



# Caregiver Succession Planning:

## How To Pass The Torch Effectively

NJCDD-RFSPC Presentation  
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“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.”



**INDEPENDENT  
LENS**



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](http://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** ► noun 1 a person who looks after and protects something. 2 a person who is legally responsible for someone who cannot take care of themselves.

# 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
- In 2018, A Companion Guide – Case Studies of Stories shaping new housing opportunities.

# 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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