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**BACK TO THE
FUTURE** 2024

 **NCIL ANNUAL CONFERENCE ON INDEPENDENT LIVING**

2024 Annual Conference on Independent Living

BACK TO THE FUTURE

Presented by the National Council on Independent Living

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Supportive Decision Making: An Alternative to Guardianship

Subtitle / Date

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When we make mistakes, why are we held to a different standard?

Why should IL be against guardianship?

- 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 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?
- Guardianship contradicts the IL philosophy and self-determination.
- We are a cross-disability movement and there are no exceptions to the rules to protect rights or thinking some people with certain disabilities are the exception.

This is supported by 40+ years of research on self-determination



Horror Stories From Our Movement

- CILs provide services to help consumers secure guardianship against their will.
- Staff from CILs and SILCs saying that there should be exceptions to the rules for people with intellectual and developmental disabilities.
- CILs testifying in court that someone needs guardianship.
- CIL staff becoming someone's guardian.

This is our community so why would IL go against the rights of disabled people?

Statements Opposing Guardianships

- National Council for Independent Living
- Association for Programs for Rural Independent Living
- American Bar Association
- National Council on Disability
- Autistic Self Advocacy Network
- Disability-led organizations such as CILs. Do you have a statement on your website and policies?
- Center for American Progress
- Family Law Self Help Center
- And many more!

What IF..

- You are a mother of two and had a stroke. You were in a coma, and a petition for guardianship was being filed on you? Would you want your rights removed and separated from your children?
- You are an 18-year-old individual with autism who cannot do laundry, handle your finances, and need support to make decisions? Would you want your rights taken away?
- You used a communication device and were assumed to be incapacitated? Would you want to lose your rights?
- Others just thought they knew best for you because of your disability? How would you feel about getting guardianship?

Key Definitions

- **Guardianship** – (aka “conservatorship”) a judicial process for taking partial or complete control of a senior’s or PWD’s decision making, real property, and personal property

- **Alleged incapacitated person** – a PWD (including seniors and young adults) who is voluntarily or involuntarily being placed under guardianship at the request of a petitioner

Levels of Guardianship

- **Plenary guardianship** – (aka “full guardianship”) complete control of a PWD’s decisions, property, finances, and person
- **Limited guardianship** – narrower than a plenary guardianship, a limited guardianship only grants power to make decisions for a PWD in areas and under terms specified by the court
- **Supported decision making** – a less restrictive alternative to guardianships that helps the PWD live independently in integrated community settings with the support, services, and programs they need to live in the community

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Historical Context

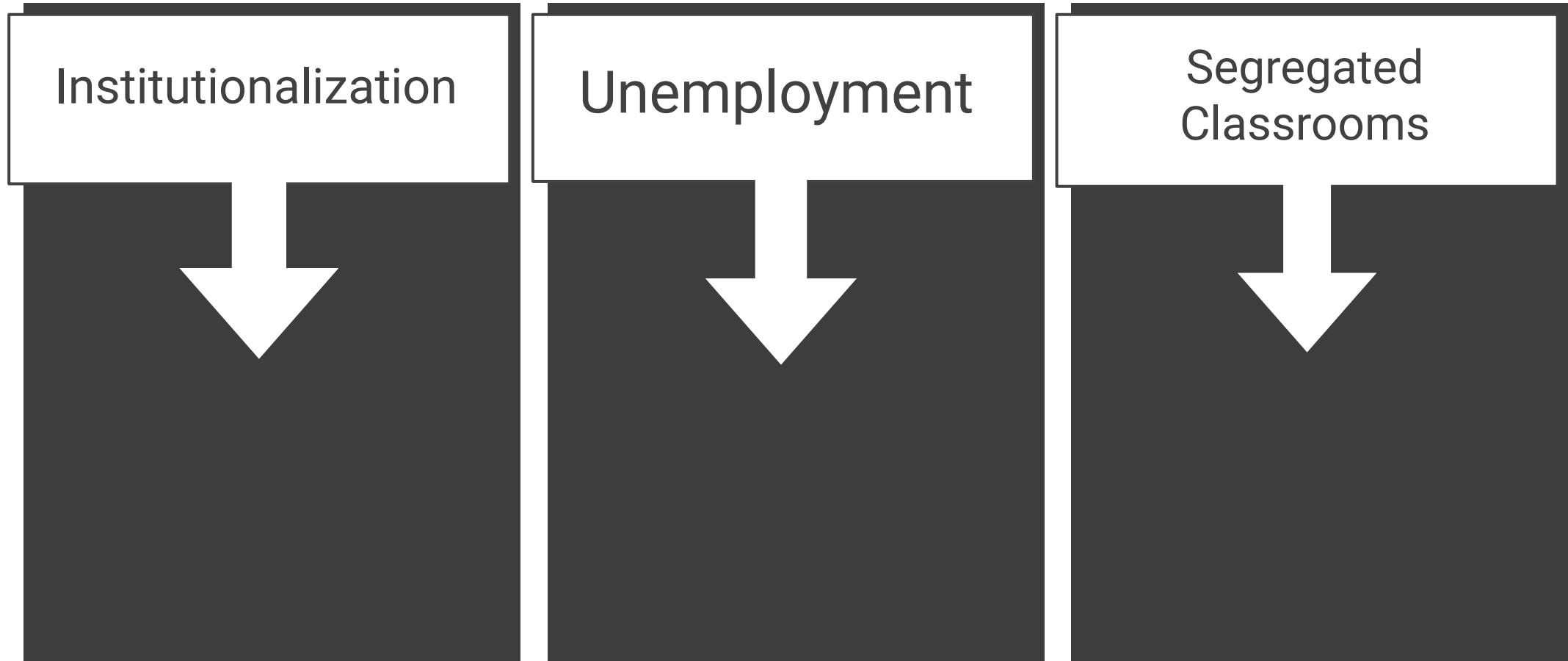
1990- Americans with Disabilities Act
Passes

Comprehensive Disability Rights Legislation

“It will ensure that people with disabilities are given the basic guarantees for which they have worked so long and so hard: independence, freedom of choice, control of their lives, the opportunity to blend fully and equally into the rich mosaic of the American mainstream.”



Since the ADA..



Yet still far behind from the realization of the ADA's goals

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Meanwhile..

The number of people under guardianship has more than tripled since the signing of the ADA.



Confusion over Guardianship

When an individual turns 18, the rights automatically transfer from the parent to the individual.

Some parents think they are a person's guardian simply because they provide shelter and care to an individual with a disability.

Guardian is a term given by the court.

Ask for documentation to verify guardianship.

Full Breadth of Guardianship

Court Declares
Person Does Not
Have Capacity to
Make Decisions

Difficult to Modify
or Terminate

Costly

Requires court
reporting

Power is with the
court

Infringe upon
rights, stunt
decision-making
growth

Increased
likelihood of
abuse/neglect

Could limit
post-secondary
opportunities

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.

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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?

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Potential for Guardianship Abuse

- Restricting the PWD's rights to independence, liberty, and basic freedoms
- Often lacking appropriate due process
- Too often, no right to independent counsel or legal representation
- Little to no credentialing, clearances and/or certification of court-appointed guardians
- The seizing of some or all of the PWD's personal property, cash/monetary assets, automobiles, and real property
- Forced isolation and placement in nursing home facilities, or other institutional settings against the PWD's will
- No federal oversight, consistent regulations, or uniformity across the country

Institutions often Involved

- Adult Protective Services (APS)
- Area Agency on Aging (AAA)
- Administration on Community Living (ACL)
- Schools/Educators
- Medical Professionals
- State Bar Associate
- Probate Courts
- Elected Officials
- Protection & Advocacy
- Centers for Independent Living

Youth Conflict

- IEP and education consent
- Court system
- Age of the Majority
- Educator training
- Parent education/Social workers
- Understanding of disability & assumptions
- Expectations
- Lack of skill building

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Guardianship is
a
rubber-stamped
process





Examples of Questions to Demonstrate Incapacitation and is Based on the Medical Model

Does the patient have the capacity to:

- Care for self
- Prepare means and/or cleaning their house
- Maintain bank account or funds
- Pay bills
- Live Independently
- Operate a care
- Take their medication unsupervised

Why are we held to different expectations without considering support or modifications?

Guardianship Facts

- Well over **1.3 million adults** are placed under guardianship nationwide (Source: National Center for State Courts (NCSC) (2016)).
- Each year over **\$50 billion** in real estate & personal property assets owned by people with disabilities are seized by guardians nationwide (Source: NCSC (2016)).
- Systemic negligence by AAAs/APS have led to wide-ranging schemes that use guardianships as **cover for criminal enterprises**, as exemplified by the federal criminal convictions in New Mexico of the leaders of the Ayudando and Desert State Guardianship companies, which held the guardianship of over 1,500 at-risk adults.
- Systemic negligence by AAAs/APS in Pennsylvania alone permitted the criminal activities of professional guardian Gloria Byars, who held captive over 100 individuals and operated with impunity for over a decade.

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Ideal Recipient of Guardianship?

- Older adults
- Youth with disabilities turning 18-years old
- People with intellectual disabilities, developmental disabilities, physical, blind, deaf, non-verbal, etc. All of us.
- Someone who is in a medical emergency



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Alternatives to Guardianship

Protective order

Natural support, personal care assistance, assistive technology

Supported decision making

Social Security representative payee

Automatic bill payment

Oversight on bank accounts

Joint bank accounts

Power of Attorney

Shared emails

Advance directives

Naming healthcare agent in writing



Presume Competence

- All adults should be presumed to have the capacity and the right to be able to live in the manner they wish and to accept or refuse support, assistance, or protection as long as they do not harm themselves or others.
- All adults should be able to be informed about and, to the best of their ability, participate in the management of their affairs
- The values, beliefs, wishes, and traditions that an adult holds should be respected in managing an adult's affairs
- The manner in which an adult communicates with others is not grounds for deciding they are unable to make decisions

Give People a Chance and Provide them with the proper tools



Dignity of Risk

- Adults have the right to make their own decisions, and to be assumed to have the capacity to do so, unless there is evidence to the contrary.
- Capacity should be viewed as decision-specific.
- Adults should be offered all reasonable support and assistance in making and following through on decisions before others step in to make decisions for them.

Don't avoid risks, but instead focus on how you can support the persons safely.

Moving Forward

- DOJ investigating APS/OAPS in PA (Result of OCR complaints filed with HHS)
- ACL OAA proposed rulemaking (Public comment due Aug. 15th, 2023)
- Ohio's expanded use of alternatives to guardianship including supportive decision making
- Liberators for Justice – Sign our petition

https://liberators4justice.org/acl_letter/



Empowering people with all disabilities by providing: Resources, Options, And Disability related Services needed to obtain individual Freedom in their lives.

www.cilncp.org

Statement for the Written Record

**Submitted to
The Special Committee on Aging
United States Senate**

**Hearing on
Guardianships, Conservatorships, Protective Arrangements,
and Alternatives**

Submitted on March 23, 2023

On behalf of the Roads to Freedom Center for Independent Living (RTFCIL), we thank the Special Committee on Aging for planning this hearing and for seeking public comment for reform related to the guardianship, conservatorship, interdiction and other protective arrangements (collectively referred to here as "guardianship"). RTFCIL is the federally funded Center for Independent Living (CIL) serving people with disabilities in the North Central Pennsylvania area. Individuals RTFCIL serves are at serious risk of segregation and institutionalization. Pursuant to the Rehabilitation Act of 1973, Section 504, Part C funding; the Workforce Innovation and Opportunity Act (WIOA) of 2014 and the final rule adopted by the Administration on Community Living (ACL); RTFCIL is federally mandated to provide independent living, individual & systems advocacy, community-based core services, including institutional transitions and deinstitutionalization work.

In compliance with these federal laws, RTFCIL has an obligation to uphold the Independent Living (IL) Philosophy, which respects individuals' dignity, responsibility and self-determination. In the United States, guardianship is often based on implicit biases regarding people with disabilities. Guardianship assumes that disabled people cannot make decisions for themselves. Meanwhile, the IL movement reveals that dependence is created by society's failure to accommodate a disability. To the extent that guardianship limits our dignity, personal responsibility, self-determination, participation, or control over our own lives; guardianship is incompatible with the independent living philosophy and the IL mission.

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What can you do to help avoid conflict of interest?

- Conflict of interest– no one works in other fields that promote guardianship
- Advocating for alternatives to guardianship
- Make it understood that your organization is against guardianship
- Avoid Reporting (we need to be a safe place for all disabled people)
 - Crisis Intervention
 - Mandated report rules and processes to demonstrate capacity
 - Process to protect your organization

Demonstrating Capacity

- Does the individual understand their situation? (Can they accurately describe what is going on?)
- Does the individual understand the risk related to their situation? (Can they describe the consequences or harm that may come as a result?)
- Are they knowingly choosing to assume that risk? (Are they making this decision on their own accord, even if it is a bad decision?)
- Does the individual understand what they need to do if they want to self-report or get assistance? (Do they know how to call 911 or other relevant phone numbers? Do they have the information or know how to access relevant information about shelters, suicide hotlines, emergency rooms, etc.?)

Questions

