

1. Describe the overall purpose of your program and how it aligns with the ADDPC goal of self advocacy. Explain in specifics why the ADDPC should continue funding your program.

The purpose of the Supported Decision-Making Pilot Project is to increase the use of supported decision-making agreements among individuals with developmental disabilities as an alternative to legal guardianship. Supported decision-making agreements fall in line with the self advocacy goals of the ADDPC by increasing independence and encouraging people with IDD to speak up for themselves.

People with intellectual and developmental disabilities have often been considered unable to handle the responsibilities one gains when becoming an adult. Family members may be told by service providers that it is in the best interest of the person with the disability to take away their rights as adults and have family members or caregivers become legal guardians. Upon attaining legal guardianship over a person with IDD, that person is no longer able to make their own decisions in a variety of areas including where they may want to live, employment, finances, and voting to name a few. Yet, this is not the only option available to people with IDD and their families who are trying to decide what to do as they near adulthood.

Supported decision-making agreements allow people with IDD to keep their rights and responsibilities as adults while still receiving the support they need to make well-informed decisions. This is done through formalized agreements between the person with the disability and people they trust who agree to provide support in the areas identified by the person with a disability. In contrast to legal guardianship, supported decision-making agreements do not take away the rights of people with disabilities. Supporters who enter into these agreements can only provide advice and help the person with the disability understand what their choices are when they have to make decisions. Furthermore, supported decision-making agreements are nonbinding and the person with the disability can choose to add or remove any supporter they feel is not meeting their needs.

Aside from increasing independence, supported decision-making agreements increase the person with a disability's ability to self advocate. When a person with a disability has their rights taken away from them through legal guardianship, they no longer have the right to make decisions about how they want to live their lives. This may lead to a lack of understanding about their own needs and personal care. Without this knowledge, a person with a disability may be forever reliant on their guardian. However, supported decision-making agreements require the person with the disability to understand what their needs are and be willing to advocate for themselves to ensure those needs are met. With the help of supporters when needed, people with IDD are able to advocate themselves to live the life they want to live.

2. Provide a summary of the program achievement for the current year of funding. Include all key activities that have been undertaken based on the

implementation plan. Describe success and barriers that were overcome, and what activities are being undertaken in the last quarter.

During the first year of the Supported Decision-Making Pilot Project, SWI and its partners The Arc of Arizona and Arizona Center for Disability Law have successfully laid the groundwork for a strategic plan whose goal is to increase the use of supported decision-making agreements as an alternative to guardianship. To do so, key objectives have been accomplished or are in the process of being accomplished including:

- establishing an advisory committee
- writing a white paper on guardianship issues
- creating a strategic plan for years two and three
- developing curriculum

To achieve the goal of increasing the use of supported decision-making agreements, it was important to establish an advisory committee to develop a clear understanding of the issues around guardianship and other alternatives such as supported decision-making. Meeting on a monthly basis, the advisory committee is comprised of people affected by guardianship as well as stakeholders from a variety of service providers. The advisory committee includes:

- self advocates
- a parent of a child with IDD
- SWI
- The Arc of Arizona
- Arizona Center for Disability Law
- attorneys specializing in guardianships
- vocational rehabilitation
- Arizona Health Care Cost Containment System
- Division on Developmental Disabilities
- Service Providers
- Representative form Autism group
- a medical doctor
- NAU-IHD UCEDD
- The Sonoran UCEDD
- Arizona Developmental Disabilities Planning Council

SWI and its partners are currently working on a white paper. The paper will identify the issues and concerns young adults with IDD, parents, caregivers, and stakeholders face when determining whether to pursue legal guardianship for young adults. To gather information, interviews are being conducted throughout the state with the above mentioned groups. The interviews determine:

- What do they know about guardianship or other alternatives?
- Where did they receive information?
- Who provided the information?

- What are their concerns as the young adult enters adulthood?
- What would they like to see on a curriculum about supported decision-making?

A barrier encountered in working on the white paper is gathering enough information to make inaccurate representation of the issues and concerns people face. Initially, the plan was to host forums for parents and caregivers to discuss their issues. However, it has proven unsuccessful together enough people to host forums. To overcome this barrier, SWI and its partners are now doing one-on-one interviews in person or over the phone. Interviews are scheduled at a time and place that is most convenient for everyone involved to increase the chances of a successful interview. Our goal is to have a completed white paper submitted to the advisory committee for review by the end of August.

A key objective for year one of the project is to develop a strategic plan to reach the goal of increasing the use of supported decision-making agreements among people with IDD. The strategic plan outlines objectives for years two and three of the pilot project. To determine those objectives, SWI and its partners worked with the advisory committee and the information gathered from the interviews with people and stakeholders to identify how to best reach our goal. Those conversations determined the strategic plan will have two objectives in the areas of education and legislation. The strategic plan has been submitted to the advisory committee for review before it is submitted to the ADDPC.

Education will be a key component of the strategic plan for years two and three of the pilot project. During the fourth quarter of year one, SWI and its partners will develop three separate curriculums. The first curriculum will be geared towards people with IDD, families, caregivers. The second curriculum will be geared towards social service providers, education, and medical providers. The third curriculum will be given in the form of Continuing Legal Education credits for legal professionals. To reach the most people possible, the advisory committee has recommended that the curriculum be provided through in-person trainings and through online video trainings. All curriculums will teach the benefits of supported decision-making agreements, how to develop them, and what is needed from everyone involved to ensure they are successful. The curriculums will also teach the importance of disability history, the self advocacy movement, and how to work with people with disabilities.

The education component will also be important in achieving the legislative objective. SWI and its partners expects to submit a bill to Arizona state legislature recognizing supported decision-making agreements as a less restrictive alternative to legal guardianship. As part of the objective for legislation, SWI and its partners will educate lawmakers about the bill in order to gain support for its passing. Education will also be provided to people with IDD, families, caregivers, and stakeholders so that they may advocate for the bill to their legislators.

3. Describe the role of the community partners that are part of the project and how they support your project.

The Supported Decision-Making Pilot Project is a collaborative effort between Southwest Institute for Families and Children, The Arc of Arizona, and Arizona Center for Disability Law. Each organization provides a positive benefit to the success of the project. SWI has years of experience working directly with families and people with disabilities to promote independence. The Arc of Arizona is a local advocacy organization with connections to the national Arc organization and has years of experience advocating at a state and national level in legislatures across the country on behalf of people with disabilities. Arizona Center for Disability Law is part of the DD network and provides protection and advocacy for people with IDD.

Besides the three partner organizations, the pilot project utilizes an advisory committee that meets on a monthly basis to monitor the progress of the project and provide advice as to how to achieve the projects intended goals. The advisory committee includes:

- self advocates
- a parent of a child with IDD
- The Arc of Arizona
- Arizona Center for Disability Law
- attorneys specializing in guardianships
- vocational rehabilitation
- Arizona Health Care Cost Containment System
- Division on Developmental Disabilities
- a medical doctor
- The Sonoran UCEDD
- Arizona Developmental Disabilities Planning Council

During the first year of the pilot project, the advisory committee has provided guidance in the areas of developing a white paper, strategic planning, and curriculum development. Their expertise has proven invaluable in ensuring the project is able to reach its goal of increasing the use of supported decision-making agreements.

4. Summarize feedback from participants, professionals and other stakeholders during the current funded period. Explain how this feedback will be integrated in program design for year two, and part of the overall evaluation process.

Feedback for the project has been received through two different forms including the advisory committee and through interviews with people throughout Arizona. The advisory committee has advised the project partners on how to implement the grant objectives. When the grant was first written, information from the public was going to be gathered through online surveys. The advisory committee suggested that more information would be gathered through forums and interviews than online surveys. The advisory committee has also provided the project partners with curriculum guidelines. Upon the advice of the committee, any curriculum created by the project partners will be

provided in person as well as online through short video vignettes during year two and three of the grant.

The public has provided valuable feedback that has served the project partners well in writing their white paper and developing curriculum. Upon the recommendation of the advisory committee, the project partners set out to host forums and interview people with IDD, families, caregivers and all relevant stakeholders. The purpose of the interviews and forums was to determine the issues and concerns people have around guardianship and other alternatives as young adults near the age of 18. Since April, project partners have interviewed young adults with IDD, parents, caregivers, social service providers, doctors, and lawyers throughout Arizona.

The feedback provided by those interviewed is nothing less than troubling and heartbreaking. There is a lack of information regarding options for young adults with IDD as they near adulthood. Parents and caregivers are often in the dark about what will happen to their child once they become an adult. Many times, the only information they receive is from a case manager or a social worker who contacts them when their child is 17 1/2 years old to inform them that their child is now old enough to begin guardianship proceedings. Furthermore, parents and caregivers are told that they must start the process immediately so that they can continue to be part of their child's service appointments.

Social service providers, healthcare providers, and legal professionals are also in the dark when it comes to alternatives to legal guardianship. When interviewing the stakeholders, each one has expressed a need for more information to share with their clients and patients. It seems that guardianship is promoted only because there is no other alternative.

The feedback gathered during year one of the pilot project will serve as a guide to meeting the objectives set out for years two and three. In particular, the feedback gained through the interviews has informed the project partners as to what needs to be included in the curriculum that will be implemented in the coming years. Parents and caregivers have demonstrated a lack of understanding of how legal guardianship works and how it affects their loved ones. They also lack information about alternatives to legal guardianship such as supported decision-making. When taught the difference between both, parents and caregivers are shocked as to the extent of how legal guardianship will affect their child and express interest in other alternatives.

5. Describe efforts to work in or promote the program in underserved or unserved areas of the state or with certain populations that are often overlooked.

Gaining feedback among underserved populations has been an important goal for the project partners. The advisory committee is comprised of a diverse group of individuals that include people with disabilities, parents and caregivers, social service providers, men and women, and a diverse mixture of racial backgrounds including African-

American and Latino. Each advisory committee member provides feedback shared through their own perspective.

Aside from having a diverse advisory committee, the project partners have worked hard to gain feedback from the public that matches the diversity of the state. Being that our largest minority population in Arizona is Latino, it was important to host a forum of Latino Spanish-speaking parents and caregivers. To host the forum, SWI worked with The Leti Foundation, a parent group for parents with children with IDD. The parents who attended the forum all had children nearing the age of adulthood.

The issues and concerns expressed by the Latino parents and caregivers are in line with the concerns of their parents have mentioned in our interviews. However, there is an added issue and concern when it comes to parents being in two separate countries and having to decide who will support the child when they become an adult. Immigration status, parenting rights, and their child's right to independence was all issues brought up by the parents.

- 6. Summarize evaluation findings to date, including the number of participants served, and their level of satisfaction. Explain if your program is on track with proposed target numbers, if not describe barriers to reaching target numbers. Include other data from the performance measures applicants were asked to track.**

No trainings have been conducted during the first year of the pilot project.

- 7. Describe any changes that will be planned for the second year, including program design, target numbers, collaborators, implementation, staffing, evaluation, and other activities.**

SWI and its partners plan to implement the objectives for years two and three as set forth in the strategic plan approved by the advisory committee. This will include educating the public about supported decision-making and passing legislation recognizing supported decision-making agreements as a less restrictive alternative to legal guardianship.

The first objective in reaching our goal will be to educate the public about supported decision-making. To do so, SWI and its partners will utilize the three separate curriculums developed during year one to provide in in-person trainings as well as online. The first curriculum will be geared towards people with IDD, parents, caregivers, and supports. The second curriculum will be geared towards social service providers such as case managers, social workers, and healthcare providers. The third curriculum will be geared towards legal professionals and offer continuing legal education credits. In the trainings, participants will learn about disability history and philosophy, self advocacy, the differences between supported decision-making and other alternatives, as well as how to create their own supported decision-making agreements.

To provide the trainings in-person around the state, SWI and its partners will conduct six trainings each year for years two and three. The trainings will be geared towards people with IDD, family, and caregivers. Over the course of a year, two trainings will be provided in Flagstaff Arizona, two trainings in Phoenix Arizona, and two trainings in Tucson Arizona. The trainings will utilize the curriculum developed during the first year of the pilot project.

Trainings will also be provided to educators and social service providers such as case managers, social workers, and medical providers. The curriculum will be the same as that provided to parents and caregivers but will be modified to be relevant to each stakeholder. During year two of the project, educators will be provided with two in person trainings to be held one in Phoenix and the other in Tucson Arizona. Social service providers will also receive two trainings during year one to be held in Phoenix and one in Tucson.

An online version of the curriculums will also be provided utilizing short videos that people can access at any time. The online training videos will be created during the first six months of year two. Once created, the video curriculum will be available well past years two and three and will help in the sustainability of the project.

The third curriculum will be geared towards legal professionals. To target this population, the curriculum will be provided as part of Continuing Legal Education (CLE) courses that legal professionals are required to take. Four in-person trainings will be provided each year during years two and three in Phoenix and Tucson Arizona. Each year there will be two trainings in Phoenix Arizona and two trainings in Tucson Arizona.

As in the curriculum provided to parents and caregivers, legal professionals will also learn about disability history of philosophy, self advocacy, as well as the differences between supported decision-making and other alternatives. Legal professionals will also learn about the requirements of the law if and when Arizona passes a law recognizing supported decision-making as a less restrictive alternative to guardianship.

An online curriculum geared towards legal professionals will also be created during the last six months of the year two. The online curriculum will utilize short video trainings that will be available at any time participants choose to view them. Unlike the in person trainings, the online curriculum will not be available for Continuing Legal Education course credits.

Aside from creating curriculum, SWI and its partners plan to submit legislation during the 2020 legislative session recognizing supported decision-making as a less restrictive alternative to guardianship. In an effort to increase support around the proposed bill, SWI and its partners will educate lawmakers about the benefits of supported decision-making agreements and how the bill aims to recognize such agreements as a less restrictive alternative to guardianship.

SWI and its partners will also work with the community to educate them about the bill and how to advocate for the proposed legislation to their legislative representatives. Advocacy trainings will be provided to people with IDD, parents, caregivers, and all relevant stakeholders.

8. Elaborate on the sustainability efforts the organization will or has currently undertaken to support the program. Describe efforts that show commitment from other sources of funds.

As part of our sustainability efforts, the curriculums created for the pilot project will be available online for free. By providing online trainings, anyone interested in learning about supported decision-making will have access to the curriculum at a time and place that is most convenient for them. Furthermore, the curriculum will be available beyond the third year of the project.

SWI and its partner organizations are also looking into grants for supported decision-making programs. The Administration on Community Living has posted a request for proposal funding a planning project around supported decision-making. The grant will fund existing projects that incorporate people with IDD and the aging population. SWI and its partners are working with the UCEDD in Tucson Arizona and the AARP to form a partnership of the grant. The grant will be submitted August 19 and the decision will be provided by September 2019.

Arizona Supported Decision-Making Task	Responsible person	Measurement	Completion date
Work with partner organizations to write SDM draft legislation	SWI, ACDL, The Arc of Arizona	Create draft legislation	December 2019
Submit legislation to AZ legislature	SWI, ACDL, The Arc of Arizona	Sponsored bill submitted to legislature	January 2020
Educate Arizona State legislators about bill	SWI, ACDL, The Arc of Arizona	Meetings with state legislators	March 2020
Educate public to advocate for bill	SWI, ACDL, The Arc of Arizona	2 Webinars, 1 in person training	March 2020
Create online curriculums for people with IDD, family, caregivers, social service providers	SWI, ACDL, The Arc of Arizona	One online curriculum uploaded to YouTube and posted on SWI website	March 2020
Create online curriculum for legal stakeholders	SWI, ACDL, The Arc of Arizona	One online curriculum uploaded to YouTube and posted on SWI website	September 2020
Provide in-person trainings for people with IDD, family and caregivers	SWI, ACDL, The Arc of Arizona	Six in-person trainings conducted (two in Phoenix, two in Flagstaff, and two in Tucson)	September 2020
Provide in-person trainings to social service providers and medical providers	SWI, ACDL, The Arc of Arizona	Two in-person trainings (one in Phoenix and one in Tucson)	September 2020
Provide in-person trainings per year to education professionals	SWI, ACDL, The Arc of Arizona	Two in-person trainings (one in Phoenix and one in Tucson)	September 2020
Provide in-person trainings to legal professionals for continuing legal education (CLE) credits	SWI, ACDL, The Arc of Arizona	Two in-person trainings (one in Phoenix and one in Tucson)	September 2020

Key staff

George Garcia

Executive Director Southwest Institute for Families and Children

George Garcia is project director for the Supported Decision-Making Pilot Project. George will be responsible for submitting all reports and documentation to the ADDPC. George will also be working with ACDL and The Arc of Arizona to provide trainings to people with IDD, families, caregivers, social service providers, and health care workers. George will also work with the grant partner organizations to provide education and support of supported decision-making legislation.

Juliana Huereña

Operations Manager Southwest Institute for Families and Children

Juliana will be responsible for providing trainings to people with IDD, families, caregivers, social service providers, and health care workers. Juliana will also be responsible for notetaking and minutes collected during advisory committee meetings.

Sey In

Staff Attorney

Sey has been assigned 75 hours of Project time

3 years law school experience in health law policy and 1 year as a licensed attorney

Sey will be one of the attorneys working in the project. Sey will be the lead ACDL staff member assigned to the Project. Sey will be responsible for all tasks identified in the year two renewal timeline.

Natalie Luna Rose

Outreach and Communications Manager

Variable depending on needs of grant. Natalie has been assigned 9.6 hours of project time.

2 years as staff member for ACDL

Natalie will be one of three ACDL staff members working in the project. More specifically, Natalie will be assigned to working on the tasks related to submitting

legislation to the AZ legislature and educating legislators and the public about the SDM bill.

J.J. Rico

Chief Executive Officer (CEO)

Variable depends on needs of the grant. J.J. has been assign 8.5 hours of project time.

18 years (Staff Attorney, Litigation Director, and CEO)

J.J. will be the third ACDL staff member working on the project. More specifically, J.J. will be assigned to working on the tasks related to submitting legislation to the AZ legislature and educating legislators and the public about the SDM bill. J.J. may also responsible for conducting training for legal professionals and trainings held in Tucson.

Jon Myers

The Arc of Arizona

The Arc of Arizona will be an advisory committee member and facilitator, assisting in creation and implementation of curricula for individuals with I/DD and family members/caregivers, legal professionals, healthcare and social services providers, and educators. The Arc will be the lead in refining draft legislation for introduction in the 2020 Arizona legislative session, stewarding the bill through the legislative process, and working toward passage. The Arc will also engage in additional formal and ad hoc outreach to raise awareness of SDM within a variety of stakeholder communities.

Nicole Jorwic,

JD, Senior Director of Public Policy for The Arc,

Nicole will: review draft legislation and make recommendations, as appropriate, utilizing experience gained on SDM efforts in other states; offer in-state and remote consultation on work with legislators and legislative staff, including accompanying SWI, ACDL, and The Arc of Arizona to a limited number of meetings with state legislators and staff; and provide guidance in outreach to stakeholder communities as we educate them to increase both grassroots advocacy for passage of the bill and support for implementation once the bill passes.

Budget Request form

Contractor Name: Southwest Institute for Families and Children

Contractor Address: 255 E. Osborn Rd, Suite 103 Phoenix, AZ 85012

Project Name: Supported decision Making Pilot Project ADDPC-FFY18-SDM-010

Budget Category	Requested ADDPC Funds	Non- Federal Cash Match	Non-Federal In-Kind Match	Total Program Cost
Personnel/Salaries	17,640		1880	19,520
Fringe Benefits	2,443.14		260.38	2703.52
Supplies Operating Expenses	0		400	400
Travel	0		0	0
Rent or Cost of Space	0		2,520	2,520
Contracted Services Professional Services	33,960		14,575	48,535
Administrative /Indirect Costs	5200			5200
TOTAL	59,243.14		\$19,635.38	78,878.52

It is understood that Non-Federal Funds identified in this budget will be used to match only ADDPC Federal Funds, and will not be used to match any other Federal Funds during the period of the ADDPC funded Project

Additional description and background information shall be included as a budget narrative, including for match. The contractor agrees to submit additional background information to the ADDPC upon request.

George Garcia

Name of certifying Official

Executive Director

Title of Certifying Official

602-235-0354 extension 801 G.Garcia@SWIfamilies.org

Phone

Email

AZ SDM Budget Narrative

Personnel/Salaries, \$19,188.62

George Garcia, \$10,140

Project Director George Garcia, MSW .15 FTE (\$10,140) salary for one year x \$50,000/annual wage to serve as the senior administrator, provide programmatic oversight, develop, deliver, and evaluate supportive decision making trainings.

Juliana Huereña \$7,500

Logistics Consultant to training participants- Juliana Huereña, MT-BC, .17 FTE (\$7,500) salary for one year x \$45,000. Participate with Garcia to develop, deliver, and evaluate supportive decision making trainings.

Priscilla Perkins, **\$1880**

Priscilla Perkins in-kind will provide bookkeeping and financial support for the project.

Priscilla Perkins, .035 X \$53,200/annual wage to maintain the financials and HR for the project.

Fringe Benefits, \$2657.62

Employee Related Expenses -SWI has a formula that yields the following: 13.85% which includes FICA 6.2%, Medicare 1.45%, and FUTA 6.2%.

George Garcia, \$10,140 X 13.85% = \$1404.39

Juliana Huereña, \$7,500 X 13.85% = \$1,038.75

Priscilla Perkins in-kind, \$1880 X 13.85% = \$260.38

Supplies/Operating Expenses in-kind \$400

Office supplies (copy paper, transparent paper, binder coils, and ink)

Travel, \$0

Rent or Cost of Space, \$0

In-kind of office rental \$210 X 12 month = **\$2,520** for 10% usage of office space, including phone and internet services at SWI.

Contractual Services/Professional Services, \$33,960

ACDL will be an advisory committee member and facilitator. They will be lead organization in creating the curriculum for legal stakeholders and provide CEUs to attorneys, attorney staff, and judges. They will assist in teaching support decision-making for individuals with I/DD and family members and supports. They will work with The Arc of Arizona to draft legislation regarding supported decision-making.

Arizona Center for Disability Law will receive **\$16,960** for the work provided in the grant.

J.J. Rico CEO of ACDL: 8.5 hours x \$250/hour= \$ 2,125

Staff Attorney Sey In: 75 hours x \$185.00/hour= \$13,875

Natalie Luna Rose - Communications and Outreach: 9.6 hours x \$100/hour= \$960

Match

Arizona Center for Disability Law will provide a matching fund of **\$9200** that will be divided between the use ACDL staff and interns working on the grant and the use of the Ability360 conference room.

ACDL staff: 46 hours x \$145.00/hour= \$6,670.00

Intern (ASU & UofA Law Students): 25 hours x \$50.00/hour= \$1,250.00

Ability 360 Conference Room Rental: 16 hours x \$80.00/hour= \$1,280.00

The Arc of Arizona will be an advisory committee member and facilitator. They will assist in teaching supported decision-making for individuals with I/DD and family members and supports and teaching curriculum for social service providers, medical, and other professional stakeholders. The Arc of Arizona will draft legislation regarding supported decision-making. Services in the amount of \$17,000

Match

The Arc will provide an in-kind match in the form of technical assistance from the Public Policy staff of The Arc of the United States. Nicole Jorwic, JD, Senior Director of Public Policy for The Arc 25 hours X \$215 = **\$5375**

Administrative/Indirect Cost, \$5200