

ODP News

January 2019



ODP Continues Progress on Addressing Waiting List

Over the years, service expansion has made a definite impact on the ODP waiting list. In April 2006 there were 24,500 people waiting for service. As of Nov. 30, 2018, the waiting list is nearing half that size with 13,309 people awaiting service.



Through Targeted Supports Management funding, ODP also expanded supports coordination for 2,000 people who were waiting for services. The 2018-19 budget includes funding to enable an additional 1,765 individuals with ID and/or autism to access waivers to provide supports and services, so they can remain in their home and community and live an “everyday life.”

ODP has reduced the waiting lists through several initiatives, including:

- Expanded services for 100 individuals on the emergency waiting list through the Consolidated Waiver.
- \$10.2M to serve 800 2018 school graduates on the waiting list through the Community Living and Person/Family-Directed Support waivers, and 800 2019 school graduates in the Community Living and P/FDS waivers (beginning June 1, 2019).
- Expanded services for 40 additional adults with ASD on the waiting list through the Adult Community Autism Program.
- Expanded services for 25 individuals currently residing in the state centers.

Service Providers, We Need Your Input!

What training will help you to support individuals with intellectual disabilities, autism, or other developmental disabilities, and their families? The Office of Developmental Programs (ODP) and the ASERT Collaborative are trying to learn more about training needs among service providers. ODP constantly strives to build capacity by developing resources and trainings to help individuals live an everyday life.



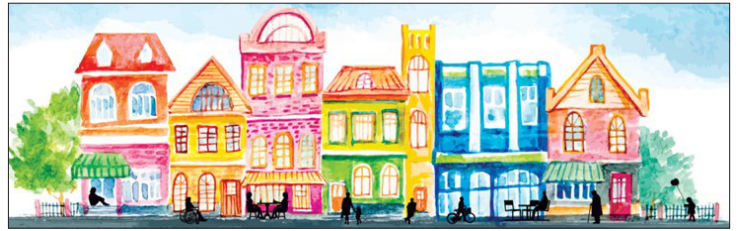
We seek input from those who provide behavioral, clinical, transportation, medical, and educational services, as well as those who oversee/supervise direct care staff, provide support to individuals at their jobs, in their homes/communities, and/or in a facility-based setting.

By responding to [the ODP/ASERT Collaborative Training Needs Survey](#), you will help ODP to create trainings and resources to better meet these needs. The survey is anonymous and any contact information that you provide will be kept separate from your survey responses.

The survey should take less than 10 minutes to complete. **Deadline to participate is Jan. 18.** If you have any questions, please contact info@paautism.org.

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Songwriter's Internship Leads to Sesame Street

(Story provided by Keystone Autism Services)

Can you tell me how to get to Sesame Street? Cody Landis, a participant in the Adult Community Autism Program (ACAP) can! He recently journeyed to New York City to learn about how the famous show is produced.

Since he was 4 years old, Cody has been following Steven Courtney, a singer/songwriter who has performed more than 6,200 concerts and recorded 30-plus full-length albums. Courtney is especially known for creating children's music and family entertainment. Cody aspires to be a children's songwriter as well. Cody's job developer set up a tour of Courtney's music studio and arranged a short-term internship with the musical mentor, who shared his experience in submitting songs for use on Sesame Street.

When news of this collaboration was shared with a Keystone Autism Services Board member, it led to further networking with a contact at Sesame Street's New York City studio. A tour was arranged.

After touring the set and meeting his favorite characters, Cody sat down with the music director and was given a sneak peek of the show's Thanksgiving song in the Macy's Thanksgiving Day Parade.

Thanks to Cody's recent internship with Courtney, Cody was able to identify the different elements of the multi-track recordings used by the show.

Cody plays harmonica, guitar, and a computerized drum machine to accompany the lyrics he writes. In the future, Cody hopes to continue writing children's music and collaborating with Steven to pursue a career that will complement his musical talent.



Cody Landis recently visited the set of Sesame Street as part of his internship with singer/songwriter Steven Courtney.

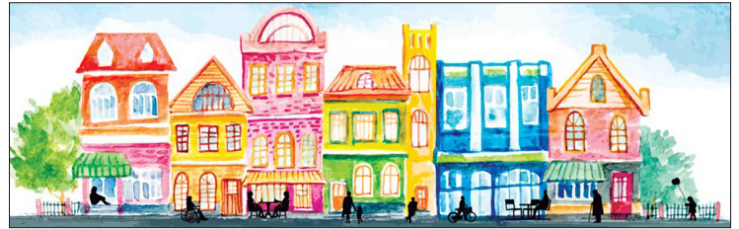
PA ABLE Savings for Disability-Related Expenses

Since launching the PA ABLE Savings Program almost two years ago, the Commonwealth of Pennsylvania has helped people with disabilities to save more than \$10 million for disability-related expenses. You or someone you know may be able to save, while maintaining important benefits as part of your PA ABLE account. A complete list of qualified disability-related expenses may be found in the PA ABLE Savings Program disclosure statement (available at PAABLE.gov or by calling 855-529-2253). Additionally, savings in a PA ABLE account may be deducted from Pennsylvania state income tax. Contributions to a PA ABLE account up to \$15,000 per person can be deducted from Pennsylvania state income taxes for 2018.



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The Arc of Washington Co. Launches Visual Project

The self-advocates who meet monthly at The Arc of Washington County know that a picture can paint a thousand words. Their hope is that the words featured in their ongoing Photo Voice project help proclaim, *"We Belong."*

We Belong showcases photographs, taken by members, and paired with impactful messaging they choose. The Arc of Washington County loaned cameras to self-advocates who did not have their own.

The photographers explored their community, took photographs and then presented their photos to the group via projector to share the meaning behind them.

The Rev. Sally Jo Snyder from the Consumer Health Coalition in Allegheny County spearheaded the project and introduced it to the self-advocates. Photographs were featured in the *We Belong* 2018 calendar and displayed at various locations during the year. Temporary exhibits also were held at various locations, including local libraries, hospitals, malls, and municipal buildings. Some continue to be displayed year round at locations such as local legislators' offices and the County building.

The focus for the first self-advocates' project was taking pride in the community, featuring what they liked and didn't like, and things they would like to see changed. The overall message of *We Belong*, however, is that disabilities are not what defines a person.

The topic for this year's visual project will be on "Transportation and Accessibility."

The self-advocacy group meets the fourth Thursday of each month and is open to the entire community, including self-advocates, providers, and everyone/anyone yet the main objective is on empowering individuals to use their voice. A self-advocate leadership group meets weekly in Houston, Pa., to discuss topics of concern, compile information for the *We Belong* newsletter, and to create trainings to present to direct support professionals as well as other self-advocates. Contact The Arc of Washington County at (301) 733-3550.



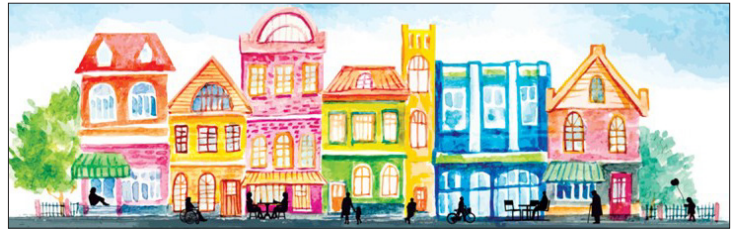
"We are people, not disabilities."



**"A library is one of the very best things a community can have!
I love to read!"**

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Lifesharing Provider Spotlight: Southeast Region

In the next few newsletters, ODP News will be highlighting winners of the Excellence in Lifesharing Awards, featuring providers from our four regions. This month we highlight Bennie Council, SPIN, Inc. in the Southeast Region.

Bennie and Michael have been sharing their lives for more than 20 years. Bennie's nomination letter reads as follows:

"Throughout life's good times and bad, they have stuck together. SPIN, a provider of supports for people with autism and developmental disabilities, and inclusive early childhood education in the Philadelphia/Lehigh Valley area, couldn't ask for a better Lifesharing partner than Bennie. He does anything for Michael, anything to complete his responsibilities as a Lifesharing partner and SPIN, in return, tries to give Bennie and Michael every support they need to continue their life of possibilities."



Pictured: Dwanae Bowens, Kathy Smith, Deputy Secretary Kristin Ahrens, Bennie Council, and Michael Hendy.

FDA Finalizing Ban on Electric Stimulation as Treatment

The FDA is finalizing [a ban on electrical stimulation devices](#) used to treat self-injurious or aggressive behavior. The FDA has determined that these devices present substantial and unreasonable risks of illness or injury that cannot be corrected or eliminated by labeling or a change in labeling. In the proposed rule, FDA sought comments on its proposal to ban these devices and on associated issues. The comment period ended in 2016.

Pennsylvania prohibited these devices decades ago as part of Chapter 6400 of the PA Code, but they are permitted in other parts of the country. Evidence exists to show the practice is painful and traumatizing to individuals who have been shocked. [NASDDDS signed on to a letter](#) to the Secretary of Health and Human Services and leadership at the FDA in support of banning these devices in 2016.

Get Free Access to Braille and Talking Books

The National Library Service for the Blind and Physically Handicapped, or NLS, provides braille and talking books free to people who cannot see to read or handle printed materials. Its books, magazines, and music materials circulate to eligible patrons through regional and local libraries. NLS is a part of the Library of Congress. [You can learn more and apply for the service online.](#)

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CDC Reports Increase in Prevalence of ASD

In April, [the Centers for Disease Control and Prevention \(CDC\)](#) released current estimates of autism prevalence, which show a marked increase in Autism Spectrum Disorder (ASD). According to the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network, 1 in 59 children are estimated to have ASD. This represents an increase from the 2014 estimates of 1 in 68. According to Alycia Halladay, chief science officer at the Autism Science Foundation, as quoted in a [Disability Scoop article](#), the true prevalence rate is probably somewhere between 1 in 40 and 1 in 59.

A separate study using the 2016 National Survey of Children's Health (NSCH) estimates that the prevalence of U.S. children with a parent-reported Autism Spectrum Disorder (ASD) diagnosis is 1 in 40, with rates of ASD-specific treatment usage varying by children's socio-demographic and co-occurring conditions. The study, published in the journal, *Pediatrics*, used parent-reported information on whether children ever received an ASD diagnosis by a care provider, their child's current ASD status, health care use, access and challenges, and methods of treatment. [Read the Pediatric article online.](#)

To address the increase in prevalence, ODP's Consolidated and Person/Family Directed Support (P/FDS) waivers, effective July 1, 2017, expanded eligibility to include people with autism. Also, expanded resources in the FY2017-18 budget provided individuals with ID and/or autism access to Targeted Support Management (TSM) that can help them with life planning and accessing community resources. **(Please see "ODP Continues Progress on Addressing Waiting List" on page 1)**

Information, Upcoming Events, & Training

PaTTAN Welcomes Transition Conference Proposals

The Pennsylvania Training and Technical Assistance Network (PaTTAN) announces a Call for Proposals for the 2019 PA Community of Practice Transition Conference - Ignite the Future! Sparking Engagement in Career Readiness on July 17-18, 2019 at Penn State Conference Center, State College PA. The conference planning team is requesting proposals from individuals or groups to present on a wide array of subject matter including: navigation of the education system and transition process for students and families; current research; practical applications for the classroom and the job site; identification and development of support systems; and setting a personalized vision for a meaningful life. Proposals must be submitted via [online application](#) by January 30, 2019. Contact paconf2019@gmail.com.

Wanted: Voters With Disabilities

During the week of January 22, the Department of State will hold an examination of the Hart Verity Voting 2.3 voting system. The examination is open for the public to observe. Voters with disabilities are needed to test the accessibility features. Appointments can be scheduled for the days and times listed below. This will take 30-60 minutes. Testing takes place at the Capitol Complex - Finance building, G-24B 613 North Street, Harrisburg. Contact Sindhu Ramachandran sramachand@pa.gov or call at 717-525-5743.

Available Dates:

- Tuesday, January 22 from 1 pm until 5 pm
- Wednesday, January 23, from 9 am until 5 pm
- Thursday, January 24, from 9 am until 5 pm

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Summary of ODP Communications Issued December 2018, With Links



1. 103-18: [ISAC Action Plan for Sexual Abuse Prevention Now Available Online](#)
2. BAW 18-26: [AAW Supports & Services Directory \(December 2018\)](#)
3. 104-18: [Medication Administration Training Program Scheduled System Outage](#)
4. 105-18: [Expectations for Supports Coordinators Regarding the Right to Be Free From Abuse](#)
5. [ODP/ASERT Training Needs Survey](#)
6. 106-18: [Final Public Notice For Fee Schedule Rates and Department-Established Fees For FY 2018-19](#)
7. 107-18: [College of Direct Support Administrative Overview and Refresher](#)
8. [ODP Newsletter December 2018](#)
9. BAW 18-25: [IT Employment Positions Through Autism2Work](#)
10. 108-18: [Home & Community-Based Services Settings Provider Self-Assessment Update 5](#)
11. BAW 18-27: [Adult Autism Waiver \(AAW\) Amendment Delay](#)
12. 109-18: [Fair Hearing Request Form & Instructions](#)

The Arc of PA Names New Executive Director

Sherri Landis is The Arc of Pennsylvania's new Executive Director. Sherri began her tenure at The Arc of PA on January 7, 2019. Ms. Landis fills the position following the retirement of Maureen Cronin who served 7 years as The Arc of PA's Executive Director.

Collins and Casey Propose Guardianship Accountability Act

On November 29, 2018, Senator Susan Collins (R-ME) and Senator Bob Casey (D-PA) introduced the [Guardianship Accountability Act](#). According to the National Association of State Directors of Developmental Disabilities Services, the bill was proposed in response to a report from the Senate Special Committee on Aging, and draws on already existing policy structures focused on elder justice. The legislation would require criminal background checks for guardians and call for greater scrutiny in regards to money management.

We'd love to hear from you.
Email us at RA-PWODP_OUTREACH@pa.gov with news or suggestions!