

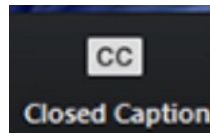


Tools and Strategies for Independent Living Advocates Mentoring Families of Children with Disabilities

*A Webinar Collaboration of The National Council on Independent Living and
The National Resources for Access, Independence, Self-determination and
Employment (RAISE) Technical Assistance Center*

Using Closed Captioning

- To start using CC, click the caption button →



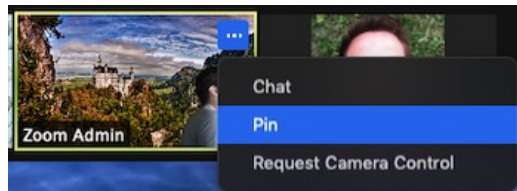
Uso de la interpretación de idiomas

- Hagan clic en el icono de interpretación →
- Seleccionen "Spanish" →
- Después de seleccionar "español", hagan clic "Mute Original Audio" →



Using ASL

- To pin the interpreter, hover over the video of the participant you want to pin and click ... →
- From the menu, click Pin.



Objectives

- The role of parent-led organizations in educating families about how to support self-determination, empowerment, and independent living goals.
- The role of Centers for Independent Living in communicating to families the independent living philosophy and how to support their transitioning youth's self-determination and empowerment.
- How disability-led CILs can work with parent-led organizations to facilitate the self-determination, empowerment, and independent living goals of youth preparing for and experiencing transition.
- Strategies for assisting youth to maintain self-determination when their families work against their goals.

Speakers

- **Wednesday Jones**, Employment and Financial Literacy Specialist, Able SC Center for Independent Living
- **Dawn Monaco**, Program Director for Youth Engagement, Project Director for REAL Transition Partners at the SPAN Parent Advocacy Network, National Advisory Board Member for the Center on Youth Voice, Youth Choice.
- **Mary-Kate Wells**, Program Director at the National Council on Independent Living.

Role of the Parent Centers

- Educate and empower families & youth on their rights in special education and health care.
- Encourage families to teach independence skills
- Help families to understand the importance of youth learning self advocacy skills as early as possible
- Explain the importance of 'dignity of risk'
- Understand that when self advocacy is taught early there is a greater chance of utilizing supported decision-making as an alternative to guardianship
- Provide resources and support



Wednesday Jones: Who I am

- My name is Wednesday Jones
- I am a 26 year old Black woman who has a developmental disability
- I also have a physical and psychiatric disability
- I work at Able South Carolina as an Advocacy and Independent Living Specialist.
- I focus a lot on intersectionality, multi marginalization in the disability community, and inclusive and equitable policy.



My Experiences At Home

- Mother described me as a “slow child”. My family met me where I was at, and helped me work on skills like crawling and communicating.
- Parents expected me to achieve and set high expectations, as they did for my brother who doesn't have I/DD
 - I am grateful for this because I avoided the trap known as “Learned Helplessness”
- Though my parents knew I was experiencing some delays and showed signs of autism I was never taken to be evaluated for autism.
 - The way I was told about it was less than ideal
 - There was more stigma around I/DD and autism when I was younger
 - Information was also more limited in the late 90's and 2000's.
 - Was taken for an ADHD evaluation in middle school.
- I didn't have connections to disability resources at the time.
 - I had to do catch up later, for example OT to tie my shoes and use silverware better.

My Experience with School and College

- In grade school, I struggled but didn't receive any official accommodations.
 - My mother did try to get them for me, but I was denied.
 - Teachers worked out some unofficial methods, but they were othering and I didn't have any input.
- I did have an interesting experience with a somewhat integrated classroom.
 - It was some of the best years in school I had, and benefited from the set up.
- In college, I needed additional support and was referred to a psychologist and was diagnosed with autism.
 - I also received therapy through the school and developed better communication and social skills.
- I was able to receive accommodations at college
 - It was sometimes still a fight to get them in place, and I was working off of a lack of knowledge.
 - A major support I received was the school hiring a graduate student to work with me.

My Experience with Centers for Independent Living

- I attended the Youth Leadership Forum
 - I had learned some things about leadership and advocacy from my experiences at home, like Girl Scouts, and from my experiences advocating at college.
 - I was introduced to the Independent Living philosophy, and got involved with the CIL in my area that was one of the main sponsors for the event.
- At the Center for Independent Living, I met lots of advocates, professionals, and leaders who were disabled. Some like me, and some different than me.
 - It was really important that I was guided by my peer mentors with disabilities because they were able to share with me from lived experiences and (often) spoke to me as an equal.
 - They were able to provide something to me that professionals and my parents were not able to by the virtue of lived experience.
 - I was also able to build networks of support
- I was able to implement what I learned at the CIL in my home, college, and community.

National Council on Independent Living



The National Council on Independent Living (NCIL) is the longest-running national cross-disability, grassroots organization run by and for people with disabilities.

What is Independent Living?

- . A Program
- . A Movement
- . A Culture/Philosophy

The Independent Living Movement and Centers aim to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream of American society.

Centers for Independent Living (CILs)

Centers for Independent Living (CILs) are consumer-controlled, community-based, cross-disability, nonresidential private nonprofit agency for individuals with significant disabilities (regardless of age or income).

CIL Core Services

1. Information and Referral Services
2. Independent Living Skills Training
3. Peer Counseling
4. Individual and Systems Advocacy
5. Transition
 - a. Transition back into the community
 - b. Assistance to stay in the community,
 - c. Transition of youth to postsecondary life**

Disability-led and Consumer Control

- Nothing about Us without Us!
- People with disabilities are the best experts on their own needs.
- People with disabilities have the right to make choices and to control the decisions in their lives.
- People with disabilities deserve equal opportunity to decide how to live, work, and take part in their communities, particularly in reference to issues that powerfully affect their day-to-day lives and access to independence.

Quote from Judy Heumann

“Independent Living does not mean that we want to do everything by ourselves, do not need anybody or like to live in isolation. Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbors and friends take for granted. We want to grow up in our families, go to the neighborhood school, use the same bus as our neighbors, work in jobs that are in line with our education and interests, and raise families of our own. We are profoundly ordinary people sharing the same need to feel included, recognized and loved.”

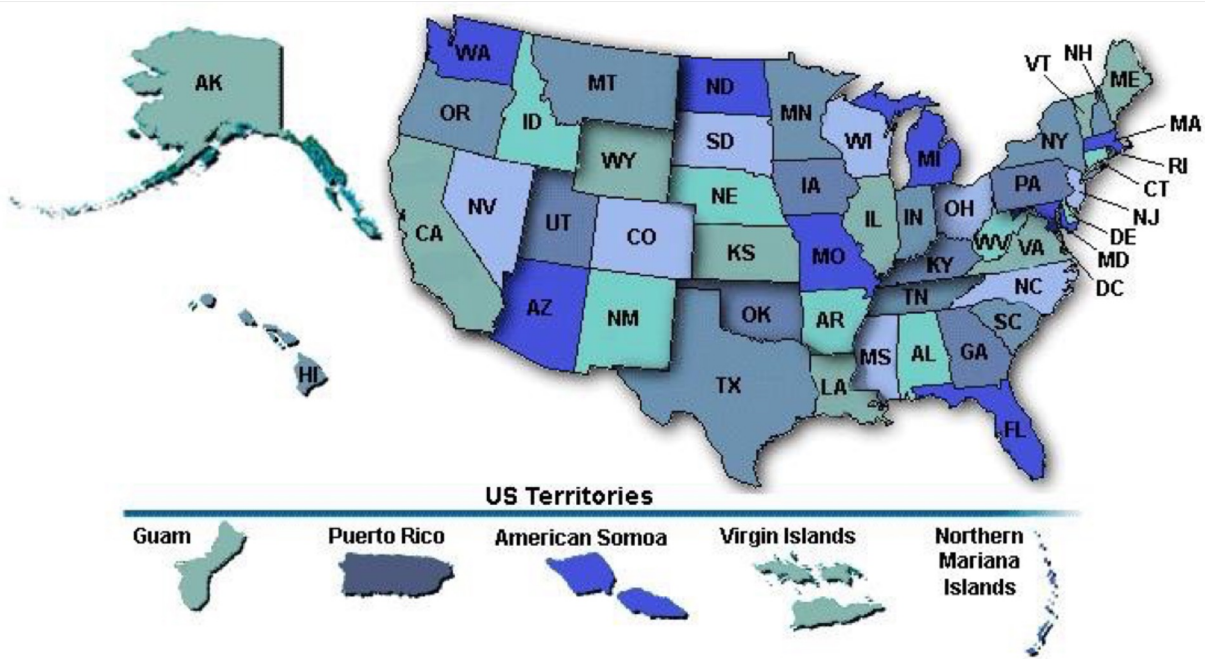
~ Judy Heumann, principal founder of the disability rights movement.

The Role of Centers for Independent Living in Youth Transition

- Consumer Control
- Role of parent and family involvement
- Self-determination, empowerment and independent living goals

Find your Local Center

<https://www.ilru.org/projects/cil-net/cil-center-and-association-directory>



For More information: Check out the Tools and Strategies Briefs at [RAISEcenter.org](https://www.raisecenter.org)

- Teaching Vocabulary
- The Independent Living Model vs. Parent-led Model
- Overview of the Parent-led Movement
- Overview of the Independent Living Movement
- Enabling Empowerment
- Enabling Self-Awareness and Self-Acceptance
- Maximizing Abilities without Over- or Under- Estimating them
- Boundaries, Self-Trust, and Dignity of Risk
- Defining Independent Living
- The Role of Centers for Independent Living in Youth Transition

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Thank you!



RAISE