Lehigh Valley Center for Independent Living Newsletter

LVCIL Newsletter

Spring, 2025





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Lehigh Valley Center for Independent Living

Who We Are

LVCIL is a non-profit organization based in Allentown, PA that provides services and support to people with all types of disabilities.

At LVCIL, we believe that every individual has the right to live a healthy, happy, and productive life in a community that is free from all barriers. We can help you achieve or maintain your independence through many of our supportive services and programs.

The Lehigh Valley Center for Independent Living (LVCIL) is a registered 501(c)3 non-profit organization that serves people with disabilities, and their family members, living in Lehigh and Northampton Counties.

What We Do

LVCIL offers a many services and programs. But like all Centers for Independent Living we offer our 5 core services.

Information and Referral

Information and referral can help you find the programs, services, and support you need to live independently.

Advocacy

To put it simply, advocacy is standing up for your rights and what you believe in.

Peer Support

If you feel like no one understands you, or that people treat you differently because of your disability, LVCIL's peer support can help.

Independent Living Skills

We can help you achieve independence by providing you with the information, support, and education you need to live independently and remain independent.

Where To Find Us

713 North 13th Street, Allentown, PA 18102

By appointment only

Contact Us

610-770-9781 - info@lvcil.org

HAPPY BIRTHDAY LVCIL



Empowering persons with disabilities For 35 Years

A message from LVCIL's Executive Director

o you remember your 35th birthday? Or maybe you are still looking forward to it. Either way, it is a milestone celebration. On June 11th, 2025, LVCIL celebrated our 35th birthday - a birthday we share with the 35-year anniversary of the signing of the Americans with Disabilities Act. So really this is a celebration for us all!

You have helped us grow from a small advocacy group into a real community, making a real difference in the lives of people. You have stood with us as we evolved to meet our community's changing needs, and we're glad you are still standing by our side today. Through the visionary leadership of former Executive Directors Carl Odhner and Amy Beck, and with your unwavering support, LVCIL has become what it is today.

While LVCIL celebrates our birthday - CIL's across the country are also celebrating our shared history. For those who may not know, Centers for Independent Living were born out of the Civil rights movement of the late 60's. People with disabilities saw the changes happening and knew they needed to fight for their rights too. As a result of their monumental efforts, the Americans with Disabilities act was put into effect in 1990, 35 years ago this July. The ADA wasn't just another bill - it was one of the strongest comprehensive pieces of legislation to enshrined the equal rights for people with disabilities in the world. So to honor those people who came before us, I urge everyone to please take some time to read about Ed Roberts and the other leaders of the Independent Living movement.

So, as we blow out 35 candles this year, we are making a wish, for every person with a disability who dreams of living independently, who needs to be included, who fights daily against barriers both visible and invisible. Our mission -- "*Empowering people with all types of disabilities to achieve independence in an inclusive community*" -- rings as true as ever. And now its message feels more urgent than ever.

That is why we are launching "Thrive in 35", because surviving isn't enough and we want our community to thrive. This year will not be about looking back. We will be celebrating what is ahead. Keep an eye out for fun events we're planning throughout our birthday year, as we would love to celebrate with you! But most of all, please know that we appreciate your support and are thankful that we have you as a partner in doing this work.

With gratitude and birthday wishes,

lett Am

Seth Hoderewski LVCIL Executive Director

Let's make 35 the year everyone thrives! Want to give LVCIL a birthday gift? Visit lvcil.org/donate



A conversation exploring how intimacy, relationships, and sexual health are often left out of the conversation when it comes to people with Disabilities

At the time of this interview Syelee Doshi was a third year occupational therapy doctrinal student, completing her capstone project at LVCIL. Her focus was on developing curriculum which addressed the sexual and intimate needs of individuals with intellectual and developmental disabilities.

How did you get into this field? What made you want to focus on the subject of intimacy, sexuality, and relationships for people disabilities?

Syelee: I went into the professional occupational therapy because I saw patients with differing abilities wanting to get back to life, I could have focused on many different areas, but I just met a lot of individuals who were saying things like: "I want to get back to being intimate with my wife. I want to set up a date with someone. I want to go to Prom with a date"

In this field we really try to focus on everyday aspects of life and being able to integrate that into the service we provide. So, with my capstone, it's such a great opportunity to expand what I can do outside of what's the imaginable.

Sexuality and intimacy are ingrained in every human like. It's so intrinsic that we want connection, connections like being in a relationship, being intimate with a partner. But for individual with disabilities, there are just so many harmful misconceptions: that people with disabilities are always asexual, or they don't have the capacity to engage in intimate relationships, or that they even want to pursue intimate relationships. And I want to address that.

What do you see as an important issue that need to be addressed in the field?

Syelee: I would say within the last decade, while there has been a been growing awareness around it in the medical profession. We really need to include individuals with disabilities and their advocacy within the research. Because how are you supposed to preach evidence-based 1st person narratives, if you're not including or even respecting work published by those individuals. Where is the research being led by an individual with a disability? So that I feel like that is one of the largest gaps.

You said before there were a lot of misconceptions about people with disabilities and the whole topic of sexuality, relationships, and intimacy. What are some of those that you find to be particularly important to address?

Syelee: I really want to break the stigma about comprehensive sex education. In general, sex education that is offered, is not inclusive to individuals with disabilities. I feel like that's my main approach as an occupational therapist is to take my skill to adapt things to fit an individual and their abilities, then add that to the movement of expanding and raising awareness about comprehensive sex education.

It's not about what happens *"under the sheets"* all the time. It's things you'll encounter on the streets like a stranger

"I've always just been the person not afraid to challenge, you know, harmful misconceptions, or just have that conversation."

asking you for a hug or a person online in a chat room asking you to send explicit photos. It's often about the dynamics of being able to navigate safe dating practice and safe intimate practices, and that is a big concern for me.

Where do you think some of these big challenges and misconceptions come from?

Syelee: It's not coming to people's mind that sexuality and intimacy are part of independent living. And when it comes to youth, the trusted adults working with them are not even considering the concept. They focus on protecting and empowering them – but often still hold the stigma that individuals with disabilities aren't sexual or intimate beings.

Do you think that has anything to do with the fact people with disabilities are often treated and thought of in terms of Children. You often hear a person described as being some age like 24, but "With the mind of a 4th grader"

Syelee: You might be told your child is a different cognitive age than their typical age, but that doesn't deter that their physical development. Their sexual development is at the same age as their peers and the age that they're at. So it's not that they shouldn't be taught information that information just should be taught differently, and that goes along with the whole message of being accessible, being inclusive within the material you preach.

"How can you say you want to empower someone when you don't view them at their current age and their current status."

That mindset is dangerous, it leaves them more vulnerable to exploitation. For example, females with disabilities are 7 times more likely to be sexually assaulted than their typical female peers. ¹

Not having these conversations around sexuality isn't just missing an aspect of independent living but its also opening the gate for people for them to be more exploited or to be victims of abuse.

I think finding ways to ensure people with disabilities are safe from abuse is a major concern for many people. Why is that number so high for this community?

Syelee: Because they're not given the tools to protect themselves. Without them they are at a big disadvantage to navigate or recognize threats from people around them.

I know there is also an uncomfortable issue regarding people with disabilities getting in trouble, both in school and outside of it, with inappropriate sexual behavior. Can you speak on that bit? Why it happens, and how it can be better addressed?

Syelee: If a person with a disability doesn't understand what their sexual needs and drives even are, and then if they're never taught what is and what's not appropriate – how do we expect them to make appropriate choices?

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If appropriate ways to express sexual urges and interest in romantic or intimate relationships are never taught, then, its common that people with disabilities get in trouble for inappropriate sexual behaviors within school, cyber stalking or harassment of individuals, inappropriate behavior within the workplace, or even indecent exposure within public.

That feeds into another stigma that individuals with disabilities somehow both hypersexual and asexual. They got two stigmas going on. They're somehow both at the same time.

A lot of this seems to be about education. While the topic of sex-ed in school is always on going, how can parents and care takers start that education with their children?

Syelee: It starts with teaching about "yes or no" It's empowering a child to be able to say no. A lot of times we preach to individuals with disabilities a compliance based culture, where you're really trying to regulate behaviors and fit that individual into a box to be societally appropriate. And so that individual learns to say yes, follow what people say - but that also brings harm within assault and exploitation, and also a negative mindset of "I can't explore, I can't advocate for myself,

I always have to say yes." Which leads to what they call a culture of consent

"Sex education is not always what people assume it is"

Self-Autonomy is at the center of things. That's really the building block of a relationship, understanding consent boundaries and being able to communicate. And that ends up leading to self-autonomy within sexuality and intimacy.

Parents need to accept and embrace when their child is showing signs of puberty and showing signs of sexual / romantic interest, rather than trying to avoid, dismiss, or discourage it. For example:

Let's say your 4th graders coming home and saying like, "I love my teacher! I want to marry my teacher." You don't treat that in, cutesy way. Rather you should teach your child that It's okay to have a crush, but you don't always act on a crush. Teach them why it's not appropriate or even how harmful it is to have a relationship like that with an authority figure, but without shaming them for having those feelings. It's really treating them as miniature adults – not just a kid with a disability who will never have to deal with love, relationships, or intimacy.

If someone, a young adult or anyone with disabilities reads this article, what message do you want to leave for them?

Syelee: You as an individual with a disability have a right to explore your sexuality and identity, because it directly affects your sexual health, and your ability to engage in intimate relationships.

You should feel empowered that you can gain the skills to make informed decisions about their life regarding sexuality and intimacy. Know that you have the right to be a sexual being, and you have the right to be in relationships. You have the right to be a mom or a dad to have a child. You have the right to have the kind of relationship and life you want for yourself. Just because you have a disability does not mean you don't get to experience this part of life.

1. People with intellectual disabilities are the victims of sexual assault at a rate seven times higher than those without disabilities. (https://www.npr.org/2018/01/08/570224090/the-sexual-assault-epidemic-no-one-talks-about)

"Just Another Day"

Debbie Rozear reflects on her 20 year journey working at LVCIL

"Everyday there are new people and situations. I began on May 26, 2005 and still going strong on May 26, 2025."

After that introduction to LVCIL, I began volunteering on occasion to fold news letters, work the front desk a few times and do a few more ILS groups. I do not remember when I first started participating in all these activities, however, I know it was several years of volunteering. I enjoyed the interaction with the other people who volunteered.

As I had stabilized after acquiring my disability, I noticed that there was a position open and applied - his year LVCIL is 35 years old. I never had the privilege of meeting Carl Ohdner. However, soon after his successor, Amy Beck began working here, someone had called me up to run an Independent Living Skills (ILS) class. I graciously accepted.



Image: A photo of Debbie Rozar

- Had an interview, and did not get hired.

About a year later I had applied for a different job at LVCIL and again someone else was better qualified. About 3 weeks later, after being told that I didn't get the job, I got a call and was offered an entirely different position at LVCIL. I accepted and had no idea what was expected of me.

I was hired as a Community Support Coordinator in the Housing department. I started with little knowledge in this new chapter of my life, learning as I went.

I began as a Community Support Coordinator and have gone through a few different positions and now am the Supervisor of the Core and Housing Services. Starting by applying for 2 different core positions that I didn't get to have all the core services and housing.

- Debbie Rozear

A message to Debbie

Words can not express the impact Deb has had on everyone.

She has supported hundred of consumers. My favorite are the messages that Deb shares from consumers who are so very thankful for all that she has done for them. The impact she has had on the staff she works with day in and day out is incredible. She has positively impacted every staff that has come through LVCII's doors.

She lives the Independent living philosophy and that influence shines though in its influence on all the staff she has supported over the year. She has impacted interns, board members and the community. It's always fun to hear from community members. More than likely Deb is the LVCIL staff person that they had contact and worked with. We are all better for having Deb's influence in our lived.

Thanks Deb for all that you do! 20 more years, here we come!

- Seth Hoderewski

The Large Flowerheads Return

Another Year of Rockin' Inclusion

pril showers bring May flowers – or Flowerheads in this case! This past May 16th, The Large Flowerheads returned, bringing their array of classic 60's and 70's songs to help LVCIL put on another great show.

Though those April showers never exactly let up, the morning of the show brought torrents of rain down upon the venue: The American Club of Coplay, PA. But lucky for us, Mother Nature must be a fan of the band, because the weather cleared up just in time. By the time the doors opened and the crowds arrived, the spring air was clear and calm.



Image: Consumers and party goers dancing together, the Large Flowerhead's play in the Background.

The band lit up the stage with their groovy tunes, the audience danced along, and community came together again – people of all backgrounds and abilities just enjoying the night together.

While the staff of LVCIL had done their best to make sure everything went right, the night's success was truly a group effort. The owner of Hijinx, a local brewery right here in Allentown, didn't just donate beer for the event – he showed up in person to serve it himself. Meanwhile, the Red Robin Food truck rolled up to serve delicious meals, donating a portion of their proceeds back to LVCIL's mission.

FLOWERHEADS RETURN

During a break in the band's performance, our amazing guest speakers stepped into the spotlight to share their personal stories. They spoke of how LVCIL had helped them achieve greater independence, work towards their goals, and lead more fulfilling lives. Being able to put those we serve up front and center to tell their stories and communicate what they think is important was, and continues to be, the best way we can show what LVCIL has to offer.

By the end of the show, the line between those there to support LVCIL and dedicated fans of the Flowerheads had faded away. And that is the real heart of it all – inclusion. Real inclusion – not just having diverse people around, but having everyone there as one people.

While we are thrilled at



Image: People eating and listening to the band.

seeing how much fun everyone had, we are also happy to say what a success the event was on all accounts. Not only did it raise more funding for LVCIL's programs, but it also effectively spread awareness about the organization's vital work. As the last notes faded and the dance floor finally emptied, one thing was clear:

This community knows how to come together for a cause.

And a huge thanks to all our sponsors!









Meet the AT and AccessCheck Team

(Formerly known as CARP)

uch like the artist Prince we decided a re-branding was in order. Our Community Accessibility and Related Programs name did not fully embrace the services that we provide to LVCIL and the greater community – connecting them to technology and ensuring accessibility.

Spring Updates: We are just barely into Spring and our Assistive Technology and AccessCheck Team are hard at work.

Bob Amelio (AccessCheck Consultant), Ashley Patete, and Bryan Cohen

presented at the 2025 Pennsylvania Recreation and Park Society conference held in Hershey recently. They educated attendees from various cities, counties, and developers on disability sensitivity for trials and provided some great lowcost ways to start integrating accessibility into their trail systems. We are excited to see the progress that will occur in the coming years



because of the education by LVCIL's AccessCheck team.

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Image: Members of AT and AccessCheck Team presenting in Hershey PA.

Phone Updates: The 3 bears of phones.

LVCIL is very fortunate to partner with Temple University Institute on Disabilities to be the Assistive Technology Resource Center for Berks, Carbon, Northampton, Lehigh, Monroe, and Schuylkill Counties. We work with individuals to find devices and offer demonstrations to help individuals integrate assistive technology into their lives.

Through this program, we offer phones specifically designed for people who are blind or have vision loss. Eligibility is determined based on factors such as disability, income, and other qualifying criteria. Here's a quick rundown of the options:

- **MiniVision 2+:** A super simple phone that mimics older-style phones with large tactile buttons and a talking voice guide. It's ideal for first-time users and makes calling, texting, and using basic apps effortless, with added SOS functionality for emergencies.
- **BlindShell Classic 2:** This phone is great for individuals with vision loss, combining a tactile keypad and voice control with apps like WhatsApp and tools such as a color sensor and screen reader. It's simple to use but packed with practical features.
- **SmartVision 3:** A hybrid device that bridges mobile and smartphone features. It offers a tactile keypad with audio feedback, a touchscreen, and voice commands, as well as one-touch access to Google Assistant.



Image: Visuals of the three phones offered.

If you or someone you support lives in Berks, Carbon, Lehigh, Luzerne, Monroe, Northampton, or Schuylkill counties and would like more information, contact the team at **atinfo@lvcil.org or 610-770-9781 Ext 123**

Statewide Coalition Project

What is the Project?

Also called Statewide Advocacy Group or SWAG. We are a collective body of individuals from 15 Centers for Independent Living across Pennsylvania who advocate for systemic change in areas identified by PA Statewide Independent Living Council through a listening tour every 3 years.

We are building a digital and physical history of the Independent Living Movement and Disability Rights across Pennsylvania through interviewing former CIL Directors and leaders. Individuals who wish to contribute can fill out the interest form: https://forms.gle/ixjsfEVu6BLt8KB37

In addition to that, we have 3 other focus groups which are, increasing access to Supports and Services by increasing access to:

- **Housing:** Our group will shortly be releasing an infographic for local officials that shows what "Accessible" housing means and why it matters in the community. Infographic to help consumer navigate requesting a reasonable accommodation from the Public Housing Authority (PHA).
- **Transportation:** Working with private rental car agencies to increase the availability of adaptive driving tools at local offices/rental locations.
- **Home and Community Based Services:** Working on opinion pieces/ guest editorials to local newspapers to help bring awareness to HCBS program and direct care worker rate crisis.



INVESTING IN INDEPENDENCE



Image: LVCIL group standing in front of PA State Capitol

Investing in Independence

LVCIL heads to Harrisburg

by Levi Walbert

sking for donations, funding, grants – money of any kind never feels particularly easy. Or at least it's not for a person like me. I didn't grow up poor – but I certainly wasn't rich either, so early on I understood that money was not something easy to get. For most people, they have to work hard for it – especially now more than ever.

Even a small amount of money can go a long way these days. To ask for ten, fifty, a hundred dollars can sometimes feel like a lot – but, as we try to show people – that donation can mean a lot to those who need it. Enough to change the course of a life even.

So, to be sitting in Harrisburg and request lawmakers to support us in our ask for over a Million Dollar increase to the State's budget for Centers for Independent Living felt surreal. It felt almost more surreal when one of our representatives said it was surprising that we were asking for so little, considering the work we do. On June 11th, 2025, the 35th anniversary of LVCIL – we loaded up a bus full of consumers, staff, and volunteers, 22 in total, and took off to our state's capital. The Mission: talk to our lawmakers and show them how much Centers for Independent Livings do. Show them how vital the services they provide are. And most importantly, show them firsthand how our services can change the lives of their constituents.

We arrived on that sunny day knowing that even a small group like us could help turn the tides in the favor of all peoples with disabilities. Inside that old marble-clad building debates over the new state budget were in full swing. A million dollar increase to CIL's across PA still felt like mind blowing number to me and others, but knowing that that the proposed budget is \$47.6 BILLION, did help to put things into perspective.

We all knew how important that "modest" increase would be to us. How it would let us serve more people and change more lives. Housing, direct support, peer to peer work, job training, education, and opportunities we can barely imagine right now – all of it reinvigorated and supported if this increase was passed....If.



Image: LVCIL talks with Rep. Steen Samuelson, 135th district. Photo credit - Kimi Longo-Walbert

Just like most things in life – we understood that the proposed increase was not a guarantee. As law makers debate and re-organize the budget, there are always changes happening. Programs are added and cut, funds change, and some programs get cut. So we were determined to make sure our little section of the budget was not forgotten – to show lawmakers the good it would do, and why it deserves to be considered.

INVESTING IN INDEPENDENCE

While I'm proud of the work our staff and volunteers did that day (and do every day) the real heroes of this story are the consumers who chose to come advocate for themselves.

All young adults with disabilities who chose to brave the bumpy ride all the way to the state capital. Who spent the day practically running from one side of the massive building to the other to make our meetings. And who sat down face-to-face with Senators and Representative, sharing their stories and showing why services like LVCIL's are life changing.

Because when our law makers make their way into the chambers to debate and vote - the first thought that will come to them isn't going to be a person like me, the Development Coordinator and the numbers and statistics I rattled off to them - it's going to the faces of our consumers. It's going to be the stories they told, challenges they've overcome, and the lives they are living. That's what we know they are going to see.



Image: LVCIL talks with Rep. Mike Schlossberg, D-132nd District. Photo credit - Phil Gianficaro

While the work we as staff do here is important – the LVCIL and all Centers for Independent Living have their heart in the consumers they serve. All CIL's were born out of people with disabilities fighting for their own rights, for their own futures – and now CIL's like ours continue the fight – uplifting people with disabilities, like those who spoke that day, to continue to fight for a brighter future.

Interested in being a part of LVCIL?

Check out our job postings for current positions, or visit our website to learn more about volunteer opportunities with us!



Volunteer

Volunteers are essential to any non-profit organization, including LVCIL! Our volunteers complete endless tasks that contribute to our success as an agency. They also help make our CIL a great place for people with disabilities. Volunteers are always welcome, and everything our volunteers do is much appreciated.

> Please visit our website at: https://lvcil.org/volunteer/ or scan the QR code below to find out more.



Our Thanks to You

LVCIL would not be who we are without the support and kindness of our community

s a Non-Profit organization, LVCIL exists and sustains itself through various grants, awards, and donations from our community. To the many who have, and continue to, give their time, attention, and financial resources to our organization - we can't thank you enough.