Future Planning for Self-Determined Lives

And the Quality Trust grant for Supported Decision-Making in NC

First In Families of North Carolina

October 1, 2015
Our Mission

The FIFNC mission is to help individuals with disabilities **Believe** in their dreams, **Achieve** their goals and **Give Back** to others.
Snapshot of FIFNC:

- Assists people of any age with I/DD or TBI, and their families
- Over 3,000 met requests each year throughout NC
- Nonprofit since 2001; began in 1995 as a pilot project
- Customer-led at every level
- Not a Medicaid provider
Celebrating 20 years of supporting families as experts

Å Founding parents (moms) envisioned entirely different way of how their loved ones could receive support and interact in the community
Examples of requests:

**In NC, state funding** may be used for:

- Special formulas for children;
- Requests for food;
- Home modifications and “smart home technology”;
- Tuition for classes or payment for therapy or camp;
- Communication technology;
- Vehicle Repairs;
- Adapted swimming goggles; and
- **Future planning support, increasingly**
Supporting Families to Plan for the Future

Future Planning Checklist

Steps to consider when planning for the future of your loved one with an Intellectual/Developmental Disability or TBI:

Future Planning Task:

- Do you have a Will, or a recently updated Will?
- Have you prepared a Letter of Intent pertaining to your family member?
- Do you have an Executor named?
- Do you have a Special Needs Trust or participate in a Pooled Trust?
- If so, do you have a personal and/or agency Trustee?
- Do you need or want a Trust Protector?
- Do you have life insurance or other means to fund a Trust?
- Have you considered alternatives to Guardianship? For example:
  - Do you have a Representative Payee for your family member?
  - Has your family member given you Power of Attorney?
  - Has your family member given you Health care Power of Attorney?
- Do you have a personal support network?
- If you plan to pursue Guardianship, do you know what steps to take?
- Do you have an Attorney that specializes in Elder care or is knowledgeable about Disability issues?

If you can check off any of these boxes, congratulations! You have begun your planning and are ahead of the majority of people. If not, and you would like to begin there are many resources available to help you. (See these)
Lifetime Connections

• Provides support to families with future planning services in NC since 2005
• Promotes and educates on *alternatives to guardianship* for adults with I/DD or TBI
• Considers SDMA to be one important tool to use in place of guardianship

www.fifnc.org
Where does the *individual* fit into future planning by families?

- Self-determination can be consistent with family choice
  - Include individual in all phases of future planning; worksheets
  - Supported decision-making
- Employment First gaining momentum in NC
- Explore and utilize alternatives to guardianship whenever possible
FIFNC received a grant from the National Resource Center on Supported Decision-Making (SDMA)

- Received 1 of 6 grants to various states
- SDMA an innovative and tangible alternative to guardianship
- Provides needed support through an Advisor
- Protects autonomy and dignity
- Documents the agreement in writing

www.fifnc.org
More on the grant

Å FIFNC has a SDMA tool it developed in 2010 to offer families it supports, and their adult loved ones;

Å Purpose of grant is to

   ï Vet the tool thoroughly by self-advocates and families;
   ï Pilot its use for at least 9 individuals currently served through FIFNC programs and those of the Arc of NC (partner)
   ï Also share widely with Aging community partners

Å Currently in month 4 of 12.

www.fifnc.org
Efforts to date:

Å FIFNC has feedback from 35 individuals who have reviewed the SDMA tool and provided feedback on word use, clarity, etc.

Å Tool is being adjusted now based on feedback

Å Families being approached to try it out with training

Å Outreach and training events being scheduled

www.fifnc.org
Some early lessons and perspective on the use of Supported Decision Making Agreements
What is needed for an SDMA to work as part of a comprehensive Plan?

1- Will & ability to be a Self Advocate
2- Financial & Legal Docs in place
3- Crisis specifics clear
4- Personal Connections For a pool of Advisors
Case study: Implementation of Janie’s SDMA (work in progress)

1. Getting Janie on Board specifically with idea of Advisors
2. Reassembling her Personal Network (since graduation)
3. Approaching people/buy-in
Janie’s network: “the Pool”
+ immediate family
Especially the youngins
New neighborhood
Breaking it down to *very specific* pieces

1. Would you be willing to be the point person on whether to purchase.......(us) or Janie:
2. Can you help me figure out stuff that costs a lot of $$ ?

1. **NOT:** Can you be *responsible* with Janie for all her financial decisions for the next sixty years? !!!!
Home ownership!
Sue- if it can be repaired, where?
Or...
Shaleigh- help select the new one?
Tina- figure out how to pay for it?
Sandy and pets? Lisa and health?
The Advisors

• Figure out who for what- Janie, with help as needed
• Ask them gently- “ ”
• Figure out how that organizes into specific agreements (Finances? Personal?)
• Ask them again!
• Sign/file/remind Janie now and then
• Celebrate with a party- keep building bonds
Desired Outcomes of project

Â NC will have an effective SDMA tool to assist self-advocates to have self-determined lives;
Â Family members will experience greater peace of mind with SDMA’s in place to support their family member with disabilities or aging;
Â NC policy makers will have practical information on the use of the tool to guide their legislation
Â General public will be more aware of viable alternatives to guardianship
Peace of mind, making it real!
Questions?

Contact Information:

Scott Secor
FIFNC
ssecor@fifnc.org
Or 919-251-8368