

# Transition, CILs, and Independent Living 2023

# What is a Center for Independent Living?

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Centers for Independent Living (CILs) are consumer controlled, non-profit organizations that provide services and advocacy to persons with all types of disabilities.

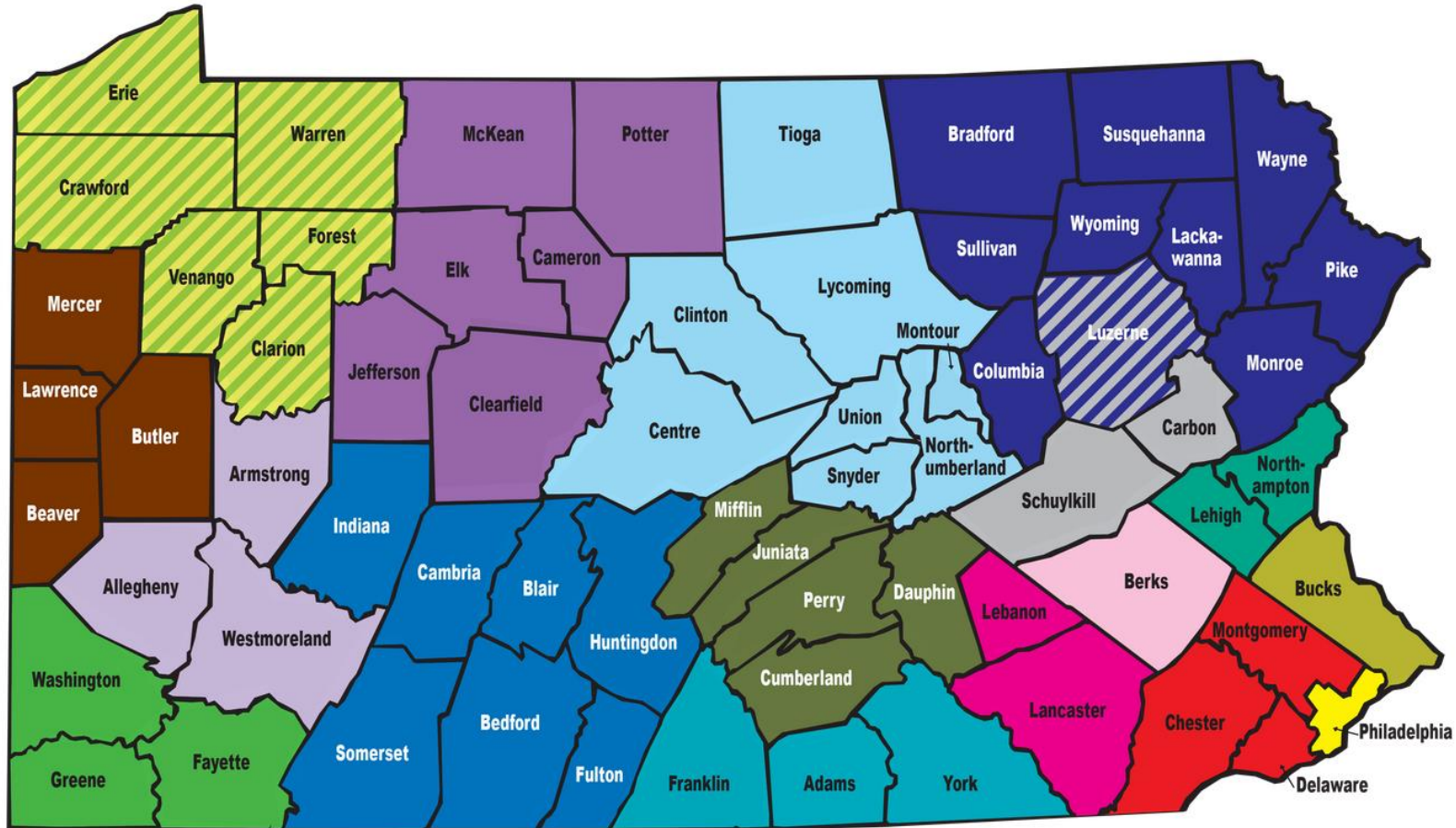
CILs work to ensure fair treatment and access for persons with disabilities in all areas, including housing, transportation, employment, social/recreational areas, health, and social services.

# What is a Center for Independent Living?

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- CILs emerged from the Civil Rights Movement in the 60s
  - First CIL established in Berkley, CA in 1972
  - Ed Roberts
- CILs are rooted in the Independent Living Movement
- CILs became a support network for advocacy and rights
- More than 400 CILs exist across the US and internationally
- 17 CILs in Pennsylvania
- LVCIL founded in 1990, covers Lehigh & Northampton Co.

# CILs in Pennsylvania



# LVCIL's Mission and Vision

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Mission - Empowering persons with all types of disabilities to achieve independence in an inclusive community.

Vision - LVCIL envisions a world free of barriers where people with all types of disabilities can live their dreams.

# LVCiL's Core Services

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- Information and Referral
- Peer Support
- Individual and Systems Advocacy
- Independent Living Skills
- Transition (nursing home and youth)

# Additional LVCIL Services

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- Specialized housing search and support
- Sign Language Interpretation Referral Service
- Waiver coordination
- Technology and assistive devices
- Accessibility
- Community outreach, including disability sensitivity
- Services for youth in transition
- Employment services

# Employment and Transition Services

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- Work-Essential Skills Training
- Pre-Employment Transition Services (students only)
- Vocational Independence Program (students only)
- Group work and job shadowing experiences (students only)
- School-Based services (students only)
- Career Exploration and Assessments
- Job Development and Job Coaching
- LCCC SEED
- Young adult peer/social groups
- Local, statewide, and national work



# The Concept of Consumer Control

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- CILs are governed, managed, and staffed at all times by a majority of persons with disabilities
- At least 51% of all CIL employees and board members are individuals with direct life experience with a disability
- People with disabilities have oversight of all services, programs, and operations
- The concept of consumer control is part of everything we do, including how we interact with our consumers

# Person-First Language

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- Language is important.
- People with disabilities are, first and foremost, people who have individual abilities, interests and needs.
- 1 in 5 – 54 Million people in the US.
- Person-First Language puts the person before the disability, and describes what a person has, not who a person is.

- A person or group on socially characteristic grounds that are perceived, and serve to distinguish them, from other members of a society.
- Limited expectations.
- Portrayal in the media.
- Inspiration.
- [https://www.ted.com/talks/stella\\_young\\_i\\_m\\_not\\_your\\_inspiration\\_thank\\_you\\_very\\_much](https://www.ted.com/talks/stella_young_i_m_not_your_inspiration_thank_you_very_much)

# What is Independent Living?

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- “Independent Living is a state of mind.”
- In what areas does your young adult want or need to be more independent?
- IL is NOT just living on your own.
- IL is NOT living in a nursing home.

# Transition is Life!

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- What to expect from the rest of the presentation:
  - Set the tone for parents.
  - Set the tone for young adults.
  - Discussing different areas that are important for young adults as they transition.
  - Sharing resources.

# Setting the Tone: Parents

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- Parents are familiar with the education system.
- Navigating the adult system can be tricky and sometimes it's hard to find resources.
- “Don't know what we don't know.”
- “What happens if something happens to us?”
- No more IEPs.
- Maybe dealing with guilt.
- May just have a tough time getting through the day.
- May quit their jobs to stay home with their young adult.
- Are transitioning as well.

# Setting the Tone: Young Adults

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- Everything changes!
- Entitlement vs Eligibility.
- May not be sure about next steps into adulthood.
- Don't know where to go for information and support.
- Don't know how to access the adult service system.
- Want the same things that everyone else wants!
- Want to be treated like young adults.
- May graduate "to the couch."
- The social piece is huge!

# Letting Go...

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- Acknowledge that letting go can be difficult.
- It can be a cruel world.
- No one wants to see their child struggle.
- Let's talk about the dignity of risk.



# Making Choices...

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- Many children or young adults are told what they should do.
- Not given choices or ability to make decisions.
- Learn from experience.
- Practice choice making, even early on.
- Natural consequences.

# Expectations...

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- Low expectations.
- Out of pity or feeling bad.
- What does the young adult want?
- Assume ability!

# Entitlement versus Eligibility

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- While a young adult is in school:
  - The law says a young adult must receive a free and appropriate education.
- After graduation:
  - Everything is different.
  - All school services are gone.
  - The systems are completely different.
  - One must apply for and qualify for programs and services.

# School until 21?

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- Speak to your IEP team about this being an option.
- Take this time for opportunities like work study / gaining experiences.

# Employment Skills

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- Interest in working.
- Interests.
- Work experience and exploration.
- Knowing oneself.
- Teamwork, Communication and Interpersonal skills.
- Parent involvement.
- We're not looking to be dream squashers!
- OVR

# Post-Secondary

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- No IEPs in college.
- More and more options.
- Leads to employment.
- Parent involvement.
- Disclosure.
- Each college has a disability center of some sort, but may also have additional supports.

# Housing

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- Where will your young adult live?
- Where do they want to live?
- Do they need some level of help?
- Options – group homes to Independent living – many models.

# Transportation

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- Driving.
- Public Transportation.
- Shared ride systems.
- Bike or walk.
- Uber or Lyft.
- Parent.



# Independent Living Skills

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- You call them chores – We call them getting ready to be independent!
- Recognition that something needs to be done.
- Taking care of oneself.

# Self-Care

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- Many different parts to this.
- Thinking through taking care of oneself and how that impacts a job, social opportunities, etc.

# Healthcare

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- Many layers to this.
- Taking care of oneself.
- Medications.
- Doctor appointments.
- Insurance.
- Pediatric vs. adult doctor.

# Self-Advocacy Skills

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- Knowing oneself.
- Knowing their disability and how it impacts them.
- Strengths and weaknesses.
- IEP prep.
- Making choices and making decisions.
- Accommodations.
- Bullying and how to deal with it.

# Finances

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- Cashing a paycheck.
- Cash versus a debit card.
- Understanding credit.
- Paying bills.
- Trust funds.
- ABLE accounts.
- Taxes.
- SSI/SSDI.

# Technology

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- There is more and more out there that can help in many ways: cell phones, apps, talk to text, etc.
- Tech Owl.
- PATF: Pennsylvania Assistive Technology Foundation.

# Social

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- Must have a good relationship with others on some level.
- Teamwork/ Communication /Problem solving.
- How do you make friends?
- Dating and relationships.

# Safety

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- In every area.
- Being aware – practicing.
- Crossing the street.
- Kitchen safety.
- Online safety.
- Equipment safety.
- General safety.



# Guardianship vs. Other Options

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- How is your young adult making the bigger decisions?
- What are options?
- How do people make these tough decisions?
- Guardianship: referred to as conservatorship, is a legal process, utilized when a person can no longer make or communicate safe or sound decisions .
- Other options? Supported Decision Making.

## At 18...

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- A young adult is considered an adult.
- They can vote.
- Young men must register with selective service.

# Transition as it relates to...

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- Schools and their roles.
- Community integration.
- Parent Support.
- Sibling Support.
- County supports.
- Waivers.
- Leadership.
- Mentorship.
- All the different providers.
- Navigating the systems.
- When does transition stop?

# Person-Centered Planning

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- A tool that helps a young adult and their family put in place a plan for their young adult's future.
- Like an IEP but.....
- Positive, realistic, and with the young adult as a focus.

# Resources

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- <https://www.secondarytransition.org/>
- <https://www.paiu.org/>
- <https://www.disabilityrightspa.org>
- <https://www.pealcenter.org/>
- <https://www.parenttoparent.org/>

# For more information...

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- [www.lvcil.org](http://www.lvcil.org)
- <https://www.facebook.com/LVCIL/>
- [info@lvcil.org](mailto:info@lvcil.org)
- <https://pasilc.org/>
- <https://thepecil.org/>

# Questions?

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