

# Final Report

**Grant:** National Resource Center for Supported Decision-Making's State Grant Program : North Carolina

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**Project Title:** Supported Decision-Making: North Carolina

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## **Initiative Overview**

First In Families of North Carolina (FIFNC) in partnership with The Arc of North Carolina received a grant from the National Research Center on Supported Decision-making through Quality Trust. The purpose of the grant was to increase awareness of Supported Decision making as well as pilot Supported Decision Making as a tool to increase self-directedness in decision making for individuals living with I/DD living in North Carolina.

## **Organizational History and Qualifications**

First In Families of North Carolina (FIFNC) is a 501(c)3 not-for-profit organization serving individuals with developmental disabilities and their families throughout all 100 counties of North Carolina. FIF supports an average of 2,300 families per year to meet their self-defined needs. FIFNC provides future planning resources and trainings, as well as professionally facilitated networks of support to individuals with I/DD.

The Arc of North Carolina is a private non-profit, 501(c)3, membership organization, founded in 1953. The primary mission is to secure for all people with intellectual and developmental disabilities (I/DD) the opportunity to choose and realize their goals related to where and how they learn, live, work and play.

## **PRESENTATIONS COMPLETED**

<b>Date</b>	<b>Audience</b>	<b>Topic</b>
9/15	The Arc of North Carolina	Supported Decision-Making as an Alternative to Guardianship
10/15	Presentation to “Rethinking Guardianship” Taskforce NC	Overview of Supported Decision-Making as alternative to guardianship at statewide taskforce group.
11/15	North Raleigh (NC) Civitas	Future planning overview including SDM as alternative to guardianship
12/15	Statewide Training for NC Managed Care Organizations	SDM as alternative to guardianship.
1/16	Webinar Presentation to Aging Providers throughout NC	Overview of SDM and benefits for those who are aging. (88 attendees)

## **ANALYSIS OF PILOT SUCCESSES**

**Current use of SDM.** Through our Lifetime Connections program FIFNC is now (since July 2015) utilizing Supported Decision Making in five of our personal support networks as a way of promoting independence, and embed it in all future personal networks that start up. For the five currently using SDM, stakeholders report its benefit or purpose specifically in the following areas:

- 3 networks identify “help with improving a personal skill” as an important value of the Supported Decision Making; and
- 3 networks list “help making financial decisions” as the purpose for their use of Supported Decision Making.

**Who are the advisors typically?** Although focus persons (the individuals with I/DD) have chosen a mix of family and non-family network members to serve as advisors, it is interesting to note that it is mostly family that has been chosen to support focus persons in the domain of *financial decisions*.

**How have we introduced and normalized SDM in our networks?** Our network meetings include a sharing exercise where all network members share examples of decisions where support was needed since the last meeting. This has helped point out how common the practice of supporting decision making is in all of our lives, including

people without disabilities. Some specific areas where support has been requested include:

- "I am sometimes annoying to my friends because I always want to be with them"
- "I don't know how to email and need someone to help me"
- "I am 22 and have never bought anything myself in my life! Someone has always done it for me so I need some help understanding what things cost"
- "I have my own debit card and use it when I want but usually call mother before I spend more than \$25"
- "I haven't gone to the Dr. in several years and am moving to a new area so need help getting a doctor"

## **OPPORTUNITIES**

**Effective Collaboration.** It was encouraging to have the support and infrastructure provided by the NC "Rethinking Guardianship" workgroup which opened the opportunity to work directly with the UNC School of Social Work to begin implementing SDM as a pilot within Cabarrus County (Hickory, NC) in conjunction with DSS and Clerk of Court personnel to identify individuals that might benefit from alternatives to guardianship such as supported decision making.

**Use by Court.** The most serious demonstration of our application of Supported Decision Making in this pilot has been its use by one of our networks through the Orange County Community Resource Court as a tool to monitor the focus person's progress in making healthy decisions, including keeping scheduled appointments with service providers and contacting her advisors for support before contacting authorities.

## **CHALLENGES**

- The Arc of NC presented information on Supported Decision Making and draft agreement to 20 regional managers and QA/QI staff. Arc staff solicited from this group any individuals they were supporting (outside of LIFEguardianship supports) who might be good candidates for piloting the draft agreement. They discussed piloting with several people, but none worked out. One person was hospitalized with multiple medical issues over a long period and it was not a good time in his life to pilot something new. After discussing other potential candidates, our [Arc's] main obstacles were that these folks had no relationships with people in their lives who could become trusted advisors or mentors in a Supported Decision Making approach.
  - What was learned –
    - typically, it's better to start this process while someone is stable and not in a crisis situation, and
    - our first step has to be helping people develop relationships with folks they can trust before we can move into helping them build a Supported Decision Making team.

Stated Outcomes	Activities towards Outcomes	Outcome Achievements
<p>North Carolinians with I/DD and their families/allies will have available a working Supported Decision-making tool fully vetted by at least 25 self-advocates and members of the aging community partners who participate and a field-tested process for implementing a Supported Decision-making Agreement with the confidence provided by their adoption and recommendation by both FIFNC and The Arc of NC.</p>	<ol style="list-style-type: none"> <li>I. Introduction of the tool to self-advocate members of FIF and ArcNC chapters, and others and adjustment of the tool based upon their feedback regarding clarity word choices, relevance and usability of the tool.</li> <li>II. Contact Service Division of the The Arc of NC and FIFNC Chapters and Management Teams, and make them aware of the pilot</li> </ol>	<ol style="list-style-type: none"> <li>I. Solicited feedback on draft Supported Decision Making tool from the following:               <ol style="list-style-type: none"> <li>a) 35 self-advocates and family member volunteers from FIF Chapters vetted the tool and provided feedback on usability.</li> </ol> </li> <li>II. Information and training was provided to:               <ol style="list-style-type: none"> <li>a) Staff and volunteers at all 13 Chapters of FIF</li> <li>b) 25 local chapters of The Arc of NC</li> <li>c) 30 Board members of The Arc of NC</li> <li>d) 11 Board members of FIFNC</li> <li>e) The Arc staff, including 4 Regional Directors, 5 Senior Directors, 25 regional managers and QA/QI staff</li> </ol> </li> </ol>
<p>Participants (Lifetime Connections family members, Choice program members, and aging community volunteer participants) in Pilot will experience greater peace of mind by the existence of a Supported Decision-making Agreement between their loved one and the Advisor(s).</p>	<ol style="list-style-type: none"> <li>I. Survey FIFNC Lifetime Connections members and individuals receiving advocacy and services through The Arc of NC and partners to determine who is interested and willing to participate in project.</li> <li>II. Select and invite 9 individuals to who will participate in the Pilot project</li> <li>III. Upon agreement by focus person to adopt and pilot SDMA, identify the natural supports and key staff who work with the 9 individuals in the pilot and provide them training on Supported Decision-Making and the Pilot Project</li> </ol>	<ol style="list-style-type: none"> <li>I. 11 active Lifetime Connections members were surveyed to determine if they were interested/willing to participate in the project.</li> <li>II. 5 Lifetime Connections Members identified agreed to utilize the tool as part of the pilot.               <ol style="list-style-type: none"> <li>a) The Arc worked with program staff to identify potential candidates in their program. None were identified during the grant period (see Challenges) The Arc continues to provide SDMA as an option to its clients.</li> </ol> </li> <li>III. Network facilitators and members were trained on how to implement SDM and a walk through of the process was conducted with each pilot participant and their networks.</li> </ol>

	<p>IV. Check in with participants at 4, 7, and 11 months points to answer questions and determine if there has been a need to utilize the Advisor.</p>	<p>IV. At each participant's regularly scheduled network meetings (typically every 4-6 weeks, est. 35 meetings during grant period) SDM was a regular agenda item, and participants and network members shared how they have utilized SDM since they last met including, successes and challenges. Each of the 5 networks participating consistently used and discussed the value of SDM at throughout the grant period.</p>
<p>NC Policymakers will have practical information on the use of Supported Decision-making that can inform policies and future legislation concerning alternatives to guardianship and Supported Decision-making.</p>	<p>I. Distribute final report to stakeholders and policy makers.  II. Presentations to policy makers and key stakeholders on SDMA as an alternative to guardianship.</p>	<p>I. A copy of this final report will be shared widely with stakeholders, policy makers by FIFNC and The Arc of NC.  II. Presentations to the Statewide "Rethinking Guardianship" taskforce (10/15) and information sharing with DD Consortium members and a webinar presentation to professionals (1/16) with 79 participants on the benefits of SDM for individuals who are aging.</p>
<p>People with I/DD, aging individuals, family members, and professional allies in both the disability and aging services sectors will be more aware of "alternatives to guardianship" and Supported Decision-making as one specific alternative.</p>	<p>I. Engaged local FIF and Arc chapter staff to collect information on civic clubs, organizations serving individuals with disabilities and aging caregivers to scheduled presentations on SDM.</p>	<p>I. 12 presentations to community partners were made throughout the state by FIFNC and The Arc.  a) These included a presentation to a Raleigh Civitas group, a presentation at The Arc of NC annual conference (part of a future planning track) by FIFNC (9/15), and at two public schools (See Education Section)  b) Distributed over 600 brochures on Options to Guardianship.</p>
<p>Sustainability of the project will be ensured</p>	<p>I. Compile final report on their entire pilot with formal input from all participants in the</p>	<p>I. This final report was compiled under the advisement and with the formal input of pilot participants.</p>

	<p>outcomes and recommendations.</p> <p>II. FIF and The Arc will continue to train, inform and use SDM within their organizations and in trainings and workshops for the public beyond the grant period.</p>	<p>II. FIFNC and The Arc remain active in the “Rethinking Guardianship” workgroup, attending monthly meetings, and continue to share information on SDM with legislators, families, individuals with I/DD and those who are aging.</p> <p>a) Lifetime Connections will continue to offer SDM as a training topic and utilize the tool with Network participants.</p>
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### **Conclusion, Deliverables and Ongoing Efforts**

FIF continues to remain engaged in promoting Supported Decision Making as an alternative to guardianship and remains on the Rethinking Guardianship taskforce, active with legislative efforts and in informing other agencies working with people living with I/DD or those who are aging about SDM and how to use the tool. Information and links are shared on the FIFNC website.

A final version of the Supported Decision Making tool is included as an addendum to this report. It has been shared with the following:

- I. Staff of The Arc of NC and its Chapters.
- II. Staff and Board of FIFNC and all Chapter staff, as well as volunteer management team members (each group comprised of at least 51% individuals with I/DD and/or their family members)
- III. 88 Webinar participants representing the aging supports network.
- IV. Members of the “Rethinking Guardianship” Taskforce overseen by the Jordan School of Social Work at the University of North Carolina at Chapel Hill. (Part of an online library of documents available to interested parties).
- V. Supported Decision Making page on FIFNC website:
  - a) Materials included in the NC Dropbox (Rethinking Guardianship) with tool and presentation info.
    - i) <https://www.dropbox.com/sh/ewidgy757yi3ja1/AABfOmysBVHoFlxOGPD/RnNIba?dl=0>
    - ii) Link to Overview of Supported Decision Making on FIFNC website: <http://www.fifnc.org/programs/connections.html>