

# Family Forum

A QUARTERLY NEWSLETTER PRODUCED BY VISION FOR EQUALITY

## GOVERNOR TOM WOLF'S 2017-2018 BUDGET ADDRESS

On February 7, 2017 Governor Tom Wolf delivered his 2017-2018 Budget Address before a joint session of the General Assembly at the State Capitol in Harrisburg. The Governor took a different approach to this year's plan.

The 2017-2018 budget does not involve any broad-based tax increases, he instead suggested closing the deficit by making the state's government more efficient. This includes a \$2 billion spending cut for government agencies, and the merger of the Departments of Aging, Drug and Alcohol Programs, Health and Human Services into one department.

Education seems to still be one of Governor Wolf's priorities, his new proposal includes investing a little over \$200 million in schools. However, this includes \$215 million increase in spending for basic and our own special education community.

In regards to Intellectual Disability and Autism funding, the

Governor's proposal includes some of the following highlights:

- \$54.7 million to provide for rate increases from the renewal of the waiver program;
- \$109.7 million to provide for increases in utilization and costs;
- \$15.4 million for the Community Living Waiver to create a new program for family caregivers to ensure 1,000 individuals currently on the waiting list can continue to live at home;
- \$8.5 million to expand services for individuals with disability to provide home and community-based services for 820 students graduating from special education - a figure that is projected to cover every student this coming year;
- Funding to begin to transition individuals from the Hamburg State Center to Home and Community-based Services;
- \$9.3 million for new

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## BE A PART OF THE SOLUTION



Gov. Tom Wolf at Budget Address

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To include an event or submit an article for publication, please email: [visionforequality@visionforequality.org](mailto:visionforequality@visionforequality.org)

# PHILADELPHIA COORDINATED HEALTH CARE (PCHC) SOUTHEASTERN REGION HEALTH CARE QUALITY UNIT: NEW INITIATIVE INDIVIDUAL TRAININGS ON IPADS

*By Philadelphia Coordinated Healthcare*

Philadelphia Coordinated Health Care's (PCHC) mission is to enhance access to community physical and mental health care through education, public health outreach, advocacy, and empowerment as well as to improve health care outcomes for individuals with an Intellectual disAbility (ID).

PCHC has a new initiative that introduces iPads to individuals, while teaching them various topics of interest. We have been to a few agencies thus far and are looking to expand our initiative even further. The topics provided are:

- Social Media
- Winter Safety
- Summer Safety
- Emergency Preparedness
- Friendship
- Understanding Mental Health Challenges
- Preventing Falls



The trainings are delivered in a one-on-one format with a trainer where the individual would have their undivided attention to meet any accessibility needs. We recommend training a group no larger than 15-20 individuals at a time.

The feedback from individuals has been overwhelmingly positive and always ends with request for new topics and for us to come back out to train again.

To request the Individual iPad Trainings, please contact Peggy Cragin at [pcragin@pmhcc.org](mailto:pcragin@pmhcc.org) or Briana Downs at [bdowns@pmhcc.org](mailto:bdowns@pmhcc.org).

Feel free to ask any questions about the trainings or request for us to come out to your site to provide training. Go to [www.pchc.org](http://www.pchc.org) to check out our training topics!



## Save the Date!

### **Points of Transformation Awards Ceremony**

Thursday, September 28, 2017

Community Behavioral Health

801 Market St., Room 1154

*For more information, contact Wendy Williams at [wendywilliams@phila.gov](mailto:wendywilliams@phila.gov)*

## Philadelphia Parent Support Groups



Philadelphia Parent Support Groups (PPSG) Planning Committee Representatives meeting with Dr. Arthur C. Evans and Alma Jean Taylor from Philadelphia Department of Behavioral Health and Intellectual disAbility Services on February 10, 2017 to wish them good luck in the future and that they will be missed. Dr. Arthur Evans retired from his government position, but he moved to Washington D.C to become the CEO for the American Psychological Association. Alma Jean Taylor also retired from her position in February. The PPSG Planning Committee Representatives represent Parent Support Groups throughout the city.

## **SAVE THE DATE** **JUNE 17, 2017**



- 10a Opening ceremonies and performance  
National Constitution Center
- 11a Disability Pride Parade to City Hall.
- 11:30 Informational tables at Dilworth Plaza
- 12P Speeches, Performances, and  
Children's Activities
- 3:45 Closing Ceremonies

[www.facebook.com/DisabilityPridePhiladelphia](http://www.facebook.com/DisabilityPridePhiladelphia)

# GOVERNOR TOM WOLF'S 2017-2018 BUDGET ADDRESS

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- community participation services from the renewal of the waiver program;
- \$782,000 in Autism Intervention and Services to provide targeted services management state plan services to 1,545 individuals on the waiting list;
- \$642,000 in Autism Intervention and Services for Home and Community-based Services for 50 additional adults with Autism spectrum disorder; and

- \$230,000 in the ID-Community Base Program to provide targeted services management state plan services to 455 individuals on the waiting list.

Now that the 2017-2018 budget has been proposed, it is up to the legislators to approve it in the upcoming months.

## DIRECT SUPPORT PROFESSIONAL STORY- RENZO & JOE

Renzo was left with a life-long intellectual and physical disability after he was deprived of oxygen as a 14-year old due to a pre-existing heart condition. His everyday needs – like the tens of thousands of people in Pennsylvania with Intellectual disAbility or Autism – are supported by Direct Support Professionals (DSPs). Joe, one of Renzo's DSPs, supported Renzo for over seven years. For Joe, working with Renzo is more than a job. "Family, I think we are," said Joe with a broad smile. "We did a lot together and spent a lot of time with one another." Pausing, he added, "it is one of those jobs, when something goes wrong with your car, there goes half your savings."

Direct Support Professionals support every need for the individuals they serve. This includes: medication management, hygiene, nutrition, community participation, job support, transportation, and receiving new trainings as the needs of the people they support change.

Yet DSPs in Pennsylvania are paid poverty level wages at 25-50% below a living wage. At a time when thousands of Pennsylvanian's with Autism or Intellectual disAbility are waiting to receive services, nearly ten thousand DSPs leave this workforce every year because the wages aren't competitive with other jobs like grocery store clerks and gas station workers. Joe was one of those DSPs.

Renzo's mother, Cheryl, said "Joe came to us and was really heartbroken. Joe looked at his own life and he said, 'I'm renting a room in someone's house and struggling to make car payments, and that's all I

have.'" Eventually, Joe had to leave his job so he could support himself financially. It deeply impacted Renzo and his family.

The Commonwealth of Pennsylvania is the sole funder of DSP wages. The Commonwealth hasn't funded a rate increase for Intellectual disAbility and Autism services in a decade, causing DSP wages to flatline. Without paying DSPs a living wage, relationships like Renzo and Joe's will continue to be torn apart by this workforce crisis.

What life would you choose for yourself or your loved one? What quality of life do they deserve? That life will only be brought to them through a well-trained, committed, stable DSP workforce. We can only address the workforce crisis by asking Pennsylvania's government to pay rates that will fund a living wage for DSPs. You can visit [FixTheDSPCrisis.com](http://FixTheDSPCrisis.com) for more information and to find out how you can help.

Quotes have been retrieved from "Fix The DSP Crisis," PAR (Pennsylvania Advocacy and Resources for Autism and Intellectual disAbility).



Joe and Renzo

# PENNSYLVANIA WAITING LIST CAMPAIGN FACT SHEET SPRING 2017

By PA Waiting List Campaign



The Pennsylvania Waiting List Campaign's goal is to end the devastation of Waiting Lists for persons with Intellectual disAbility (ID) and Autism who are in need of services through the Pennsylvania Office of Developmental Programs (ODP). These people are entitled to institutional care but choose to wait for Home and Community-based Services through the ODP Waiver Programs.

## HOW MANY PEOPLE WITH INTELLECTUAL DISABILITIES AND AUTISM ARE WAITING?

<b>TOTAL ID WAITING LIST = 13,420</b>	<b>TOTAL AUTISM WAIVER INTEREST LIST = 1,925 (AAW and ACAP. Excludes ages 20 and under)</b>
Emergency (need services immediately) = 4,594	Priority 1 (receiving no services) = 1386
Critical (need services within 2 years) = 5,357	Priority 2 (receiving some services) = 539
Planning (need services within 5 years) = 3,469	

### ***What do we know about the people with ID on the waiting list?***

- Most people are living with and being cared for by their family (85%) and some are living with friends or on their own (7.7%).
- Of the 11,378 people living with families, only 1,917 are waiting for a 24/7 staffed group home. Services most requested by people living with families are individual supports like Habilitation, Transportation, Employment and Respite.
- There are 700 individuals in Emergency Need and 1,705 in Critical Need who have caregivers over 60 years old.
- There are 677 individuals who are 21 years old and are losing EPSDT and School Services. They need services to successfully transition from school to adult life in the community.

### ***What do we know about the "interest list" for Autism services?***

- People are served on a first come, first served basis and the need for services for adults with Autism will continue to grow. The Census numbers indicate dramatic increases over 15 years, from 17,075 people in 2015 to 73,592 in year 2030.

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# THE FAMILY CORNER

*This section of the Family Forum is dedicated for the support of parents, caregivers, relatives, close friends and members of the family.*

## PARENT TO PARENT OF PENNSYLVANIA

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*By Parent to Parent*

Parent to Parent of Pennsylvania links families of children and adults with disAbilities or special needs to a volunteer peer support parent for the purposes of support and information.

If a family is interested in Parent to Parent of Pennsylvania's free and confidential services, they may contact them by phoning toll our NEW PA free number which is 1-888-727-2706 or filling out the required information online at [www.parenttoparent.org](http://www.parenttoparent.org) and going to the link labeled, "\_Get Matched\_"

Upon receipt of the required information a regional coordinator will contact you to speak to you about your child/adult's disAbility, special need or concerns.

A parent/family member can be matched for physical disAbilities, developmental disAbilities, special health care needs, behavioral/mental health concerns, foster care or adoption and educational issues. The regional coordinator will then look for the best support parent for you by accessing their database of over 1200 volunteer peer support parents.

Parent to Parent is funded through Tuscarora Intermediate Unit by the Pennsylvania Department of Public Welfare, Office of Child Development and Early Learning, and the Pennsylvania Department of Education.

Additional Resources (Genetic Alliance, Parent to Parent USA, and Family Voices):

The Advocacy ATLAS, which is a joint project of Genetic Alliance, Parent to Parent USA, and Family Voices, is a compilation of over

200 resources and go-to places where families can access information and tools on advocacy and leadership. To access the on-line toolkit (Atlas), click on the following URL: [www.geneticalliance.org/advocacy-atlas](http://www.geneticalliance.org/advocacy-atlas).

# MY ODP TRAINING AND RESOURCE CENTER NOW LIVE!

ODP's new Training and Resource Center is now live.

*Below, find some useful information to assist you in registering and navigating the site:*

## Access and Registration

The new site can be accessed at the following web address: [www.myodp.org](http://www.myodp.org). Anyone can create an account on the site, but it is not necessary to do so in order to view most of the content. If you do not wish to create an account, you can login as a guest by clicking on the green "Login as Guest" button, located on the Login Page. Logging in as a guest will provide you with access to many of the resources located on the site. You will need to set up an account in order to access courses with certificates.



MyODP.org homepage

## What information can I find on this site, and where can I find it?

While the majority of the trainings, resources and communications hosted on this site have been developed for professionals who support participants within one or more of ODP's programs, anyone can review the information, including individuals and families.

At the top of the Home Page are a number of tabs. *Below is a description of what you can find under each tab.*

- **Everyday Lives:** This section features the values that guide the Office of Developmental Programs and highlights stories about Pennsylvanians with disAbilities.
- **Training:** This section contains virtual trainings developed by ODP. While the training content is available for everyone, the primary audiences

for these trainings are professionals who need to complete the courses as a training requirement.

- **Resources:** Examples of information you can find in this section include documents, forms, and recordings of public webinars and conference sessions that have been developed or presented by ODP.
- **Communications:** This section contains all of the communications that are sent out by ODP. They are organized by who issued the communication, and you can search for communications by topic, audience, subject, date issued, etc.
- **Upcoming Events:** This section contains information about upcoming trainings and events hosted by ODP. This is also the area where you can register for face-to-face trainings presented by ODP. If there are no upcoming events being offered at this time, this will be noted on the page.
- **ODP Training Partners:** Through this tab, you can connect with ODP's Training Partners for more resources and trainings on topics that you are looking for (transition-age resources, employment, etc.):

**ASERT (Autism Services, Education, Resources, and Training):** The ASERT Resource Center is a statewide initiative that provides information for individuals with Autism, their families, and the professionals who support them.

**CDS (College of Direct Support) -** The College of Direct Support (CDS) is a nationally recognized web-based training curriculum that provides learning opportunities on many topics of importance to people with developmental disAbilities and those who support them.

**HCQU (Health Care Quality Unit) -** The Health Care Quality Units (HCQUs) work to support and improve the health information and knowledge for the Intellectual disAbilities community service system by building capacity and competency within the physical and behavioral health care systems as well as the stakeholders of the ID system.

At the bottom of the Home Page are three boxes that will rotate to feature different ODP initiatives and advocacy/support groups.

## Need Help?

Contact the MyODP.org Help Desk for support using this site.

Website Technical Support Hours of operation: Mon-Fri 7am-5pm (ET)

Phone: 844-332-2121

Email: support@myodp.org

# PENNSYLVANIA WAITING LIST CAMPAIGN FACT SHEET SPRING 2017

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## HOW DO WE ADDRESS THE CRISIS IN THE COMMUNITY?

Waiting List Initiative	Number of People Served	Estimated Cost in State Dollars for Community-Based Waiver Services First Year	Cost for Public Institutional Placement per year (Entitlement)
<b>Emergency List for ID</b>	4,594 people for 6 months	\$81.4 Million	\$1.8 Billion
<b>Priority 1 List for Autism</b>	1386 people for 6 months	\$18.3 Million	\$538 Million
<b>High School Graduates 2017</b>	820 students for 9 months	\$6.9 Million	\$318 Million
<b>High School Graduates 2018</b>	820 students for 1 month	\$767 Thousand	\$318 Million

Each person on the Waiting List and Interest List *has waived their right* to institutional care, saving the Commonwealth and the taxpayers billions of dollars over their lifetime, yet they languish on long waiting lists for Home and Community-based Services. If they choose to exercise their entitlement, the state would be required to serve them immediately and at a much higher cost in both dollars and freedoms. We need to close our State Centers and reinvest the funding into a robust, flexible, and responsive Community Based system.

Individuals and their families need assurance and hope that their needs will be met in their homes, with meaningful work opportunities and the basic supports they need to experience and enjoy Everyday Lives in the community of their choosing.

# PHILADELPHIA PARENT SUPPORT GROUPS

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**Abriendo Caminos a los Latinos con Familias Exceptionales  
“Opening Paths for Latinos with Exceptional Families”**

Second Wednesday of each month except for Holidays, July and August

**Time:** 10 am -1 pm

**Place:** COMHAR, Inc. 3825 Whitaker Avenue, Philadelphia , PA 19124

**Representative:** Marisol Ramos (267) 777 - 1291

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**Community Support Group Central/South Central Philadelphia**

Fourth Thursday of each month except for Holidays, July and August

**Time:** 10 am-12 noon

**Place:** Vision for Equality, Inc. The Cast Iron Building,  
718 Arch Street, 6N, Philadelphia, PA 19106

**Representative:** Sharon Duckett (215) 298 - 2796

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**Northeast Support Group Navigated by Families**

Third Thursday of each month except for Holidays, July and August

**Time:** 10:30 AM – 12:30 PM

**Place:** Wendy’s Restaurant

501 Adams Avenue

Philadelphia, PA 19120

**Representative:** Joan Nelson (267) 642-1321

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**NW Family Support Group Germantown, Mt. Airy, Chestnut Hill**

Second Tuesday of each month except for Holidays, July and August

**Time:** 5:30 pm – 7:30 pm

**Place:** Northwestern Human Services Center, 27 E. Mt. Airy Avenue, Philadelphia, PA 19119

**Representative:** Verna Edwards (215) 248 - 4415

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**Roxborough Parent Support Group Roxborough**

Last Thursday of each month except for Holidays, July and August

**Time:** 5:30 pm-7:30 pm

**Place:** Andorra Library, 705 East Cathedral Road, Philadelphia, PA 19128

**Representative:** Carol Costello (215) 487 - 1240

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**There’s A Place for Us Parent Support Group North Philadelphia**

Fourth Friday of each month except Holidays, July and August

**Time:** 10 am -12 noon

**Place:** Warren E. Smith Health Center, 1315 Windrim Avenue, Philadelphia, PA. 19140

**Representative:** Cleo Dupree (215) 329 - 5219

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**West Philadelphia Parent Support Group West Philadelphia**

Second Monday of each month except for Holidays, July and August

**Time:** 6 pm-7:30 pm

**Place:** The Free Library of Philadelphia, 56th and Haverford Avenue, Philadelphia, PA 19139

**Representative:** Doreatha Davis (215) 303 - 3501

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# INSTITUTE ON DISABILITIES AT TEMPLE UNIVERSITY NAMES A NEW EXECUTIVE DIRECTOR

*By Institute on Disabilities at Temple University*

The Institute on Disabilities at Temple University, College of Education, has announced the appointment of Celia S. Feinstein as Executive Director, beginning on December 1, 2016. Ms. Feinstein has been a staff member and leader of the Institute for more than 35 years serving in a variety of roles, most recently as Co-Executive Director overseeing all leadership development programs and policy activities at the local, state and national levels. In addition, she has led the Institute's research and evaluation, and quality assurance initiatives, including Independent Monitoring for Quality, a statewide quality of life assessment for people with intellectual disabilities receiving support through Pennsylvania's Office of Developmental Programs.

For the past several years, Celia has shared the Co-Executive seat with Amy S. Goldman. Upon Ms. Goldman's retirement from Temple University on November 30, 2016, Celia was appointed Executive Director.

In her new role, Celia will continue to oversee the Institute's leadership development, quality of life, education and research programs, but now adds the leadership of Pennsylvania's Initiative on Assistive Technology (PIAT), Pennsylvania's Assistive Technology Act Program.

Celia brings to the position a wealth of knowledge and experience with renewed focus and energy. "I know every member of our staff is dedicated to the Institute's mission of working with people with disabilities to share knowledge, change systems and society, and promote self-determined lives," Celia says.

The more than 25 active Institute programs address different aspects of learning, living, working and leading in our society. "Each initiative touches on our mission, one that I have worked toward for more than 30 years.

"I am confident that the Institute will continue to make significant progress in fulfilling the goals of our mission and that we WILL have a society where ALL people are valued and respected."



*Celia S. Feinstein, Executive Director of the Institute on Disabilities and AUCD Board President*

In addition to her appointment as Executive Director, on December 1, 2016, Celia began her year-long term as board president of the Association of University Centers for Excellence in Developmental Disabilities Research, Education and Service, the organization representing the University Centers for Excellence in Developmental Disabilities (UCEDD), Leadership Education in Neurodevelopmental and Related Disabilities (LEND programs) and Intellectual and Developmental Disabilities Research Centers (IDDRCs). The Institute is Pennsylvania's UCEDD, one of 67 across the country.

"I'm proud of the achievements made by the Institute, the College of Education at Temple University and AUCD and I am excited by the new opportunities and challenges that we will face in the next few years."



DREXEL UNIVERSITY

A.J. Drexel

Autism Institute



**Presented by the A.J. Drexel Autism Institute,  
Transition Pathways, & Autism Speaks**

## **Transition Town Hall**

**Saturday, June 17, 2017**

**9 AM – 12:00 PM**

*9:00 AM - Registration, Continental Breakfast & Resource Fair*

*9:30 AM - Panel Discussion*

*11:00 AM - 12:00 PM - Resource Fair*

Behrakis Grand Hall  
(entrance next to JOE coffee shop)  
3210 Chestnut Street  
Philadelphia, PA 19104

The Transition Town Hall will focus on the transition to adulthood for people with autism. The event is free and will include a moderated panel discussion, audience Q&A, a resource fair, and opportunities for networking.

*For more information contact  
[transitionpathways@drexel.edu](mailto:transitionpathways@drexel.edu)*

**[drexel.edu/AutismInstitute/events](http://drexel.edu/AutismInstitute/events)**



Life Course Outcomes  
Research Program

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**AUTISM SPEAKS®**



# Vision for Equality

Serving People with Disabilities and Their Families

718 Arch St., 6N, • Philadelphia, PA 19106 • [visionforequality.org](http://visionforequality.org)

T: 215 . 923 . 3349 F: 215 . 923 . 8075



## Disaster Readiness Tips for People with Developmental or Cognitive Disabilities

### Prepare Yourself



NATIONAL ORGANIZATION ON  
**DISABILITY**

Information from:

National Organization on Disability  
Emergency Preparedness Initiative  
77 Water Street, Suite 204  
New York, NY 10005  
Tel: 646-505-1191  
TDD: 711 Relay  
Fax: 646-505-1184  
E-mail: [info@nod.org](mailto:info@nod.org)  
<http://www.nod.org/emergency>

To be better prepared as a nation, we all must do our part to plan for disasters. Individuals with or without disabilities can lessen the impact of a disaster by taking steps to prepare before an event occurs.

This information is designed to help people with developmental and cognitive disabilities begin to plan for emergencies. Developmental and cognitive disabilities include disorders that may affect a person's ability to listen, think, speak, read, write, do math, or follow instructions. It includes people with dyslexia, and extreme difficulty in reading, and attention deficit hyperactivity disorder (ADHD), an inability to focus on necessary tasks. Some people with neurological disorders, such as Tourette's syndrome or the effects of a stroke, may also have developmental and cognitive disabilities. Although many people with these types of disabilities live independently, others, particularly those with significant brain disorders or severe developmental disabilities, may need assistance with nearly every aspect of daily living.

You can take small steps every day to become better able to survive an emergency. Read NOD's general brochure, "Prepare Yourself: Disaster Readiness Tips for People with Disabilities." Identify your resources, develop a support network, make a plan and create a **Ready Kit** and **Go Bag**. **Start Today to become better prepared, safer, and more secure.**

For more information and printable brochure:

Go to:

[http://nod.org/disability\\_resources/emergency\\_preparedness\\_for\\_persons\\_with\\_disabilities/](http://nod.org/disability_resources/emergency_preparedness_for_persons_with_disabilities/)