Caregiver Succession Planning: How To Pass The Torch Effectively

“Deciding what not to do is as important as deciding what to do.”

J. Jackley
Does this sound familiar?

“My goal is to live one day longer than my son.”

“I doing the best I can and when I am gone, I leave him in GOD’s hands.”

“She is too disabled to live on her own.”

“I am afraid of what will happen to him in a group home.”

“I am just trying to get through the day, it is too overwhelming to think about the future.”

“No one will take care of her like I do?”

“When I am no longer here, my other children will take care of him, or I will haunt them.”

“She is 4000 something on the waiting list, I need to live to be 700 years old, before DDD will provide residential support.”
Succession Planning should not happen in the midst of a Crisis.
My Struggles

• She is such a joy- the light of my life- she could live with me forever, but that would not be fair to her.

• In my home, she will always be my child, in her home, she is the adult she was destined to become.

• My entire life has focused on taking care of her; who will I be if I am not caring for her?

• Is this the right time? Am I doing the right thing? Will she resent me? What guarantee do I have that this will be the right choice?
My On-going Steps In the Process

• Understanding the State’s DD System

• Create a Wish List & Prioritize

• Develop Informal and Formal Collaborations
Understanding the State’s DD System
Major Programs and Initiatives

✓ Fee-For-Service Implementation
✓ Planning for Adult-Life
✓ Supports Program
✓ Community Care Waiver
✓ Supports Across the Life Course (Charting the LifeCourse: LifeCourseTools.com)
✓ College of Direct Support
✓ Qualified Providers
My Wish List: What are Your Priorities?

- Safe permanent affordable housing
- Reliable & compassionate support staff
- Adequate private financial resources
- Adequate government resources
- Good medical & dental care
- Meaning & purpose for waking up each day
- Friends and socialization opportunities
- A healthy diet
- Opportunity to practice religious beliefs
- Appropriate transportation
- Visits and contacts with relatives
- Holiday & birthday celebrations
- Entertainment & Vacations
A Huge Decision

guardian

and protects something. 2 a person with a legal responsibility for someone who cannot take care of their own affairs.
Guardianship Facts

- Guardianship is a legal action that removes some or all decision-making from an adult.
- It is based on a decision that the adult person to be placed under guardianship lacks capacity for decision-making.
- Guardianship is held by the court and an agent(s) is appointed and called the “guardian(s).”
- It can vary in scope -- time-limited vs. permanent; plenary (full) vs. limited.
- Guardianship laws vary by state.
Supported Decision Making

- Supported Decision-Making (SDM) is a recognized alternative to guardianship.

- It allows people with disabilities utilize individualized accommodations and collaborate with...
  - friends, family members, and professionals to help them understand the situations and choices they face, so they may make their own decisions without the “need” for a guardian.
How Does SDM This Work?

- SDM encourages building natural community networks.
- It allows for the use of various individualized accommodations.
- Utilizes multiple decision-making models or only specific identified supporters.
- Can include:
  - Agreements for individual supporters
  - Agreements for accommodations
  - Powers of Attorney for specific areas of support
  - Assistive technology if needed
Decision-Making is a Skill

- Decision-Making is a skill that can be taught, learned, and practiced like any other skill.

- Decision-Making can be accommodated like any other skill.

- If a person has the ability to participate in any way in the decision-making process, then there should be ways to be accommodated.
One Size Does NOT Fit All

• There are many ways to support people to make decisions.

• Guardianship AND Supported Decision-Making are both “tools” to be used to assist people.

• **Goal** = right tool, in the right amount, at the right time for each person.
"Having a positive mental attitude is asking how something can be done rather than saying it can't be done."

Bo Bennett
Promising Practices

A few states have passed laws to give older caregivers a chance to help decide where, and how, the person they care for will live.

• Tennessee passed a law in 2015 for anyone with IDD and a caregiver over 80 to get the services they needed, and in 2016 expanded the law to those with caregivers over 75.
• In 2014, Connecticut passed a similar law that is helping about 120 people with a caregiver over 70.
• Maryland, Virginia and Pennsylvania have dedicated funding for waiting lists.
• Some states are prioritizing people with urgent needs, while others are prioritizing students as they age out of school.
Supportive Housing Guide

- In 2016, New Jersey published “The Journey to Community Housing with Supports – A Road Map for Individuals and Their Families."
  - Navigating Systems
  - Housing Options with Innovative Supports
  - Funding Sources
  - Finding Affordable Housing
Housing Options with Innovative Supports

• Supportive Living
• Shared Living
• Support Families
• Group Homes
• Intensive Specialized Group Home
• Living with Family & Receiving In-Home Supports
• Accessory Apartments and Tiny Houses
• Intentional Community Models
• Community Cooperatives
• Secure Communities
Our Journey Thus Far:

| Conversations with DDD about transitioning out of the family home | Researched real estate options and purchased 1-bedroom condo | Sink or Swim Developed a detailed analysis of activities for 24 hours per day including weekends | Working relationships with the layers of community supports: DDD, DCA, PPP, MCO, SNAP, etc. | Retooling as needed and identifying areas of concentration for future planning |
Open House Tour
Thank You for your Time and Attention

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