**SLIDE 1:**

**2024 Annual Conference on Independent Living**

**BACK TO THE FUTURE**

**Presented by the National Council on Independent Living**

**Alt text: Conference Logo: Black sans serif text says, “BACK TO THE FUTURE”. To the right, digital font in bright, bold orange says, “2024”. Underneath, [NCIL Logo: National Council on Independent Living] Annual Conference on Independent Living.**

**SLIDE 2:**

**Supportive Decision Making: An Alternative to Guardianship**

**Subtitle / Date**

**Kimberly Tissot Misty Dion**

**President & CEO CEO**

**Able South Carolina Roads to Freedom**

**SLIDE 3:**

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

**Alt text: Person with idea concept**

**SLIDE 4:**

**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**

**SLIDE 5:**

**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?**

**Alt text: A person wearing a white and black mask.**

**SLIDE 6:**

**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!**

**SLIDE 7:**

**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?**

**SLIDE 8:**

**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**

**SLIDE 9:**

**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**

**SLIDE 10:**

**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.”**

**Alt text: President George H Bush signing the ADA with other Independent Living and disability rights advocates around him.**

**SLIDE 11:**

**Since the ADA..**

**Institutionalization**

**Unemployment**

**Segregated Classrooms**

**Yet still far behind from the realization of the ADA’s goals**

**SLIDE 12:**

**Meanwhile..**

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

**SLIDE 13:**

**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.**

**SLIDE 14:**

**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**

**SLIDE 15:**

**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.**

**SLIDE 16:**

**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?**

**SLIDE 17:**

**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**

**SLIDE 18:**

**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**

**SLIDE 19:**

**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**

**SLIDE 20:**

**Guardianship is a rubber-stamped process**

**Alt text: A red stamp on a white surface**

**SLIDE 21:**

**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?**

**Alt text: Desk with stethoscope and computer keyboard.**

**SLIDE 22:**

**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.**

**SLIDE 23:**

**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**

**Alt text: A close-up of a sign that says bias**

**SLIDE 24:**

**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**

**SLIDE 25:**

**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**

**Alt text: A group of multi coloured wooden stick figures.**

**SLIDE 26:**

**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 though 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.**

**Alt text: Light bulb on yellow background with sketched light beams and cord.**

**SLIDE 27:**

**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/**](https://liberators4justice.org/acl_letter/)

**Alt text: A picture containing text, screenshot, letter, document**

**SLIDE 28:**

**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**

**SLIDE 29:**

**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.?)**

**SLIDE 30:**

**Questions**

**Alt text: Question marks in a line and one question mark is lit.**