

PADDC Outlooks

MARCH 2023



NOTE FROM THE EXECUTIVE DIRECTOR

Raising awareness, taking action, and leading the way for a better future

Every March we celebrate National Developmental Disability Awareness Month, and also Cerebral Palsy Month, Brain Injury Awareness Month, Trisomy Awareness Month, and March 21 is World Down Syndrome Day. Then, in April we will commemorate Autism Acceptance Month.

These awareness dates, days, and designations are important because they draw attention to the developmental disability community. **The awareness and attention are good, especially when it celebrates accomplishment and leads to understanding and learning.** So, while I have your attention, I would like to raise your awareness about Council, our history and purpose, and tell you how we are taking action and leading the way for a better future.

PADDC is one of 56 Councils on Developmental Disabilities across the United States and its territories. The Councils were created by the Developmental Disabilities Assistance and Bill of Rights Act, known as the “DD Act.” In the DD Act, Congress outlines the goals of the nation, the purpose of the DD Network (including Councils) and sets policy to guide our actions.

One of our nation’s key goals is to “achieve full integration and inclusion in society” for all people with developmental disabilities. In addition, the Act states that Councils must assure people with IDD and families are involved in system design and have access to community services that promote “*self determination, independence, productivity, and integration and inclusion in all facets of community life.*” PADDC plans all our actions, activities, and projects to achieve these goals and live up to the ideals set by the DD Act, our mission and our values.



Congress directs and funds Councils to engage in advocacy and system change. PADDC created its advocacy agenda by thinking about our goals and about what needs to change for people with disabilities to have self determination, community living, civic engagement, and leadership opportunities.

(continued on next page)

Raising awareness, taking action, and leading the way for a better future (continued)

The members identified many important areas but had to choose key issues to focus and guide our priorities.

Following are some of the key issues included in our advocacy agenda and why they were selected:

- Support policies like Supported Decision Making and alternatives to guardianship so that people can exercise their rights, make informed decisions, and control their lives.
- Increase access to affordable, accessible housing so that all people can live where they want and with whom they want.
- Eliminate sub-minimum wage so that all workers can earn a paycheck in competitive and integrated work, just like people without disabilities.
- End waiting lists and segregation so that people have the services they need to experience authentic community inclusion.
- Promote universal design in community places and services, so that all people are welcome and belong.

Over the next four years, Council members will actively support policies, laws, and best

practices, so that the goals of our advocacy agenda can be realized. Our efforts will be led by Council members with lived experience. They will share their stories, promote our vision of what is possible, raise their voices, amplify others, and join forces with allies in pursuit of common goals. Our members' active engagement and leadership will change things for the better.

As I said at the beginning, awareness is good, especially when it celebrates accomplishments and leads to learning. Look for PADDC accomplishments throughout the newsletter as we highlight successes from this past year. I hope you learned more about Council history and purpose, and how PADDC is creating change. We envision a future where all people in our commonwealth are valued and thrive. It will take effort, planning, passion, and patience, but I am confident that our Council members will make it happen.

So, as we all celebrate National Developmental Disability Awareness Month during March and Autism Acceptance Month in April, know that the Council is taking action and implementing our advocacy agenda.



Lisa A. Tesler, Executive Director



PADDC 2022-2026

ADVOCACY AGENDA

In 2022, Pennsylvania Developmental Disabilities Council formally adopted an advocacy agenda to advance the goals and objectives of our 2022 – 2026 State Plan. Our efforts to achieve the following priorities will include developing coalitions and encouraging citizen participation, informing policymakers, and promoting new approaches to services and supports.

- ✓ Support public policy to ensure Supported Decision Making approaches are viable alternatives to traditional guardianship in Pennsylvania.
- ✓ Ensure the transition of young children with disabilities from early intervention services to education is seamless, non-disruptive and beneficial to children and their families.
- ✓ Eliminate sub-minimum wage and promote competitive integrated employment for people with developmental disabilities.
- ✓ Increase access to safe, accessible, and affordable housing for people with disabilities.
- ✓ Increase access to technology, especially for students with disabilities in school settings.
- ✓ Support medical, dental, and behavioral healthcare policies and services which meet the needs of people with developmental disabilities, particularly as those disabilities intersect with their other identities.
- ✓ Promote universal inclusive design for community spaces and community services.
- ✓ Advocate for education policies which empower students with disabilities and their families to know their rights and make decisions.
- ✓ Support public policies to end the waiting list for services.
- ✓ End the segregation and institutionalization of individuals with disabilities, including at State Centers.

PADDC MISSION

The Council engages in advocacy, systems change, and capacity building with people with developmental disabilities and their families in order to:

- Support people with disabilities in taking control of their own lives
- Ensure access to goods, services, and supports
- Support communities so that all people *belong*
- Empower people with all disabilities
- Promote the understanding of the life experiences of people with disabilities
- Pursue equity for all people

Projects Started January 1, 2023

New PADDC Grants



SELF DETERMINATION GOAL



Supported Decision Making Grant

Lehigh Valley Center for Independent Living (LVCIL) will partner with Jewish Family Service of the Lehigh Valley (JFSLV) to promote Supported Decision Making (SDM) through a project called SDMPA. The goal is to create systems change by educating the community on viable alternatives to guardianship and will have a cross-disability focus on youth of transition-age. SDMPA will have four target audiences:

individuals with disabilities, families, supports coordinators, and school personnel. The project's activities and products will include education and outreach (virtually and in-person), surveys, a Stakeholders Advisory Council, a train the trainer manual, and a toolbox of resources for people with disabilities to use on their journey to becoming decision makers.



School Culture Grant

The Arc of Pennsylvania will launch the Self Advocacy: Inclusive Declarations of Independent Truths (SAID-IT) program, which seeks to break down stigmas and misperceptions of students with intellectual and developmental disabilities (IDD). Students will be empowered and their voices amplified by creating valued social roles as lead presenters of student-led school assemblies twice per school year. The program will create a positive social experience for students to get to know, receive, and accept diverse students with IDD without bias or ignorance. As all students gain greater understanding of each other, deeper social networks will develop among students, resulting in authentic friendships. These positive interactions will expand through students' adult life as they grow into business leaders who hire more people with IDD, based on the positive interactions created by the SAID-IT program.



Empowerment through Employment Grant

Community Options will identify and publicize stories by and about people with intellectual and developmental disabilities. The stories will focus on Pennsylvanians who are engaged in competitive and integrated employment, higher education, vocational training, or other

meaningful community-based activities. All stories will promote self-determination and choice. Every storyteller will participate in seminars and trainings where they will be encouraged to use their own voices, while also receiving support to improve public speaking and communication skills. Final products will include a recorded event series and a publication. The project's goals are to raise awareness about the capabilities of people with disabilities and to increase demand for supported employment services statewide.



SOCIAL AND SYSTEM CHANGE GOAL



Quality Healthcare Access Grant

Thomas Jefferson University will improve training for family medicine residents to better serve people with disabilities in their own communities. Self advocates and caregivers will help develop and deliver three to four training sessions for medical students. At the end of this project, a toolkit will be shared through publications and presentations. The toolkit will help educate doctors and others about how to better care for people with disabilities.

COMMUNITY LIVING GOAL



Authentic Friendships Grant

Values Into Action will help people with disabilities find and build relationships and friendships using the Friend to Friend (F2F) program. Facilitated information sharing will enable participants to explore their neighborhoods, towns, and even virtual communities. Technical assistance sessions will target the expanded focus on the experiences of people with disabilities and the lessons to be learned from each other, on their own terms. The impact of the project will be measured by how many people identify as empowered because of the knowledge, mentoring, and support received. Success will also be realized when people begin making their own decisions about where and with whom they choose to spend time and experiences, in the pursuit of authentic friendships.

SELF-ADVOCATE LEADERSHIP GOAL



Self Advocacy Training Initiative & Network Grant

Self Advocates United as 1 will work with cross-disability groups, cross-cultural leaders, school districts, regional and national disability organizations, providers of supports, and the general public to connect with people with disabilities, especially diverse youth. The project will identify existing trainings and create new ones to address gaps in information that is wanted and needed by youth to learn about advocacy.

2022 IMPACTS

Transition Discoveries Grant

Young people with disabilities, families and the stakeholders who support them make up a powerful network of relationships, knowledge, and experience for what's working in transition. Through the power of collaboration, the Transition Discoveries project connected these networks into a detailed road map for preparing students for life after high school.

George Washington University shared some of their additional accomplishments through the grant.

- On the website <https://transitiondiscoveries.org>, pathways to hundreds of resources are being created for three populations: youth, families & professionals.
- Work continues with Pennsylvania Youth Leadership Network to track youth-led organizations in PA. This expands the network and creates more opportunities for youth to develop self advocacy and leadership skills.
- The Transition Discoveries initiative has been adopted by the PA Bureau of Special Education, PA Training & Technical Assistance Network. Youth and families are leading the Transition Change Agent Teams.
- Collaboration with PEAL and other family-led organizations continues to engage families in the Transition Discoveries website pathways.
- Work continues to create Spanish translations of all materials.



More than **300 youth** participated in "Next Steps Transition Expo" at Lehigh Carbon Community College.



165 people attended or viewed PADDCC's webinar, which was designed to provide a general overview of Supported Decision Making and discuss what is happening nationally on this topic.

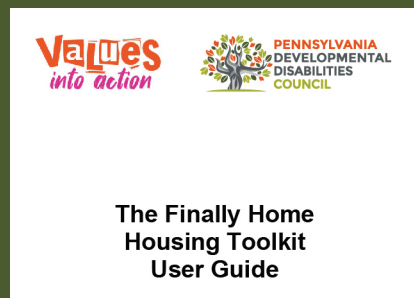
Get the video and presentation on our website by clicking this link or scan the QR code.



1,484 Pennsylvanians
were trained or educated on
Self Determination topics to

- ✓ **make informed decisions,**
- ✓ **exercise their rights** and
- ✓ **control their own lives.**

Pennsylvania Assistive Technology Foundation, PADDC's Generic Technology grantee, assisted Kelvin Alston during their grant. Mr. Alston's journey with smart home technology started with a \$35 Dot smart speaker. When he fell recently, he was able to use the Dot to make an emergency call to friends for assistance. His confidence and familiarity with smart home technology has grown and with his team, he is now in the process of getting a smart doorbell and smart security cameras.



Values Into Action created a Housing Toolkit as a part of their PADDC grant. The toolkit provides information & tools for advocates, housing service providers, supports coordinators, supports brokers, family members, and other interested parties to support people with disabilities in securing the housing of their choice. You can get the toolkit and its valuable resources at: www.valuesintoaction.org/pa/housing-toolkit

Employer Focused Employment Grant

The **United Way of Southwestern PA** created the Disability Inclusion Consortium. Through this project, a great deal of progress was achieved by working with employers to make their workplaces more inclusive and welcoming to people with disabilities.

Quarterly meetings held at various companies included discussions about mission, vision, values, and strategies related to disability inclusion and hiring of people with disabilities. Employers learned from each other. Guests were invited to speak on mental health awareness, diversity, equity and inclusion, and intersectionality of disability and strategic partnerships. Additionally, the United Way of Southwestern PA consulted with individual employers regarding their disability inclusive hiring strategies.



Over four years:

- ✓ **1,285 employees** were **trained**
- ✓ **2,648 people with disabilities** were **hired** by employers in the consortium
- ✓ **57 employers** **participated** in the consortium

When the grant ended, some employers volunteered to continue hosting quarterly meetings and to continue working on making their workplaces more inclusive to people with disabilities.

Rural Healthcare Access Grant

PA Health Access Network (PHAN) worked collaboratively with partner organizations to gather stories from people with disabilities and family members in rural communities to document barriers to accessing healthcare in PA.



PHAN sent this information to the PA Insurance Department and included recommendations for improvement. The PA Insurance Department now plans to investigate network adequacy in the state. This is an important step toward addressing the problems, and creates systems change!



Healthcare access stories are still being collected. [Submit YOUR healthcare access story by scanning the QR code or by clicking this link.](#)

3,183 people were trained or educated through PADDCC **Social And System Change** activities.

- ✓ **879 Health**
- ✓ **282 Housing**
- ✓ **1,652 Tech**
- ✓ **370 Employment**

Our goal is to make PA more **responsive, accessible, and flexible** for Pennsylvanians with developmental disabilities!

8 LEAF Scholarships

(Leadership, Empowerment, and Advocacy Fund) were awarded in 2022. **\$4,109** was granted to **support individuals with disabilities** and family members to **attend conferences, summits, and trainings**.

6 Community Response Projects

were awarded totaling **\$28,648.25** to provide **supports** (education, training, information, etc.) to **people with developmental disabilities in response to disasters and emergencies**.

Carousel Connections received a PADDCC Community Response Project grant

to provide animal-assisted activities. Their project called SoulPaw addressed the impact of social isolation during the pandemic. Animal-assisted group experiences provided **31 participants** with opportunities to rebuild authentic social connection and emotional modulation in a supportive, nonjudgmental, clinician-led setting. Pals For Life partnered with Carousel Connections to provide four activities (with both therapy dogs and therapy bunnies) for individuals with developmental disabilities.



Several participants shared that they felt deeper connections to people in the animal-assisted activity because the animals made them feel less stressed.

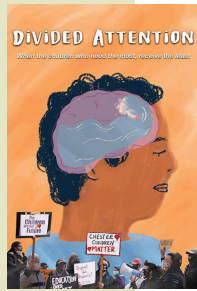
2022



IMPACTS

PADDC's **School to Prison Pipeline - Diversion** grantee, **Delaware County Advocacy & Resource Organization**, produced a documentary film called "Divided Attention."

The film is a call to action to address inequitable school funding, and it demonstrates mindfulness instruction. Hundreds of people have attended screenings. You can view the film online or request a screening by clicking www.delcoadvocacy.org/divided-attention.



Through PADDC
Community Living activities
19,622 people were
trained or educated in ways to
empower communities to provide
positive, inclusive experiences
for everyone, so that **people with**
developmental disabilities and their
families **feel welcomed**
and supported!

302 people were trained or educated through PADDC **Self Advocate Leadership** activities. Our goal is to support **policy solutions, advocacy, and civic engagement led by people with developmental disabilities**, their families, and allies.

The School-to-Prison Pipeline – Re-entry Grant

Support Center for Child Advocates identified problems students experienced when returning to school from alternate placement, and how these problems contributed to funneling them into the school-to-prison pipeline. To address these problems, they ✓ developed best practices ✓ worked with and advocated for individual students in alternate placement ✓ analyzed policies and procedures of schools, law enforcement agencies, school districts, and alternate placement facilities and ✓ talked with personnel of these institutions/facilities.

Support Center for Child Advocates provided training on the school-to-prison pipeline statewide and nationally, targeting lay and professional audiences. They provided training at the National Association for Court Management Conference, the American Bar Association's Center on Children and the Law Conference, the Pennsylvania State-Wide Adoption Network (SWAN) conference, and the national Coalition of Juvenile Justice conference. 18 trainings were held for professionals at 14 agencies at the local level across Pennsylvania. They reached juvenile probation officers, child welfare workers, schools, and intermediate units.

The "School Reintegration for Youth Returning from Residential Placement: Voices from the Field and Recommendations for Pennsylvania" [re-entry best practices guide is available by scanning the QR code or by clicking this link.](#)



ADVOCACY

Tip of the Month

It's Budget Season!

Are you ready to advocate?



In early March, we are waiting to see Governor Shapiro's state budget proposal. PADDC is hoping the new administration will invest in programs that support individuals with developmental disabilities to pursue meaningful, inclusive, and productive lives in their community.

We focus on funding for home and community-based waivers, employment, special education, transportation, waiting lists, health care, and the direct support workforce.

There are many budget lines that are important to our community, and it can be hard to understand. But our ***Slice of PIE*** publication provides a summary of disability funding to help you figure out the impact. To get on this mailing list, click this link [Mailing List Sign Up](#) or the QR code to sign up.



The governor's plan is the first step in the process. It is called "budget season" because a budget isn't passed by the

legislature until the end of June. Between now and then, there is time to influence and change what the governor proposed.

The House and Senate Appropriations Committees hold hearings to ask administration officials questions to learn more about the budget and plans. Lobbyists and other interested stakeholders meet with legislators to try to persuade them to either increase or decrease funding for programs.

You can be an important voice in the process. You don't need to be a lobbyist or a policy expert, you can simply share your story and experiences.

You can talk with your state representative and senator about your life and your family. Tell them about the services and programs you rely on to stay healthy and to live, learn, work, and thrive in your community. You can call them, write a letter, or set up a meeting.

Advocacy groups provide valuable information and support to grassroots advocates. Organizations like Disability Rights PA, The Arc of PA or your local Arc chapter, Vision for Equality, the Statewide Independent Living Council or your local CIL, PA Waiting List Campaign, Education Law Center, PA Health Law Project, and others are reliable resources.

Many have said that "budgets reflect values." Let's speak out to ensure that the final budget demonstrates that our commonwealth values people with developmental disabilities.

Click here or scan QR code to:

Find Your Legislator - PA General Assembly
(legis.state.pa.us)



2023

PADDC Council Members

Koert Wehberg, Chair • Rob Oliver, Vice Chair

Nicole Adams, *Representing the Secretary of the Department of Health*

Dana Barone, *Representing the Secretary of the Department of Labor*

Renee Benise

Lisa Butler

Heidi Champa, *Representing the Secretary of the Department of Aging*

Mary Kay Cunningham, *Representing the Institute on Disabilities at Temple University*

Keith Focht, *Representing the Secretary of the Department of Education*

Beatriz Frometa

Jennifer Garman, *Representing Disability Rights PA*

John C. Grandy

Poornima Khare

Ann Marie Licata

Maria Martin

Amy Mathewson Nieves

John Orr, *Representing Art-Reach, a Private Non-profit Organization*

Karen Plummer, *Representing Voice and Vision, a Local and Non-governmental Agency*

Nancy Richey

CJ Rine

Lea Sheffield, *Representing the Secretary of the Department of Human Services*

Lisa Sportelli

Committee Members

Robert Cummings

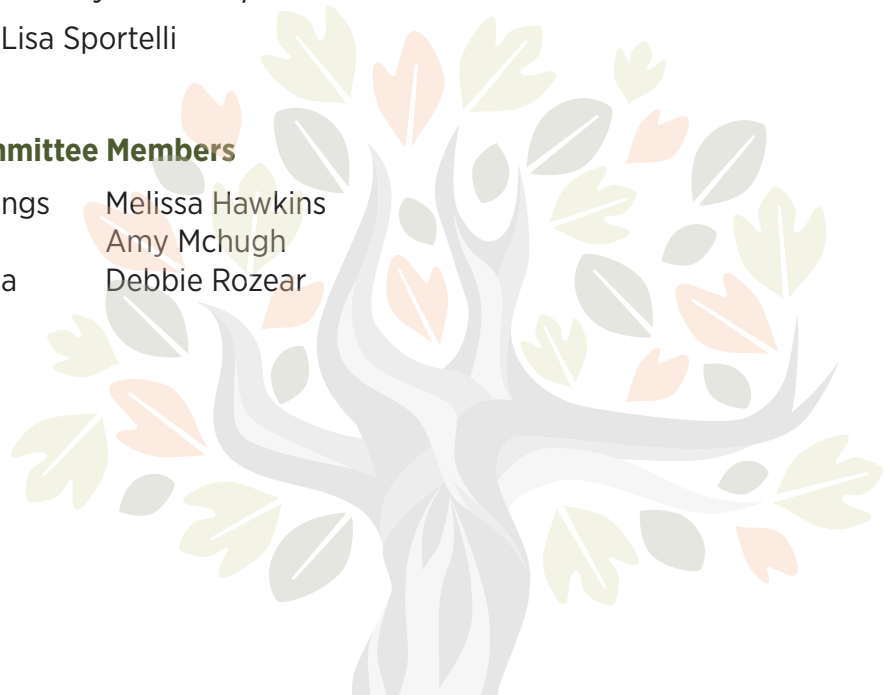
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DEVELOPMENTAL
DISABILITIES
COUNCIL**

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