

## Supported Decision Making

An Introduction to an Alternative to Guardianship

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## What We Will Cover Today

- Guardianship basics
- Understanding capacity
- Alternatives to guardianship
- Resources
- Case examples
- Introduction to the project



## What is Guardianship?

“A legal proceeding to appoint a person who is responsible to the court to take care of an incapacitated individual or minor and/or manage that individual’s property.”

(Arc of Indiana website)

“Substituted decision making”

(Blank & Martinis, 2015)



## Guardianship Proceeding

- Petition with physician statement
- Notice to alleged incapacitated person
- GAL should be appointed
  - Make recommendation regarding (1) capacity; and if incapacitated, (2) suitability of proposed guardian.
- Court makes determination regarding petition



## What does guardianship mean?

- Guardian makes all decisions
- Guardian required to alert the court regarding change of person’s address
- Guardian required to provide regular accounting of person’s finances
- Person retains the right to vote
- Person should have choice and independence to the greatest extent possible



## What does guardianship mean?

- Guardianship overseen by court
- Termination of guardianship
  - Person is no longer incompetent or
  - At person’s death
- Guardian’s death – successor guardian should be named



## Understanding guardianship

- Parents often led to believe guardianship is only option
- Tendency to seek guardianship if person cannot be 100% independent
- Presumption that disability = inability to make decisions
- Approximately 89% of Indiana guardianships are full, despite courts having power to limit
- Studies show that lack of control and autonomy can be anti-therapeutic
- Decision-making is a learnable skill



## Understanding Capacity

- Someone who is unable to manage his or her property and/or provide self care due to:
  - insanity, mental illness, mental deficiency, physical illness, infirmity, habitual drunkenness, excessive use of drugs, incarceration, confinement, detention, duress, fraud, undue influence of others on the individual, or other incapacity
- has a developmental disability (as defined in IC 12-7-2-61)



## Understanding Capacity

- Diagnosis alone should not determine capacity
- Look at the individual as a whole
- Capacity exists on a spectrum
- Capacity may be regained through training or assistive technology



## Sources of Information

- Service providers
- Doctors / Treating Health Providers
  - Diagnoses
  - Social, medical, psychiatric and other history
  - Assessments and evaluations
- Educational/Vocational records
- Adult Protective Services
- Financial records
- Family and friends



## Spectrum of Assistance

- Independence and self-advocacy
- Formalized Supported Decision-Making
- Team-based decision making (e.g., IEP, Person-centered planning process)
- Agency agreements, representative payee, trustee
- Limited Guardianship
- Full Guardianship



## Independence

- Person retains the right to make all decisions
- Family and friends can help empower person to self-advocate
- Person can sign releases of information to allow for others to get information (e.g., HIPAA, or FERPA)



# Decision-Making

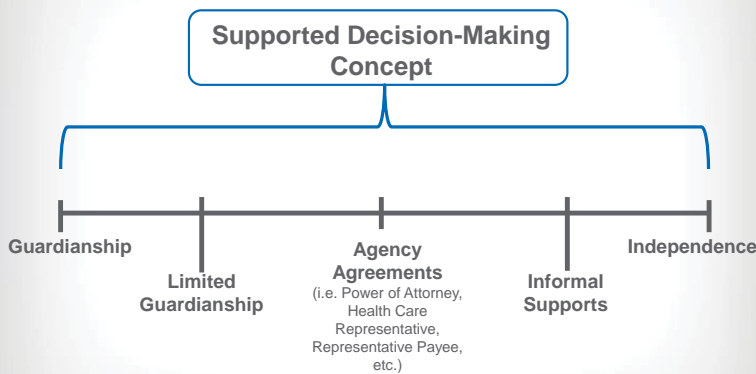


# Supported Decision-Making

- Way for people with disabilities to get help in making decisions
- Way to improve decision-making skills
- Flexible
- Promotes independence
- Improved quality of life
- Concepts can be used in any decision-making situation



# Spectrum of Assistance



# Formalized Supported Decision-Making

- Person retains legal decision-making power
- Person chooses “supporters”
- Person decides areas where support is needed
- Person decides how help should be given
- Can be formalized into a written agreement



# SDM Agreements in Indiana

- Disclaimers and acknowledgements
- Person decides
  - Areas where help is needed
  - Who will be on team
  - How they want help to be given
- Additional documents
- Supporter consent
- Notary
- Mandatory reporting statement



# Who Can Use SDM?

- Anyone!
- People who want to maintain independence but need a little formalized assistance
- Not legally incapacitated



## Potential Areas of Support

SDM could be used to assist with making decisions about:

- Finances
- Physical Health
- Mental Health
- Legal Matters
- Services and Supports
- Work
- Community Living/Housing



## Team-Based Decision-Making

- Team works together
- Person may not always make ultimate decision
- Used primarily in service delivery and educational settings
- Not recognized outside of the specific setting



## Agency Agreements

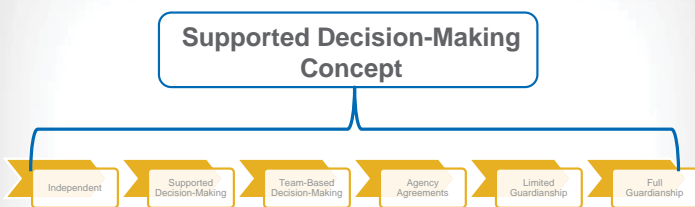
- Someone else is appointed to make decisions in certain areas or upon the occurrence of a certain situation
- Person has capacity to enter into agreement
- Court oversight not generally required
- Power of attorney, Educational Surrogacy
- Representative payee or trustee



## Choices in Support



## Choices in Support



## Resources

- WINGS/American Bar Association ([https://www.americanbar.org/groups/law\\_aging/resources/wings-court-stakeholder-partnerships.html](https://www.americanbar.org/groups/law_aging/resources/wings-court-stakeholder-partnerships.html))
- Indiana Adult Guardianship Office (<http://www.in.gov/judiciary/iocs/3425.htm>)
- Indiana Disability Rights (<https://www.in.gov/idr/>)
- Arc of Indiana (<https://www.arcind.org/future-planning/guardianship/>)
- National Resource Center for Supported Decision-Making ([www.supporteddecisionmaking.org](http://www.supporteddecisionmaking.org))



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## Case Examples

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BDDS Director of Policy



### Case #1: Kaleb

- Age 12
- Primary Diagnosis: Autism Spectrum Disorder
- Secondary Diagnosis: Anxiety Disorder
- High functioning: IQ above 80, verbal, seeing great improvement in gross motor and fine motor skills
- Living Arrangement: At family home with two parents
- IEP: 50% in a general education setting, 50% in a special education setting
- IEP focuses on behavior management, specifically staying in seat while working, following directions and completing work independently

All names and ages have been changed to protect the privacy of individuals.



### Case #2: Jocelyn

- Age 18
- Primary Diagnosis: Down Syndrome
- Able to express a few words verbally, primary mode of communication is pointing and gestures
- No hearing impairment or other chronic medical conditions
- Living Arrangement: At family home with two parents
- IEP focused on speech language therapy, behavior management, specifically staying in seat while working, following directions and completing work independently

All names and ages have been changed to protect the privacy of individuals.



### Case #3: Derek

- Age 19
- Primary Diagnosis: Cerebral palsy
- Utilizes adaptive technology to communicate
- 100% of time spent in a general education setting
- Utilizes a direct support staff (DSP) at school and at home for personal care
- Has a great relationship with his cousin who is a natural support when his DSP isn't working
- Living Arrangement: Family home with 76 year old grandmother

All names and ages have been changed to protect the privacy of individuals.



### Case #4: Harmony

- Age 19
- Primary Diagnosis: Developmental Delay, Intellectual Disability
- Secondary Diagnosis: Dravet Syndrome
- Substantial functional and cognitive limitations caused by her severe seizure disorder
- Non-verbal
- 100% of time spent in special education setting
- IEP focused on pointing, motioning and basic ASL usage to communicate wants and needs
- Living Arrangement: In family home with one parent, parent would like to transition Harmony into a waiver home setting where she can have nurses monitoring her frequent seizures

All names and ages have been changed to protect the privacy of individuals.



## 2017 WINGS SUPPORTED DECISION-MAKING GRANT PROJECT

ERICA C. R. COSTELLO, STAFF ATTORNEY, ADULT GUARDIANSHIP OFFICE



## 2017 WINGS SUPPORTED DECISION-MAKING GRANT PROJECT

- **Goal:** To develop a county-level judicial reform project that reduces the need for guardianship using supported decision-making.
- **Objectives:**
  - 1) To create a community education component, explaining the process of supported decision-making;
  - 2) To develop pre-adjudication of guardianship screening tools for cases involving alleged incapacitated adults with intellectual and/or developmental disabilities;
  - 3) To develop a case referral and management delivery model for cases referred to the project by the Court; and
  - 4) To develop a training component for judges and pro bono attorneys/GALs regarding the process of supported decision-making.

## 2017 WINGS SUPPORTED DECISION-MAKING GRANT PROJECT - STAKEHOLDERS

- **Project Stakeholders include:**
  - The Honorable Gregory Horn, Wayne County Superior Court
  - Achieva Resources, Inc.
  - Indiana Disability Rights
  - The ARC of Indiana
  - The Indiana Division of Disabilities and Rehabilitative Services
  - The Indiana Division of Aging
  - The University of Notre Dame
  - The WINGS/Adult Guardianship State Task Force

## 2017 WINGS SUPPORTED DECISION-MAKING GRANT PROJECT – NEXT STEPS

- **Planning Phase (June – December 2017)**
  - Meet regularly with the project stakeholders to work on the development, training, and implementation of the project.
  - Develop SDM agreements and screening forms for judges.
  - Conduct training on the project for judges, pro bono attorneys/GALS, and community members.
- **Implementation Phase (January 2018 – May 2018)**
  - Work with the judges and stakeholders to begin rollout of the project in Jan/Feb 2018.
  - Evaluate the project training and rollout.
  - Provide a final report on the project to the American Bar Association.

## QUESTIONS:

- **Contact Information:**

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