 14, 2016. A few groups weighed in on the language with the sponsors of the bill with concerns. The bill is awaiting a presentation on the Senate Floor. The link to S.B. #230 is <http://legis.delaware.gov/LIS/lis148.nsf/vwLegislation/SB+230?Opendocument>. Support letters for the bill are attached, as well.
2. Information and Research – The DDC subcontracted with Robin Coventry of Coati Marketing Dynamics to research the topic of Supported Decision-Making and to gather as many documents as possible on this subject to be able to share this information with the populations that we serve and with the general public. Ms. Coventry produced a Dropbox that included information and documents from 17 countries and 16 states held within 59 main folders with 49 published papers from around the world with a total of 281 documents. Our intention is to gain consent to publish these documents on our state web sites for access to anyone who needs the information. The link to the Dropbox is:

https://www.dropbox.com/sh/7ukbsvas6teqcnc/AAAPtjbEthgbII5wOc7-3_Xta?dl=0

We continue to request consents for this purpose.

3. State laws, policies and practice that serve as barriers to the option of Supported Decision-Making and laws, policies and practice that increase the use of Supported Decision-Making in Delaware were reviewed during this contract - The subcontractor, Robin Coventry completed an online review of Delaware Law, policies, and regulations that may need tweaking in order to remove possible barriers to the option of Supported Decision-Making. The Working Group reviewed her work and discussed the items in relation to real world practice. The group felt that we do need legislation to enable the use of Supported Decision-Making which was discussed in #1 above. Some places where the addition of SDM language would be beneficial are in Resource Guides for people with disabilities and those who are aging including the Guide that is published by the Division of Services for Aging and Adults with Physical Disabilities (DSAAPD). Information would be useful if added to the web site of the Office of the Public Guardian and that of the State Ombudsman. Language could be added to the Guides produced by Community Legal Aid Society for those who are older and those who have disabilities. Information should be added to the state websites for all of the agencies on the Working Group. The Delaware Code related to the Delaware Care Plan may need to add language (Title 12, Chapter 40, §4001). All Transition documents and information tools should add SDM information as an alternative to Guardianship for those students leaving the school system. Legislation (S.B. #180) was introduced to address special education decision making by students with disabilities attaining the age of majority. Many of the same stakeholders supporting SDM legislation were also involved with S.B. #180. The bill codifies a legal presumption of capacity and directs that any benefit of the doubt concerning capacity should be exercised in favor of a finding of capacity.
4. Attendance at Symposium in Washington, DC – Lexie McFassel (OPG), Pat Maichle (DDC), and Terri Hancharick (GACDDDS) attended the Symposium on Supported Decision-Making hosted by Quality Trust on November 18 –

19, 2015 at American University School of Law. This enabled us to meet the other grantees and to hear about their work on this topic, as well as to meet and hear from experts on this topic from across the country. This event allowed us to invite the speakers for our planned Summit in April 2016.

5. Educational Outcomes – The Delaware Supported Decision-Making Summit took place on April 15, 2016 in Dover. Our speakers included Jonathan Martinis of Burton Blatt, Samantha Crane of ASAN, Tina Campanella of Quality Trust, and Susie King, a parent and Legal Guardian. This was a free event to the attendees with financial support from Quality Trust through this grant and from the Developmental Disabilities Council in Delaware. 115 Attendees included Delaware attorneys, self-advocates, parents and other family members, professionals, legislators, and the Working Group members. Twenty-six Delaware attorneys who attended earned 6 hours of approved CLEs for the day. We presented a Pre and Post Evaluation to gather information from the attendees regarding with knowledge of the topic before and after the Summit and their feedback on the speakers and environment. It was interesting that 73% of the audience reported prior knowledge of Supported Decision-Making and 50% reported using SDM in their lives prior to the event. After hearing the presentations, 73% reported using SDM in their lives, mostly with the help of family members and 82% reported helping someone else make decisions. Although, 40% of the audience identified as professionals, 8% identified as self-advocates and 12% were Guardians. In preparation for this event, the Working Group developed educational documents for attendees and for other educational opportunities. These include a flow chart of the Spectrum of Capacity in Decision-Making, a one-pager with Supported Decision-Making Facts which accompanies the event flyer/invitation, and a chart of Comparison of Decision Making Options in Delaware (all attached).

Additional Education Presentations

- Special Education Leadership Presentation – Lexie McFassel (OPG) will present Supported Decision-Making on September 14, 2016. These are,

obviously, the leaders in Districts who interact regularly with students and parents whose children receive Special Education services and who would be education professionals in schools who can provide information about Supported Decision-Making to those same students and families as an alternative to Guardianship.

- Christina School District Transition Alternatives to Guardianship Presentation – Laura Waterland (DLP) presented on March 10, 2016. This presentation reached District personnel as well as families in this District. We hope to include this presentation annually for this group.
- Education Chiefs’ Council (District Superintendents) Presentation – Sybil White(GACEC), Terri Hancharick (GACDDDS), and Pat Maichle (DDC) presented to the Chiefs May 5, 2016. This is the group of top education professionals in each school District who set the tone and make the rules for each of their Districts. They are the Superintendents. It is very important to, at least, have them be aware of this option of decision making for their students and families and, hopefully, to “bless” the concept which will provide motivation for the District Transition staff to bring this concept to families and students on a regular basis.
- Delaware Statewide Education Transition Council Presentation – Pat Maichle (DDC), Wendy Strauss (GACEC), and Laura Waterland (DLP) presented to this group of Delaware educators on May 19, 2016. These are primarily education professionals who work with students during their transition years and have been the people who discuss with families the option of Guardianship prior to exit from school. We provided information to them to provide a good understanding of Supported Decision-Making as an option to consider before application for Guardianship. (Laura Waterland’s power point presentation is attached.)
- State Transition Conference 2016– It has been recommended that Supported Decision-Making be a priority topic to consider for conference planners for the fall of 2016.

- Brain Injury Association of Delaware (BIAD) Conference Presentation – Cory Nouri of Nemours presented in March 2016 to include Supported Decision-Making as an alternative to Guardianship.
- Lexie McFassell (OPG) was asked to present information on SDM at the May 19, 2016 meeting of The Improving Transition of Care meeting for Health Care Professionals at Christiana Hospital.
- Delaware People First Self Advocacy Conference April 16, 2016 - Jonathan Martinis provided the Lunchtime Keynote to introduce Supported Decision-Making to those in Delaware who are self-advocates in Delaware.
- Video – Emmanuel Jenkins (DDC), with the financial support of the Division of Developmental Disabilities Services, worked for several months to coordinate the production of a video that includes statements from people with disabilities and older Delawareans and family members about their understanding of Supported Decision-Making, their current options for decision making, and their preferences for the future of their decision making. People in the video are representative of the population in Delaware, they are of a variety of ages, and include people with brain injury, intellectual disabilities, physical disabilities, deaf/blindness, and those with significant communication supports. The link to the video produced is <https://www.youtube.com/watch?v=dGJe5KyflxM&feature=youtu.be>.
- Guardianship Commission – Lexie McFassel (OPG) serves as Chair of the Delaware Guardianship Commission and has presented to the Commission in February 2016 information about the WINGS Program and Guidelines and asked that they consider being the WINGS entity in Delaware. They again addressed this opportunity in April 2016 and agreed to pursue this status. They will also consider additional key stakeholders to invite to the Commission to fulfill this need. This outcome is a result of a conversation on December 11, 2015 with retired Judge Andrew Bissonnett of Wisconsin, Fil Callisa of the DDC in Wisconsin, Jonathan Martinis, Lexie McFassel, and Pat Maichle. Judge Bissonnett highly recommended the WINGS Program and Guidelines replication for Delaware.

- Court – Lexie McFassel (OPG) approached the Delaware Court of Chancery to provide information and to bring awareness of this option on the continuum of decision making for people November 2015.
- A “Wordle” or “Word Cloud” was developed on this topic to be used on the documents that we used.
- Baseline Data from Court for Measure of Change Over Time – Lexie McFassel (OPG) plans to research current data that is collected in the Court concerning Guardianship applications and those that are granted. We will review this data for the next several years to see if the numbers will reflect a positive change in the choice of options for people in Delaware.

Discussion of Process

Working Group Membership and Commitment – The Membership of the Working Group remained stable except for the addition of Cory Nourie from Nemours Health Care and agency trainers for expertise. The Membership is as follows:

Delaware Developmental Disabilities Council (DDC)

Mission:

The mission of the Delaware DDC is to promote and embrace inclusion, equality and empowerment. To that end the Council will:

- Fund projects that promote system change.
- Facilitate access to culturally competent services.
- Educate the public and policy makers.
- Hold agencies accountable.

The Delaware DDC believes that all individuals should be included; all individuals should be able to exercise their rights and responsibilities; the needs of individuals and families should be met; supports should be person-centered; and equality should be promoted and the accepted standard.

Primary Contact:

Patricia L. Maichle, DDC Executive Director
Margaret M. O'Neill Building, Suite 2
410 Federal Street, 2nd Floor

Dover, Delaware 19901
Phone: (302) 739-3333

More information about the Delaware DDC is available on the Web at:
<http://ddc.delaware.gov/index.shtml>

PROJECT PARTNERS

For this project, DDC partnered with the disability-related councils and agencies that previously worked together on the potential revisions to the guardianship law in Delaware. Descriptions of the councils or agencies are listed below and include their respective missions, primary contacts and links to their home Web sites.

Although Delaware is a small state, it is considered by many to be a true microcosm of the U.S., featuring culturally and racially diverse urban, suburban and rural populations within its three counties. But as a small state, the disability-related councils and agencies in Delaware have a wonderful history of effectively working together for the benefit of Delawareans with disabilities. DDC and its project partners view the State Grant Program as a valuable opportunity to facilitate the creation of a new and preferable alternative to guardianship that would also have a profoundly positive impact on levels of perceived self-determination in the First State.

Delaware Department of Health and Social Services (DHSS)

Mission:

To improve the quality of life for Delaware's citizens by promoting health and well-being, fostering self-sufficiency, and protecting vulnerable populations.

DHSS is the largest state department, employing almost 4,300 individuals in a wide range of public service jobs. The department includes 12 divisions, which provide services in the areas of public health, social services, substance abuse and mental health, child support, developmental disabilities, long-term care, visual

impairment, aging and adults with developmental disabilities, and Medicaid and medical assistance.

Primary Contact:

Deborah I. Gottschalk, Esq., DHSS Chief Policy Advisor
1901 N. DuPont Highway
New Castle, DE 19720
Phone: (302) 255-9038

More information about DHSS is available on the Web at:
<http://dhss.delaware.gov/dhss/>

Division of Developmental Disabilities Services, DHSS

Mission:

The mission of the Division of Developmental Disabilities Services (DDDS) is: Valuing persons with intellectual and developmental disabilities, honoring abilities, respecting choice, achieving possibilities...working together to support healthy, safe and fulfilling lives.

Primary Contact:

Jill Rogers DDDS Director
Woodbrook Professional Center, Building 1056
1056 South Governor's Avenue, Suite 101
Dover, DE 19904
Phone (302) 744-9600

More information about DDDS is available on the Web at:
<http://dhss.delaware.gov/dhss/ddds/>

Division of Services for Aging and Adults with Physical Disabilities, DHSS

Mission:

The mission of the Division of Services for Aging and Adults with Physical Disabilities (DSAAPD) is to improve or maintain the quality of life for

Delawareans who are at least 18 years of age with physical disabilities or who are elderly. The Division is committed to the development and delivery of consumer-driven services which maximize independence through individual choice, enable individuals to continue living active and productive lives and protect those who may be vulnerable and at risk.

Primary Contact:

Lisa Bond, DSAAPD Director
Herman M. Holloway, Sr. Campus
Main Administration Building, First Floor Annex
1901 N. DuPont Highway
New Castle, DE 19720
Phone: (302) 255-9390 or 1-800-223-9074

More information about DSAAPD is available on the Web at:
<http://dhss.delaware.gov/dsaapd/>

Governor's Council for the Division of Developmental Disabilities Services

The GCDDDS serves as an advisory council to DDDS. Terri Hancharick serves as its Chair. Contact can be made through the DDDS Director's Office.

Governor's Advisory Council for Exceptional Citizens

Mission:

The Council's mission is to provide leadership through advice and advocacy for the unmet needs of citizens of all ages who are exceptional in order to improve their lives.

Primary Contact:

Wendy Strauss, GACEC Executive Director
George V. Massey Station
516 W. Loockerman Street
Dover, DE 19904
Phone: (302) 739-4553

More information about GACEC is available on the Web at:
<http://gacec.delaware.gov/default.shtml>

Office of the Public Guardian for the State of Delaware

Mission:

The mission of the Office of the Public Guardian (OPG) is to provide quality, comprehensive, protective guardianship services to adult citizens of Delaware who are severely mentally or physically disabled, are unable to manage their personal and financial affairs, are at risk for neglect, abuse and victimization and have no one else able or willing to serve as a guardian.

Primary Contact:

Lexie McFassel, Esq., Public Guardian for the State of Delaware
Kent County Courthouse – Suite 209A
38 The Green
Dover, DE 19901
Office: (302) 674-7463

More information about OPG is available on the Web at:
<http://courts.delaware.gov/publicguardian/index.htm>

State Council for Persons with Disabilities

Mission

The mission of the State Council for Persons with Disabilities (SCPD) is to unite, in one Council, disability advocates and State agency policy makers to ensure that individuals with disabilities are empowered to become fully integrated within the community.

Primary Contact:

Kyle Hodges, SCPD Director
Margaret M. O'Neill Building
410 Federal Street, Suite 1

Dover, Delaware 19901
Phone: (302) 739-3620

More information about SCPD is available on the Web at:
<http://scpd.delaware.gov/index.shtml>

Disabilities Law Program, Community Legal Aid Society, Inc.

Mission

Community Legal Aid Society, Inc. (CLASI) is a private, non-profit law firm dedicated to equal justice for all. We provide civil legal services to members of our community who have low incomes, disabilities or who are age 60 and over. Our services help our clients to become safe and self-sufficient.

The Disabilities Law Program (DLP) is a special project of Community Legal Aid Society, Inc., which is designated by the Governor as the Protection and Advocacy agency in Delaware. The DLP provides advocacy services to Delaware residents with physical or mental disabilities. We prioritize our services based on federal agency guidance and needs identified by consumer and community groups.

The Disabilities Law Program (DLP) is a special project of Community Legal Aid Society, Inc., which is designated by the Governor as the Protection and Advocacy agency in Delaware. The DLP provides advocacy services to Delaware residents with physical or mental disabilities. We prioritize our services based on federal agency guidance and needs identified by consumer and community groups.

Primary Contact:

Brian J. Hartman, Esq., Disabilities Law Project Director
100 W. 10th St., Suite 801
Wilmington, DE 19801
Phone: (302) 575-0660

More information about DLP is available on the Web at:
<http://www.declasi.org/disabilities-law-program/>

Final Budget

State total actual project budget for one year period from July 1, 2015-June 30, 2016.

PROJECT BUDGET		
Item	Item Description	Item Funding Amt
1	Contractual Services (i.e., research, pre-post measure development and completion, dissemination of information and educational materials)	\$5,000.00
2	Publication and Printing of Educational Materials	\$2,500.00
	Cash Contribution from DDDS for Item 2	\$2,500.00
	Cash Contribution from DDDS for Video Production	\$3,600.00
	Cash Contribution from DDC for Summit	\$3,296.00
	Total	\$14,396.00

The original proposal cited a total budget of \$7,500. Actual contributions from the working group ended with an increase of \$6,896.

Path Forward Post Grant

The Working Group for this grant demonstrated commitment and passion for the progress of Supported Decision-Making in Delaware. Unlike a lot of committees and groups like this one, all of the members remained engaged and each contributed their time, energy, and expertise towards the end goal.

The reactions from groups outside of this working group were varied and, at times, polar. Health Care representatives were concerned about liability should we adopt Supported Decision-Making for Delaware. Elder Law had concerns about older folks who may be at risk for exploitation. Current Guardians are concerned about the future of Guardianship and the vulnerability of those with intellectual/developmental disabilities. Fortunately, the working group members were well versed on this form of decision making and represented the issue in a positive format when questions arose. The educational materials that we had developed helped to show clearly how SDM fit into the option of decision making that are available to all Delawareans. The majority of those we came in contact with were very excited about this option for decision making.

The issuance of a joint position statement from national organizations that represent people with intellectual/developmental disabilities helped with discussions. Those include the AAIDD and the Arc of the U.S. In addition, the Commissioner of the federal agency AIDD, Aaron Bishop, presented a statement on this topic, as well. The continued support and education by the staff of Quality Trust and ASAN was invaluable throughout the past year.

The end of this grant will not be the end of our work on this topic. We intend to:

1. Ensure that the education system in Delaware includes Supported Decision-Making in all information that they share with students and families.
2. We will continue to expose people in Delaware to this topic, in particular, include this topic in our large conferences and in smaller educational opportunities like District transition fairs and trainings offered to parents and families.
3. We will work to educate and advocate for Supported Decision-Making language in our state code and to update our guides and materials that go to the public to include the same language with resource information.
4. We intend to include on our state web sites the array of information gathered during this grant so that the public has easy access to the same information.
5. We put our video on Youtube so that the larger public can see it and become informed. It currently can be viewed on the web sites of the Developmental Disabilities Council (<http://www.ddc.delaware.gov>) and that of the Governor's Advisory Council for Exceptional Citizens (<http://www.DelDHub.com>).

Thank you for this great opportunity to learn and to educate and to bring system change to Delaware for those with disabilities and those who are aging.

Thank You!

