SUPPORTED DECISION-MAKING: A PATH TO EMPOWERMENT

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GAO is the Independent, Federally Mandated Protection and Advocacy Program for People with Disabilities in Georgia.

GAO envisions a Georgia where all people have value, visibility, and voice; where even the most difficult and long-lasting challenges are addressed by ordinary citizens acting voluntarily on behalf of each other; and where the perception of disability is replaced by the recognition of ability.
WHAT WE DO

- Protection from Abuse, Neglect and Financial Exploitation
- Nursing Facility Transition to the Community
- Assistive Technology
- Housing
- Supporting Self-Advocacy
- Voting
- Employment
- Information and Referral
COLLABORATIVE EFFORT

- The Georgia Advocacy Office is a recipient of a grant from the Georgia Council on Developmental Disabilities to implement a Supported Decision Making Pilot project in GA.
- Self Advocacy Resource and Technical Assistance Center Fellowships offer a year-long opportunity for self-advocates to develop and grow their skills as leaders in the self-advocacy movement by working with host organizations on a project or policy issue.
Roles
- Parent
- Communication partner
- Self determination
- Our story
OUR JOURNEY TO SUPPORTED DECISION MAKING

- Nonverbal for 20 years
  - Gestures
  - Actions
  - Single words
- “Guardianship is necessary”
- What if there’s an emergency?
- Consultation with an expert
WE DIDN’T KNOW WHAT WE DIDN’T KNOW
Every person is a thinking and feeling being
Every person has a right to be presumed competent
There’s nothing “special” about the needs of people with disabilities
- Physical: food, shelter, clothing, safety
- Relationships
- Full potential – defined by each individual, not imposed on them via a biased lens
The journey to anyone’s full potential involves choices
All choices mean decisions have to be made
All decisions (with very few exceptions) require some form and various levels of support
WHAT IS SUPPORTED DECISION MAKING

- More formal way to let wants and needs to known
WHAT IS SUPPORTED DECISION MAKING, REALLY?

Empowerment
“perpetual child”
“‘I was a thing, with no rights’”
Good intentions
“I’m gaining experience with each decision I make”
STARTS WITH SMALL DECISIONS

- Book club
- Voting
- GED / formal complaint
- Choosing where and when I work
- Writing my own scripts
- Medication
TERMINATION OF GUARDIANSHIP

- Fulton County Probate Court petition
- Court-ordered evaluation
- Appearance before a judge.
- “getting out from under guardianship is a dream…”
“Capacity assessments should primarily be undertaken not to judge whether people are capable to decide ‘autonomously’ but rather to assess what kind of support people with decision-making disabilities need in order to be involved in decision-making and thus to promote their autonomy.”

(Pesiah et al, 2013)
A BALANCING ACT

- Capacity is fluid
- Support should be responsive
- Support should be transparent
- Support should be beneficial
- Support should be efficient
DECISION MAKING IS A SKILL

- Taught
  - Over Time
  - Multiple modalities
- Opportunities for practice
- Mistakes enhance learning
- Can seem invisible
Supports and services that help a person make her own decisions, by using friends, family members, professionals, and other people she trusts to:

- **Help understand** the issues and choices;
- **Ask questions**;
- **Receive explanations** in language she understands; and
- **Communicate** her wishes to others.

(See, e.g., Blanck & Martinis 2015; Dinerstein 2012; Salzman 2011)
When do I need Support?
- Budgeting
- Health care
- Living Arrangements
- Choosing Supporters

Strategies for Support
- Understand information
- Focus attention in decision-making;
- Identify options and choices
- Ensure that decisions are based on the person’s own preferences;
- Interpret and/or communicate decisions to other parties.

(Salzman, 2011)
SUPPORTED DECISION MAKING AGREEMENTS

- Written agreements can be as formal or informal as necessary.
- Used to clarify roles and expectations.
- Provide a reference and model.
- Variety of samples available.
- Could be provided to a court considering guardianship as evidence that the person already has the support they need.
IMPACT OF SUPPORTED DECISION MAKING

- **Increases Self-Determination**
  - Life control — People's ability and opportunity to be “causal agents ... Actors in their lives instead of being acted upon”
  - (Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000, p. 440)

- **People with greater self-determination are:**
  - More independent
  - More integrated into their communities
  - Healthier
  - Better able to recognize and resist abuse

Guardianship has the most severe and restrictive impact on a person’s rights, so why would that be the first step we take?
GUARDIANSHIP AS A LAST RESORT

O.C.G.A. 29-4-1(4)(f): All guardianships ordered pursuant to this chapter shall be designed to **encourage** the development of **maximum self-reliance** and **independence** in the adult and shall be ordered only to the extent necessitated by the adult's actual and adaptive limitations after a **determination** that **less restrictive alternatives** to the guardianship are **not available** or appropriate.
DECISION-MAKING OPTIONS

- Makes Own Decisions
- Power of Attorney
- Advanced Directives
- Medical Proxy
- Guardianship

Less Restrictive

More Restrictive
WHAT IS LOST WITH GUARDIANSHIP?

- Right to contract
- Marriage & reproductive rights
- Place of residence & travel
- Association
- Healthcare decisions
- Financial decisions
RISKS AND IMPACTS OF GUARDIANSHIP

People who are subjected to guardianship are often perceived as:

- Unable to work
- Unable to be in loving relationships
- Unable to live on their own
- Unable to make health care decisions

People who are subjected to guardianship are also:

- Denied the “dignity of risk” – opportunity to try new things, to test limits, to discover capabilities that they never knew they had.
- More isolated and their lives often become smaller as a result.
- More likely to experience low self-esteem, passivity, and feelings of inadequacy and incompetency.

It is difficult to restore rights once a Guardianship Order is issued.
SUPPORTED DECISION MAKING

- **Ensures the person with a disability makes their own decision.**
- Is a tool that allows people with disabilities to retain their decision-making capacity by choosing supports to help them make decisions.
- Is a combination of **relationships, practices, arrangements** and **agreements** designed to assist an individual with a disability to make and communicate to others decisions about their life.
- A written agreement identifying the type of support needed and who will give it could be helpful for some people.
JOHN MCCARTY – SARTAC FELLOW

- GAO Supported Decision Making Advisory Council
- SARTAC Fellowship – SABE
  - Presentations
  - Toolkit
- Restoring rights and terminating guardianship

- Information first!!
SUPPORTERS

- Those who believe in family member
- Those who presume he/she is competent

- Family
- Co-Workers
- Neighbors
- Church members

- Ask supporters to be part of the plan!!
MY PLAN CATEGORIES

- Financial
- Work
- Medical and Health
- Volunteering and Leadership
- Leisure Time
- Housing
What do you already know?
What do you need to know or want to know?
How do you want to be supported to have more control over the topic of the category?
EXAMPLE: FINANCIAL CATEGORY
WHAT DO YOU ALREADY KNOW?

- Start broadly: “tell me one thing…”
- Sometimes a prompts can help someone remember what he already knows
- Huh! I knew more than I thought!
EXAMPLE: FINANCIAL CATEGORY
WHAT DO YOU NEED TO KNOW?

SSI:
- How much do I get?
- How do my wages affect the amount of my benefit?

Taxes:
- How much did I owe in 2018?
- How much will I owe in 2019?
EXAMPLE: FINANCIAL CATEGORY
WHAT DO YOU NEED TO KNOW?...

- STABLE:
  - How much is in it?
  - How do I get it out?
  - What can I use it for?
  - How can I get a STABLE card?
  - I want to know about managing the funds in the account

- Trust:
  - How does it work?
  - Can it be used it now?
EXAMPLE: FINANCIAL CATEGORY
HOW DO I WANT TO BE SUPPORTED TO HAVE MORE CONTROL OVER MY FINANCES?

- Answer those questions!
  - SSI, taxes, monthly bills, etc
  - ABLE and Trust
- Monthly meetings – income / expenses
Brainstorming for each category will follow the same template

- What do I know?
- What do I need/want to know?
- How do I want to be supported?

Which supporters should be invited for each category?
THE ULTIMATE GOAL
Every person should be part of every decision about his or her life.

We all need help making decisions.

People with disabilities may need more or different help, but should be supported to exercise their right to make choices in their own lives.
WHAT NOW?

- Look for opportunities to add in **choice and control**.
- **Practice, practice, practice** making smaller decisions then build to more consequential decisions.
- Sign up for Supported Decision Making News from the GAO
- Plan to attend the SDM Symposium **October 17th 2019**
RESOURCES

- Sample Supported Decision Making Agreements:

- PRACTICAL Tool for Lawyers
  - [https://www.americanbar.org/content/dam/aba/administrative/law_aging/PRACTICALGuide.pdf](https://www.americanbar.org/content/dam/aba/administrative/law_aging/PRACTICALGuide.pdf)

- Friends Manual: A Guide for Connecting People with Disabilities and Community Members*
  - [http://www.rtc.umn.edu/friends](http://www.rtc.umn.edu/friends)

- GCDD Guardianship Guide

- National Core Indicators: Impact on Self Determination
MORE RESOURCES

- Supported Decision Making Resource Centers:
  - http://www.supporteddecisionmaking.org
  - http://supporteddecisions.org/
  - http://supportmydecision.org/

- Impact of Guardianship
  - http://sdmmedicalcare.org/
  - https://health.ucdavis.edu/mindinstitute/centers/cedd/sdm.html
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