The Arc™
Indiana

www.arcind.org



Beyond Guardianship: Transitioning to Supported Decision Making and Self-Determination

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Achieve with us.

- Established in 1956 by parents of children with intellectual and developmental disabilities to advocate for a better life for their children.
- The leading advocacy organization for people with IDD and their families.
- Committed to progressive legislation and public policy to protect rights and improve services for people with IDD.
- Home to The Arc Master Trust.
- Founder of the Erskine Green Training Institute.
- Affiliated with The Arc of the United States

Desire to Protect

- View it as our obligation to protect individuals who may need additional help in life
  - Children
  - Older Adults
  - People with Disabilities
- Focused on providing the supports **we** think are necessary
- Often don't consult with or listen to the people we are trying to assist

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Done Out of Love

- We want to keep them safe
  - Physical harm
    - Afraid they'll cut themselves, so we don't teach them how to use a knife
  - Emotional harm
    - Afraid they'll be made fun of, so we don't go the school parties or join the community sports leagues
  - Financial harm
    - Afraid they'll be taken advantage of or squander their money, so we become the Rep Payee
- We do things for them rather than teach them
- We inadvertently create dependence and isolation

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We Take Something Away

- Physical harm
  - Teach them how to do things so they won't get hurt
- Emotional harm
  - When the person is always included, they learn how to interact with others and others discover people with disabilities are just people
- Financial harm
  - Suggest using Supported Decision Making to teach how to manage money and evaluate what people are telling them
- Intervention
  - Instead of calling for them, coach them to make the calls and discuss what was said

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Right to Fail

- We all learn from bad choices
- We learn from failure
- We need to let people with disabilities try, and we need to let them try again
  - Be there to help them make decisions
  - Be there to help them understand consequences of their decisions and the next steps
  - Teach them to use a Supported Decision Making Model to come to you and their support team first as a matter of routine and a regular part of the decision making process but having them make the decision

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Ethical Considerations for Failure

- When is it ethical to allow someone to fail?
  - Beneficial vs. Harmful Failure
  - Temporary vs. Permanent Harm
  - Inconvenient vs. Dangerous
- Bridging the Gap
  - Supports while learning to achieve success

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Protectionism vs. Guided Self-Determination

- Importance of self-determination
  - Restores the perception of equality
  - Improved quality of life
  - Gives the individual purpose
    - Provides ownership in life
    - Gives the individual something to work toward
    - Prepares the individual for independence

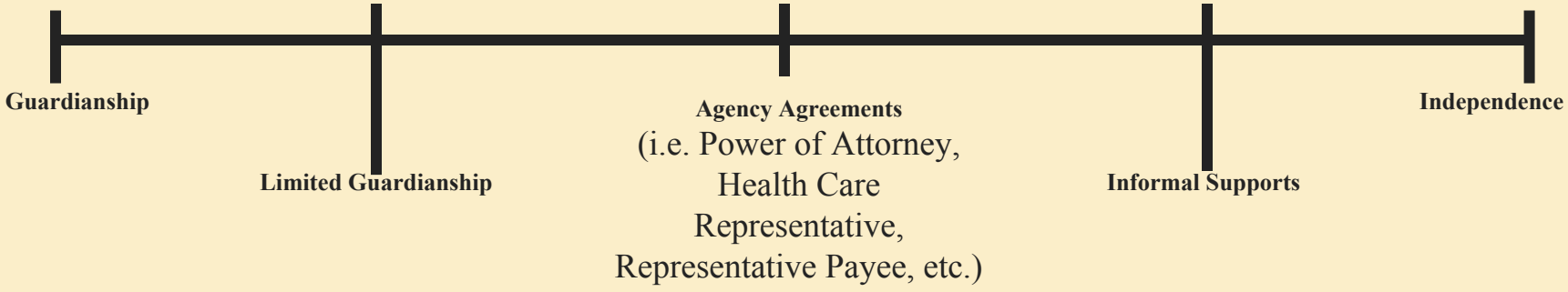
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Spectrum of Assistance

- 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

Spectrum of Assistance

Supported Decision-Making Concept



Considering What's Right for People with Disabilities

- National Guardianship Association's official position: "Guardianship should be utilized only when lesser restrictive supports are not available. Alternatives to guardianship, including supported decision making, should always be identified and considered whenever possible prior to the commencement of guardianship proceedings."
- Least Restrictive Model

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Advocate for the Least Restrictive Alternative



- Many people do not know full consequences of guardianship
- Many do not know about alternatives to guardianship
- Help identify actual needs and strategies, services, and supports that could address them

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Formal Representation

- Health Care Representative
  - Allows designated person to get information and make decisions about another individual
  - Can be set up with individual health care providers
  - State has a form available, but it's not the only option
- Educational Representative
  - No official form
  - Allows a designated person to represent the individual in educational matters, including the case conference

Psychiatric Advance Directive

- Like other Advance Directives
  - Must have psychiatric diagnosis
  - Must be signed by the treating psychiatrist
- When an individual with mental illness is competent, allows the person to state their treatment wishes when psychosis takes over
  - Doctors are NOT required to follow the person's wishes, IF the doctor believes a different treatment is necessary for the person's best interest.

Power of Attorney

- Very common among older adults and the military
- Threshold – does the person understand they are giving you permission to act on their behalf?
- Can be as general or specific as you'd like
- Powers determined by the drafting of the POA
  - Can give POA access to information and the ability to make decisions for the individual
- Must be notarized

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Power of Attorney

Pros

- No Court! Just needs to be notarized
- Can have an attorney draft a specific document or download from legal websites
- Allows independence
- Allows the individual to keep their rights

Considerations

- Revocable (although revocation can be contested)
- Easily transferable (for example, if the POA dies, can revoke the old POA and easily issue a new one or can include a successor in the original POA)

Types of Guardianship

- Limited guardianship
  - Guardian of the Person – medical treatment, living arrangements, personal contact
  - Guardian of the Estate – finances, property
- Plenary Guardianship – “Full Guardianship”
  - Guardianship of the Person and the Estate
- Temporary Guardianship
  - Emergency situations
  - Only for 90 days
    - Can extend past 90 days with court approval

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What is Supported Decision Making?

- Something you do on a regular basis
- Can be a formal legal document affirming the person's right to make decisions for themselves
- Why is it important?
  - Teaches Decision Making
  - Independence
  - Self-determination
  - Better Quality of Life

Supported Decision Making

- Going to family, friends, or experts for advice or guidance on making a decision to:
  - Build a team of supports of their choosing that they can "go to" when issues/problems arise, or for day to day advice
  - Gather information and learn to evaluate all their options
  - Review as many options as desired and **still maintain the right to make the final decision**
  - www.supporteddecisionmaking.org
- Can use as a support, alternative, or in conjunction with guardianship

Supported Decision Making is NOT…

- Supported Decision Making NOT Substituted Decision Making
  - Individuals retain the ability to make their own decisions. No one else can make decisions for them or on their behalf.
- Supported Decision Making NOT Coerced Decision Making
  - Individuals can make decisions the team does not agree with, including “bad” decisions
  - The individual’s decisions needs to be respected and honored.

Hardest Parts

- Accepting a decision you don't agree with
  - Make sure making an informed decision
  - Make sure understand consequences
- Focus on providing the supports **we** think are necessary
  - Make sure individual is driving the conversation
- Revisit as needed

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Implementing Supported Decision Making

- Many never developed decision making skills
- Expecting skills that need to be (re)taught
  - Meet them where they're at
    - What information do we need
    - Who can we contact to get (RELIABLE) information
  - How do we do that?
    - Model/be on the call at first
  - Talk it through
    - Questions/Thoughts
    - Consequences

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Improves Chances for Success

- SDM reaffirms dignity
  - Reaffirms equality
  - Conveys respect
  - Builds confidence
- Teaches needed life skills
  - Building skills so the individual can take charge of their own lives
  - Helps identify reliable sources and network of support
  - Gives the individual purpose
    - Provides ownership in life
    - Gives the individual something to work toward
    - Prepares the individual to resume independence

Dignity of Risk

- “He doesn’t make the best choices.”
  - There’s not a parent of an 18 year old out there who doesn’t feel the exact same way
- We all learn from bad choices
  - We need to let them try
  - Be there to help them make decisions
  - Be there to help them understand consequences of their decisions and the next steps
  - Teach them to use a Supported Decision Making Model to come to you first as a matter of routine and a regular part of the decision making process

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Dignity of Risk

- Right to Fail
  - We all mess up
    - Sometimes small, sometimes big
  - We get second chances
  - People with disabilities often not given that right
    - If don't do it perfectly the first time, often don't get another opportunity to try again
    - Constantly reminded they couldn't do it
    - Dehumanizing and humiliating

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Mistakes Will Happen

- Normalize mistakes
- Mistakes help us know how to do it better next time
- We all learn from “bad” choices
  - Try, try again, try again, try again…
- Talk through next steps
  - Is there a way to fix it?
  - How do we address immediate problems?
  - What can we do differently next time?
  - Teach them to go to their support team as a matter of routine and a regular part of the decision making process

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Work Toward Independence

- Include individuals in the person's life who want to help them be as independent as possible
- Identify services and supports geared toward teaching independence skills
  - Self care skills
  - Transportation skills
  - Financial independence skills
  - Assistive technology to help
  - Non-waiver services

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Resolving Conflicts

- It won't be easy
- Systemic shift in thinking and expectations
  - Families AND other professionals
- Deprogramming years of
  - Low expectations
  - Settling for what's available
- Our goal is to meet the needs of the individual

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Communication is key

- Use active listening
  - Each side has very important ideas and input
  - Be sure to capture each person's input
  - Ensure each side feels heard
- Ensure everyone is hearing the same thing
  - Ex: "Joe can't…"
    - Define can't
    - Is "can't "reflecting an inability
    - Is "can't "reflecting my beliefs (which may be open to change)
    - Iss there a medical justification or legal reason?

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Support the individual's inclusion

- We need to support and encourage inclusion and participation
- We need to reverse the message some others send

What families hear from others:

- Including the individual is a distraction.
- They make too much noise.
- They don't understand any of this, so they don't need to be here.
- They are too young for this.
- This is a business meeting. It's really for the grown ups.

What families and individuals need to hear:

- It's about the individual, so they should be here.
- We want them to speak up and tell us what they think.
- We want them involved so we remember who we work for and why we're here.
- This helps them know who they can go to when they need something.
- This reinforces that they are valuable, important, equal, and owed respect.

Disagreements or “can’t” statements based on

- Fear for the person
  - What might happen in a new situation, especially if they fail
  - Recognize the fear
  - Make plans to address the fear and solutions to overcome fear
  - List out the steps to take to build up to the goal
- Lack of knowledge of the resources available
  - Use Integrated Support Star
  - Share information and experiences
- Lack of knowledge of their loved one’s abilities

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Reintroduce dreams and possibilities

- Reintroduce dreams and possibilities
  - Use your experience
    - Share the successes you know and the possibilities you see for the individual
  - Focus on strengths
    - You may need to highlight strengths for them
      - Ex: the individual talks all the time –> they tell you what they want; they're a good communicator; they're a people person
      - Ex: They don't do well with change –> they are very detail oriented; they make sure things are consistent; they recognize when something is different or off
- Share stories about what people can do

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Achieving dreams

- Remind them NONE of this happens overnight
  - Develop and plan and process
  - Identify short term and long term goals
    - Ex: If the goal is to eventually live independently, identify the steps involved, like cooking, doing laundry, and paying bills, and work on each step
    - Recognize what's acceptable instead of insisting on perfection
    - Identify supports that can aid success including alternative ways to achieve something
      - Ex: envelop system to manage money or healthy microwave meals or meal kits
  - Can take a while and involve several steps
- Remind them dreams change and adjust
  - Happens for all families and individuals
  - It's okay to update your dreams

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Bringing in the next generation

- Identify who the individual wants to include
  - Families may not have thought about that next generation
  - May not have consulted the individual
- Encourage families to include the next generation of supporters
  - Helps demystify expectations
  - Teaches the next generation
  - Can join remotely
  - Allows an easier transition
    - Proactive rather than reactive

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Supports for the next generation

- Many times, brand new
- Treat like family brand new to services
- Considerations for next generation
  - Can have strong sense of obligation
  - Often protection was stressed above all
  - Often more open to new options
  - May be scared of expectations
    - Stress importance of individual having their own life
  - Help connect to others in the next generation

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We're Here to Help

When in doubt or confused, please ask!

If the information you receive from another source differs from this presentation, it may be because of actual changes or because the person you asked is not aware of the changes.

Please ask a Family Advocate with The Arc Advocacy Network!

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