



The Advocacy Insider

Winter, 2018

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Message From The Chairperson

The new year brings new changes as we enter 2018. One of the biggest changes is that the Intellectual/Developmental Services system is now available to people with just an autism diagnosis. If someone has an autism diagnosis without an intellectual disability diagnosis and wants to register for Supports Coordination, they must have a diagnosis of autism before age 22, require significant assistance in 3 or more areas of adaptive functioning, and be enrolled in Medical Assistance (Medicaid).

Another big change is the approval of the Community Living waiver, which has a budget cap of \$70,000. The Office of Developmental Programs (ODP) approved 1,000 of these waivers to be distributed to people across the state. By doing so, they've created 1,000 more spaces for those in need of a PFDS waiver.

On 1/11/18, The Arc Alliance hosted a Montgomery County Legislative Breakfast where staff and families had a platform to voice their concerns and share their stories. You can find more information about the Legislative Breakfast inside this newsletter. There were also breakfasts in Bucks County on 2/1/18 and Berks County on 2/2/18. This spring, just like in previous years, staff will attend "Hill Day" in Washington D.C. This provides individuals, families, and staff with an opportunity to express their needs and feelings regarding the services system, funding, and other areas to legislators.

The Arc Alliance Supports Coordination continues to advocate for what's most important, which are the people and families they support.

Sincerely,
Dan West
Board Chairperson
The Arc Alliance Advocacy Services

Making the Holidays Brighter



As mentioned in the previous issue of *The Advocacy Insider*, the *Battle of the Bands Rock & Bowl* event in October 2017 raised money for the agency to improve the lives of people supported by The Arc Alliance.

The Supports Coordination department received a portion of the proceeds, totaling \$1,000. This money was used to purchase gift cards from TD Bank. The gift cards were hand-delivered in December 2017 to 40 people in need across the region. Thanks again to everyone who participated in the *Battle of the Bands Rock & Bowl* event.

Stay tuned, because this year's *Battle of the Bands Rock & Bowl* fundraiser event is already being planned!

Achieve with us.[®]

Upcoming Events

- ◆ The Arc Alliance's Chat n Chew- 2/20/18: ESY, 2/27/18- Behavioral Issues, 3/20/18: ELS, 3/27/18: Coaching
Location: 3075 Ridge Pike, Eagleville, PA 19403 Visit www.thearcalliance.org or call 610-265-4700 for details or to RSVP
- ◆ 3/2/18, 10-11am: Project SEARCH at Drexel University. Learn about the youth transition-to-work internship program.
Location: Drexel University's Barns & Noble- Chestnut St & S 33rd St, Philadelphia, PA 19104
- ◆ 3/12/18-4/27/18: Philadelphia Museum of Art show "Philadelphia: A Spectrum of Experiences"
Location: 2600 Benjamin Franklin Pkwy, Philadelphia, PA 19130
- ◆ 3/13/18, 10am-1pm: MAX Association's Voter Registration Forum. Free event! Register to vote and learn to use voting machines.
Location: The Arc Alliance- 3075 Ridge Pike, Eagleville, PA 19403
- ◆ 3/18/18, 12-2pm: Down Syndrome Carnival Day- free event to raise awareness and gather information, carnival games, activities, resources
Location: Spring Valley YMCA- 19 West Linfield-Trappe Rd. Limerick, PA 19468
- ◆ 4/19/18, 6-7pm: The Arc Alliance's Supports Coordination Information Night- Free event for those wanting to receive Supports Coordination
Location: The Arc Alliance- 3075 Ridge Pike, Eagleville, PA 19403 Call 610-265-4700 x7231 to RSVP (not required)
- ◆ 4/14/18, 10am-1pm: Autism Family Fun Day
Location: Spring Valley YMCA- 19 West Linfield-Trappe Rd. Limerick, PA 19468
- ◆ September-June, 6-8pm: Sibshop- Open to 8-12 year olds who have siblings with disabilities. Includes games, discussions, and activities.
Location: Melmark- 2600 Wayland Road, Berwyn, PA 19312 Call: 610-325-2937

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Did you know?

There are free workshops on renters' rights and responsibilities Monday-Friday at 12:30pm and Tuesdays & Wednesdays at 6pm. Located at The Land Title Building- 100 S. Broad St. Philadelphia, PA. Call 215-940-3900 for details.

The Arc Alliance

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Visit Us Online!

<http://thearcalliance.org/>

<https://www.facebook.com/arcalliance/>

Be Aware and Take Care

February usually makes people think about Valentine's Day and love, but did you also know that it's *National Heart Month*? People are encouraged to make healthy choices and commit to lifestyle changes that will result in a decreased likelihood of heart disease and stroke. Even small changes can make a big difference.

If you currently smoke, quitting can decrease your risk of stroke, narrowing of blood vessels, and heart disease. You are never too old to quit smoking! Even if you aren't sick, it's still important to see your doctor for regular checkups, such as your annual physical. You can work with your doctor to set goals, and your doctor can answer any health questions you may have. Adding daily exercise into your routine strengthens your heart and decreases risk of heart disease. Don't know where to start? Try walking for 15 minutes, 3 times per week. Making healthy food choices such as vegetables, fruits, and whole grains provide heart-healthy fuel for your body. You can also swap out salt for various herbs and spices. If you currently are prescribed blood pressure medication, be sure to take it on time. If you're experiencing side effects, then talk with your doctor.

Also, March is *Intellectual and Developmental Disabilities Awareness Month*, which was established in 1987. In the United States, it's estimated that approximately 7 million people have an intellectual or developmental disability. The main message is to help society understand that people with disabilities are valuable, contributing members of society. People with disabilities need to be provided with encouragement and opportunities to lead a fulfilled life, just like anyone else.

If you or someone you know is looking to become involved in the community or learn new skills, there are several options out there. Here are just a few:

- The **Office of Vocational Rehabilitation (OVR)** completes employment assessments and helps people find competitive employment. Your Supports Coordinator can complete the necessary paperwork to apply for OVR.
- Social groups like **Best Buddies** and **Fantastic Friends of Suburban Philadelphia** plan outings in the community. Contact Best Buddies by calling 1-888-604-7376 and Fantastic Friends by calling 908-415-5869 .
- **Rejoicing Spirits** offers church services across the southeast region that are in an open, nonjudgmental environment where people can express themselves. To find a host church near you, call 402-896-3884. In Berks County, the **Festival of Faith** offers dinner and church services to people with disabilities on a seasonal basis. Call 610-375-6108 for details.
- Each county has a **Center for Independent Living**, which provides free training to those wanting to learn self-advocacy and new skills. To find a center near you, visit <http://cilcp.org> or call 713-520-0232.
- Ascend has a calendar of community events, which can be found on www.paautism.org/transitionagecommunication/Calendar. This calendar highlights social events all around PA.

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Looking For Supports Coordination Services? You'll Need:

*A diagnosis of intellectual disability, autism, or developmental disability and a medical assessment stating level of need.

Then, Contact Your County's Intake Office:

Berks 610-236-0530 Bucks 215-444-2800

Chester 610-344-6265 Montgomery 610-278-5666

Philadelphia 215-685-4677

The Arc Alliance

We strive to support families and individuals of all ages with developmental disabilities and other disabilities by providing exceptional personal services, support and training; inspiring hope, potential, and well-being; ensuring valued life experiences and treatment expected by all people.

Individual Spotlight- Isabel Rodriguez

Isabel moved to Pennsylvania from Massachusetts a little over a year ago after her residential home closed. After arriving in Pennsylvania, she was assigned a Supports Coordinator, received a PFDS waiver, and lived with some family members. When Isabel's SC visited her at day program, Isabel was brave enough to share details of her unsafe living situation. She advocated for herself, and stated that she didn't want to return home. Isabel and her SC worked alongside the SC Supervisor, West Whiteland police department, Adult Protective Services, and Chester County Administrative Entity to ensure that she moved into a safe home. After moving, Isabel set clear boundaries with her family, and continues to maintain these boundaries. She decides with whom she wants contact and under what conditions. Her entire team supports her self-advocacy, especially since her situation was so difficult.

On November 12, 2017, Isabel won the "Self-Advocacy Award" at the Chester County Department of Intellectual Disabilities' Self-Determination Awards Luncheon. Over the past year, she has encountered a difficult, but very self-determined journey. Isabel continues to be an extraordinary role model for self-advocacy. Congratulations to Isabel for speaking up for herself and on receiving her award!



Isabel receiving her Self-Advocacy award

Montgomery County Legislative Breakfast

On January 11, 2018, families, people supported by The Arc Alliance, legislators, legislative assistants, and The Arc Alliance staff gathered together to discuss a variety of topics such as waiver funding, obtaining competitive employment, burden of proof laws in school districts, the waiting list for waiver, and state institutions. Many families had concerns regarding businesses not hiring people with disabilities, difficulty in obtaining independent or supported housing options, and focusing on people's disabilities instead of their abilities.

Many families had the opportunity to share their stories, which included both gratitude for the supports they are receiving and frustration due to needing more services and funding. One family includes a father in his 80s, and he and his wife can no longer care for their adult child due to their own health concerns. Another attendee described having to "gladiate" (i.e. fight for services, beyond advocating) for her son to receive the supports he needs. Someone else expressed the concerns she has about her 20 year old son graduating this June, whether or not he'd receive waiver upon graduation, and that the PFDS waiver cap isn't providing a full week of services. One family spoke about the differences in the IDD service system in other states and how it compares to Pennsylvania; some other states provide a waiver right away, but their son is on the Pennsylvania waiting list. Another family has an adult daughter whose diagnosis causes behaviors. Her daughter has been on the waiting list for 13 years and will be graduating high school next year. Someone else spoke about a wonderful employment program, in which her son is enrolled. Several families expressed how thankful they were to receive waiver funding.

You can make your voice heard too, by calling your local legislators and congress-people to share your experiences and self-advocate for services and funding. Find your local and state representatives by visiting www.legis.state.pa.us online or call 202-224-3121.



Some legislative breakfast attendees