

We create opportunities for independence for people with disabilities through research, education, and consultation



Independent Living Research Utilization

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IL-NET

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Preventing Guardianship: How CILs can be the Frontline to Advocate for Less Restrictive Alternatives

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Presenters:

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IL-NET is a project of Independent Living Research Utilization (ILRU) in partnership with the National Council on Independent Living (NCIL), the Association of Programs for Rural Independent Living (APRIL), and Utah State University Center for Persons with Disabilities (USU-CPD)

Evaluation Survey & Presenter Contact Information

Your feedback on this webinar is important to us. At the end of the presentation you will have the opportunity to complete a brief evaluation survey.

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You Will Learn...

- Basic tenets of the independent living philosophy and connection to self-determination and consumer control in decision making.
- What guardianship is and how it creates barriers to independence and consumer direction.
- Strategies for raising awareness of the dangers of guardianship.
- Alternatives to and the importance of preserving civil rights for young adults with disabilities.
- Guardianship as an advocacy issue that can support or strengthen advocacy activities and support for youth in transition.

Why Preventing Guardianship?

- It's one of the most pressing issues in disability rights today.
- The IL movement speaks intimately to the issue of the right of people with disabilities to direct their own lives.
- CILs may be unaware
 - 2017 Denver IL-NET Youth in Transition Training (<http://www.ilru.org/training/youth-transition-growing-role-centers-for-independent-living>)
 - Guardianship support from CILs

Able South Carolina

- Center for Independent Living, run by and for individuals with disabilities.
- Serve Midlands and Upstate, with some programs statewide.
- Non-profit, federally and grant funded
- Cross-disability

Can you independently make decisions about...

- Complex medical procedures?
- Major car or home repair?
- Contracts for major purchases?
 - Contracts for minor purchase?
- Complicated situations in relationships?
- Financial planning or taxes?

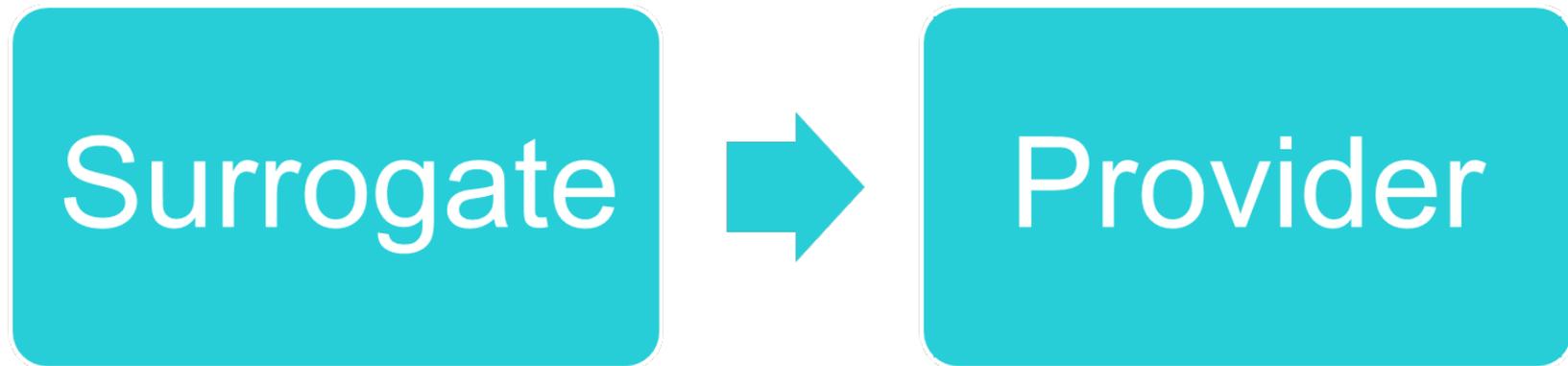
Since you were 18, who has...

- Made a terrible relationship decision?
- Bought something without understanding the terms?
- Mismanaged a checking account or credit card?
- Made a decision only to have to make another because you went in the wrong direction?
- Acted impulsively without understanding the consequences?

And what do we believe about the support we need or the bad decisions we make?

- Is it healthy to make decisions with support?
- Do all people have the right to fail and learn from bad decisions?
- Is the threat of bad decisions and/or the need for support cause to have an adult's decision-making authority taken from them?

Surrogate/Substitute Decision Making



Forms of Surrogate Decision Making

- Guardianship
- "Incapacitated person means any person who is impaired by reason of mental illness, mental deficiency, physical illness or disability, chronic use of drugs, chronic intoxication, or other cause (except minority) to the extent of lacking sufficient understanding or capacity to make or communicate responsible decisions." – Uniform Probate Code
- Power of Attorney
- Conservatorship
- Representative Payee

The Start of Guardianship

- 449 BC - Roman Twelve Tables

“The first expressed legislation on Roman private law, made reference to guardianship by providing that a family or paternal relative should protect a person and his goods if that person was unable to take care of himself.”

- By the end of the millennium, curators were being appointed to handle the affairs of the “feeble-minded.”
- By the Middle Ages, the British appoint committees to make decisions for “idiots” and “lunatics.”
- “Best interest” decision making is something we are intimately aware of in IL.
 - Forced sterilization, facility placements, and on and on

Setting the Stage for Guardianship

- 18 is the age of majority (19 in Alabama and Nebraska).
 - Before Age of Majority: Rights and responsibilities of the parent are emphasized.
 - Upon Age of Majority: Rights of the parents automatically transfer.
- For youth without disabilities, no assessment of fitness is given for this transfer.
- For many youth with disabilities, this transfer causes many families to worry....
- What's different about turning 18 for young adults with disabilities?
 - The IEP process and systematic detailing of individual weaknesses
 - IQ scores and developmental ages, grade level measurements, assessments of adaptive functioning, etc.
 - Lower expectations
 - Beliefs about the role of parents of youth with disabilities

The Truth About Guardianship

- There is not a single study out there that shows guardianship improving lives.
 - There are hundreds that show the positive effects of empowerment and self-direction.
- Over 90% of guardianships awarded in the US are full (plenary) guardianships. (TASH, 2015)
 - Guardianship referrals: teachers (IEP process), service providers (service decisions), medical providers (exposure)
- Since 1995, the rate of guardianships in the US has tripled. (TASH, 2015)
 - In 20 years, we've put 1,000,000 more people under guardianship.
 - This is post-ADA, post-Olmstead decision, and post-HCBS Final Rule (sort of – implementation has been pushed back).
- Some states require people to try less-restrictive options first, many do not.

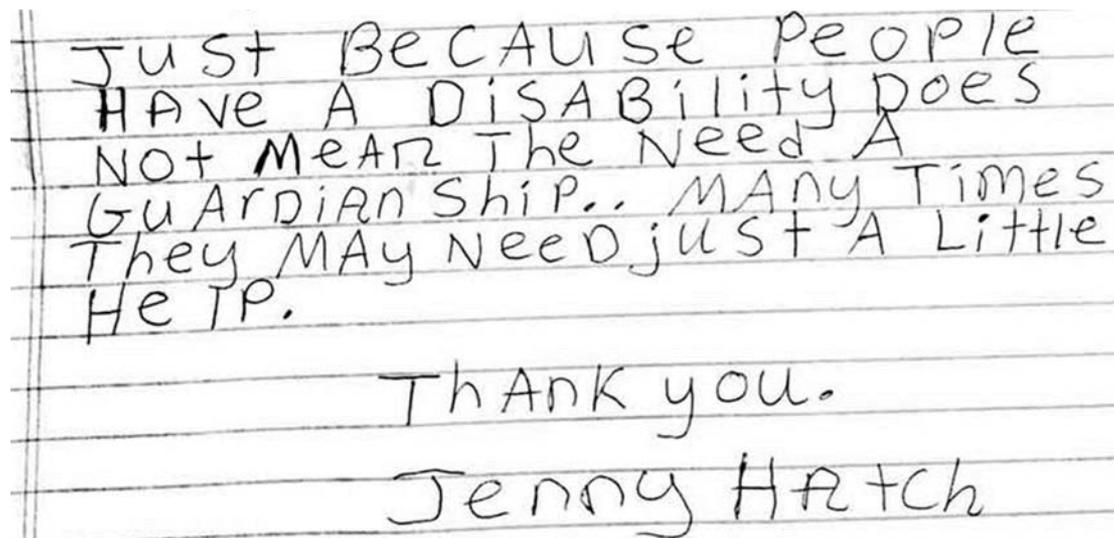
The Truth About Guardianship, cont'd.

- Loss of autonomy and self-determination is associated with higher incidents of abuse, neglect, and exploitation.
- People under guardianship are less likely to be employed, practice their religion of choice, or have friends other than service providers.
- Process is expensive – attorneys, hearings, evaluations (follow the \$!).
- Very difficult to modify or terminate.
- Tremendous and continuous responsibility of the guardian.
- Damages relationships.
- Guardianship hinges on one's incapacity – what range of movement do people with the label "incapacitated" have?

The Truth About Guardianship, cont'd. 2

"The typical ward has fewer rights than the typical convicted felon. They no longer receive money or pay their bills. They cannot marry or divorce ... It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen, with the exception ... of the death penalty."

U.S. Representative Claude Pepper

A photograph of a handwritten note on lined paper. The text is written in black ink and reads: "JUST BECAUSE PEOPLE HAVE A DISABILITY DOES NOT MEAN THE NEED A GUARDIANSHIP.. MANY TIMES THEY MAY NEED JUST A LITTLE HELP." Below this, it says "Thank you." and "Jenny Hatch".

JUST BECAUSE PEOPLE
HAVE A DISABILITY DOES
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HELP.

Thank you.

Jenny Hatch

Questions & Answers

Self-Determination and Consumer Control

- In IL we live by consumer control. Why?
 - We are the best experts on our own lives.
 - We know our consumers often come from environments where they are not trusted to direct their own lives.
 - Many understand decision making with support very intuitively and we all should understand the value of self-direction.
 - Are our practices around guardianship and decision making always based in consumer control?
- This is supported by 40+ years of research on self-determination

Let's Talk About Self-Determination!

- Many people believe that people with intellectual disabilities cannot be self-determined because of their cognitive impairment – research consistently shows that while SD is positively correlated with IQ, that relationship is generally weak and IQ is not predictive of self-determination status.
- Multiple research studies find that a person's self-determination status predicts higher quality of life.
- Self-determination status is positively correlated with more positive post-secondary outcomes, including employment, independent living, and community inclusion for youth with disabilities.

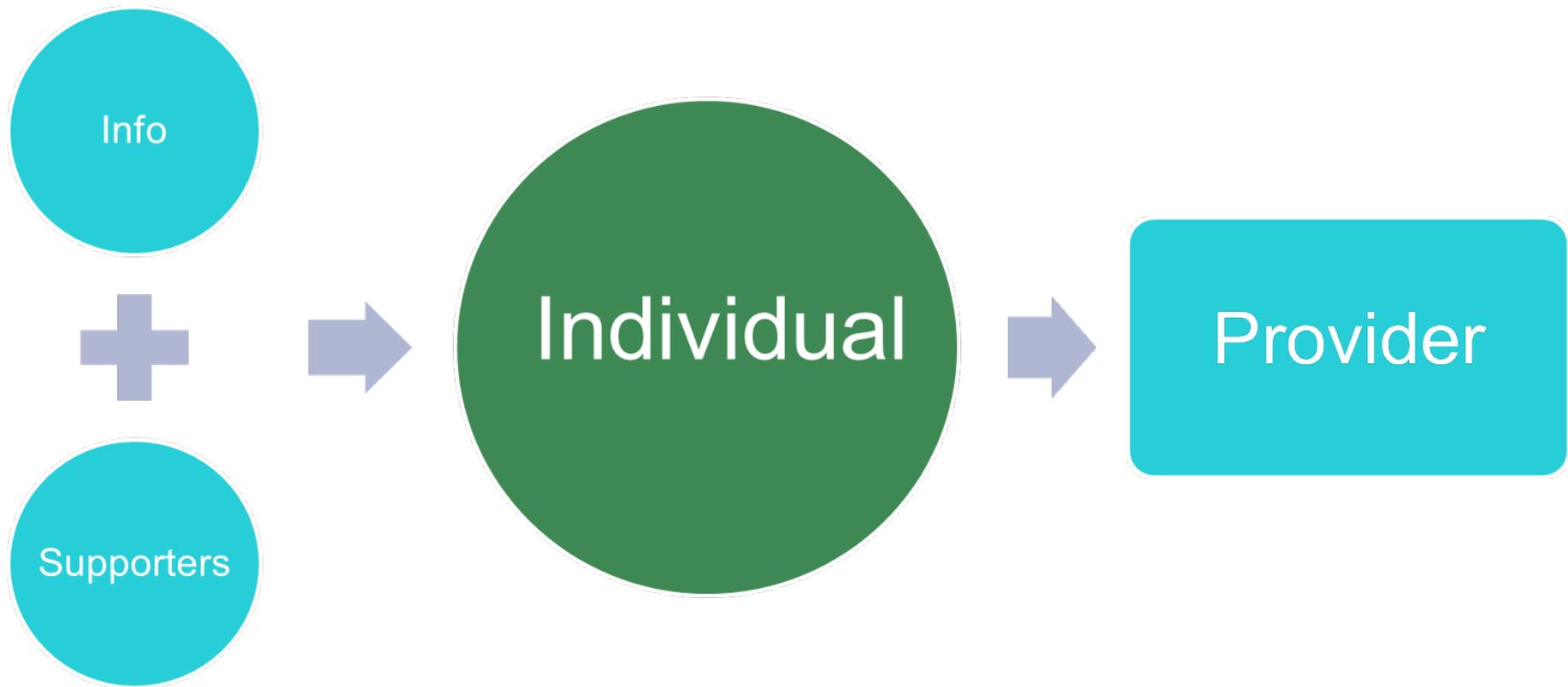
A National Gateway to Self-Determination, funded by the US DHHS, Administration on Developmental Disabilities

People with Greater Self-Determination Are:

- Healthier
- More independent
- More well-adjusted
- Better able to recognize and resist abuse

(Khemka, Hickson, & Reynolds, 2005; O'Connor & Vallerand, 1994; Wehmeyer & Schwartz, 1998).

Supported Decision Making



Supported Decision Making, cont'd.

Supported decision-making is a process in which individuals with disabilities are assisted in making decisions for themselves. Supported decision-making happens when an individual is the decision maker but is provided support from one or more persons who explain issues to the individual in a manner that he or she can understand. There is no one model of supported decision-making.

(Adapted from the American Bar, 2012)

Supported Decision Making, cont'd. 2

- Formal agreements
 - Notarized SDM Agreement
 - Outlined in a POA
- Informal agreements
 - Knowing who to go to for what
 - Example: I talk with mechanic friend before making car repairs
- Most states do not formally recognize SDM
 - This is not a barrier!
 - Right to accommodations under the ADA, HIPAA, etc.

Benefits of Supported Decision Making

- Individual is always at the center of decision making.
- Individual decides who offers support.
- Individual retains legal rights.
- No expensive attorney fees or court fees.
- Teaches individual about decision making and details of his or her affairs.

Who Led the Charge?

- The Rehabilitation Act?
- The ADA?
- The Olmstead Decision?
- Others?

Grassroots Advocacy: South Carolina

- The awakening of one parent serving as a parent advocate with decades of recommending guardianship
 - A relationship with Able SC
 - Trainings to parents on alternatives to guardianship
- 3-year grant from the SC DD Council to work with the Arc of SC, Protection & Advocacy (P&A), and Family Connection of SC to create resources and provide trainings
 - A website, short informational videos, brochures, manuals on alternatives, professional and family trainings, family counseling, and systems advocacy in between
 - P&A advocated for a change in the state guardianship law, making it far more difficult to revoke rights without proof of incapacity (2019)

Grassroots Advocacy: South Carolina, cont'd.

Resources

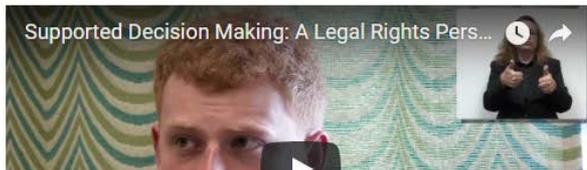
RESOURCES CREATED BY THE SC SUPPORTED DECISION MAKING PROJECT:

- Supported Decision Making Agreement Template
- Supported Decision Making Manual for Individuals and Families
- Supported Decision Making Manual for Service Providers
- Supported Decision Making Manual for Attorneys

VIDEO: A FAMILY'S PERSPECTIVE



VIDEO: A LEGAL RIGHTS PERSPECTIVE



What Next?

- Learn about SDM momentum in your state and get on board.
 - If no projects currently exist, look to state affiliates of national groups that support SDM and alternatives to guardianship (e.g. ARC, P&A, State Bar Association)
 - The voice of IL and the disability community needs to be heard here!!!
- Research your state's guardianship law and start talking with people encountering the issue first hand.
 - A great website to start with to research current [state guardianship policy](http://www.supporteddecisionmaking.org/states) (<http://www.supporteddecisionmaking.org/states>)
 - This includes understanding why families pursue guardianship (e.g. fears about authority in the IEP process, medical issues, money management, etc.).
- Think grassroots!

Let's Talk!



- Jerri Davison, Assistant Director at Able SC and Project Lead for the SC Supported Decision Making Project
- Charlie Walters, Director of Transition Programs at Able SC: cwalters@able-sc.org
 - [Able South Carolina Website](http://www.able-sc.org/) — <http://www.able-sc.org/>
 - [South Carolina's SDM Website](http://scsupporteddecisionmaking.org/) — <http://scsupporteddecisionmaking.org/>
 - [National Resource Center for SDM](http://www.able-sc.org/) — <http://www.able-sc.org/>

March 2018 Guardianship Brief from [National Council on Disability](#)

- <https://ncd.gov/publications/2018/beyond-guardianship-toward-alternatives>

Final Questions and Evaluation Survey

Any final questions?

Directly following the webinar, you will see a short evaluation survey to complete on your screen. We appreciate your feedback!

<https://www.surveygizmo.com/s3/4325377/Webinar-Evaluation-May-23-2018-Preventing-Guardianship-How-CILs-can-be-the-Frontline-to-Advocate-for-Less-Restrictive-Alternatives>

CIL-NET Attribution

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