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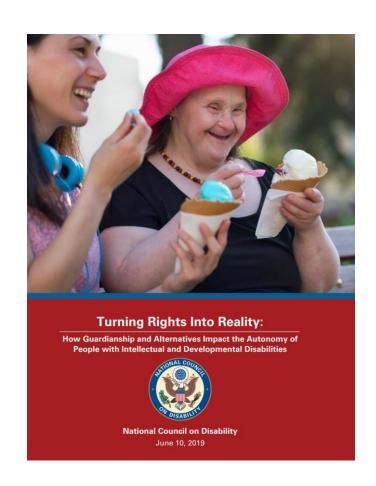
# Debunking the Myths of Supported Decision-Making and Guardianship

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### 2019 NCD Report

#### **Turning Rights Into Reality**

How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities



## **Decision-Making**

- Self-determination = better outcomes
- Yet, guardianship is still heavily relied on
- Continuum of decision-making
  - Substitute decision-making
  - Supported decision-making
  - Independent decision-making



## What is guardianship?

- Determined by state law
- Generally: a process of going to court to determine whether someone is incapacitated (unable to make their own decisions) and needs someone else (a guardian) to make some or all decisions for them.

## What is the guardianship process?

- Must go to court
- File a petition
- Court appoints an attorney for the person with a disability
- Attend one or more hearings
- Judge makes a decision
  - o Is a guardian needed?
  - o If so, what should the guardianship cover?
  - O Who will be the guardian?



## How does guardianship work?

#### Guardian responsibilities:

- Determined by each state
- Make decisions according to the order
- May need to submit reports
- May need to attend additional hearings
- Ends at death or rights are restored
- Support people in building their ability to make decisions
- Seek restoration of rights



## Myths of Guardianship

- Parents are automatically guardians of their adult children with disabilities.
- 2) Individuals appointed guardian of a minor child with a disability remain guardian when the child becomes an adult.
- Parents need guardianship to review their child's school, medical, and other records.

## Myths of Guardianship

- 4) Parents need guardianship to attend school, planning, and other meetings.
- 5) Guardianship will protect people with disabilities from abuse.

## What is supported decision-making (SDM)?

Making your own decisions by using friends, family members, professionals, and other people you trust to understand the issues, situations, and choices you face by asking questions and receiving explanations in a language you understand.

## Myths of Supported Decision-Making

- 1) SDM isn't available in my state because we don't have SDM legislation.
- 2) People with intellectual disability don't have the capacity to use SDM.



### **SDM** in Practice

- Involve people in their meetings, including IEP and other service planning meetings
  - Introductions
  - Presentation on likes, struggles, preferences, and future goals
- Keep meetings friendly
- Use basic language
- Ask for reasonable accommodations for a person's disability
- Sign a release, share information
- Complete a supported decision-making agreement

Examples: A Letter for My Doctors Model Agreements

#### **SDM** in Practice

- Prepare people for meetings
  - Explain evaluations and reports
  - Discuss progress and areas for improvement
  - Write down comments and questions
- Check for understanding
- Give prompts and reminders
- Share your opinion, if asked
- Request breaks
- Give the person additional time



### **Less Restrictive Alternatives**

- Representative Payees
- Special Needs Trusts
- Joint Bank Accounts, Direct Deposit, and Automatic Billing
- Powers of Attorney (POAs)
- Health Care Directives

## Representative Payees

- Appointed by Social Security Administration (SSA)
- Manage Social Security benefits like SSI and SSDI
- Do not have to go to court



### **Special Needs Trusts**

- Save for the future
- Protects public benefits like SSI and Medicaid
- Parents appoint trustee
- Trustee manages money held in trust
- Purchase good and services

## Joint Bank Accounts, Direct Deposit, Automatic Billing

- Manage income and expenses
- Monitor where money goes and how it's spent



## **Powers of Attorney**

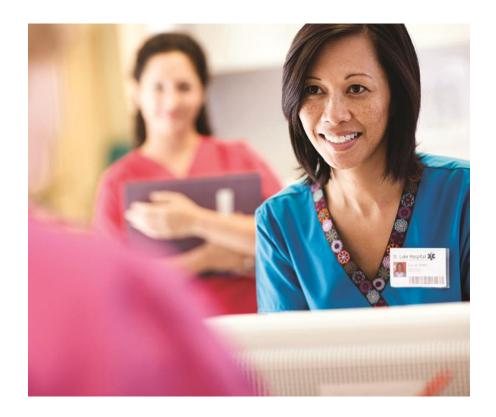
- Legal document
- Voluntary
- Do not have to go to court
- Choose who makes some or all decisions
- Flexibility; can change your mind
- Capacity needed to choose person, not to understand underlying decision



COPAA Annual Conference

### **Health Care Directives**

- Power of attorney for health care
- Who can make decisions
- Medical care they do and do not want



### **Questions?**

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