BEST STATE BUDGET PROPOSAL IN A DECADE

Governor Wolf proposed a budget that includes the strongest investment in intellectual and developmental disabilities/autism services Pennsylvania has seen in a decade. The overall proposed $32.3 billion budget for the 2017-2018 fiscal year includes plans to close the current $3 billion deficit Pennsylvania is facing through $2 billion in cost-savings and $1 billion in new revenue.

This budget clearly reflects Pennsylvania’s belief in the community supports system for people with intellectual and developmental disabilities. It includes plans to get people off the emergency waiting list as well as serve every graduating high school student with intellectual and developmental disabilities through community waivers.

Disability highlights from Governor Wolf’s budget include:

- Funding to support waivers for 1,000 individuals currently on the emergency waiting list for services and 820 graduating high school students with disabilities.
- The creation of a new waiver, called the “Community Living waiver”. It will support individuals who want to access employment and/or day supports and who do not want residential services.
- Funding to provide waivers for 50 people on the autism interest list.
- Rate increases to stabilize the disability services system, including a wage increase for Direct Support Professionals.
- Funding to provide case management services to individuals who are waiting for services on the autism interest list and intellectual disabilities on the waiting list.

Now that Governor Wolf has released his budget proposal, the House and Senate will have budget hearings before releasing their own budget proposals. The Arc of Pennsylvania will be working with elected officials to ensure this proposed funding makes it into the final state budget. Visit page 5 to see how you can get involved.

STATE BUDGET DETAILS

The 2017-2018 budget proposal includes significant investment in the disability community services system. The following initiatives will increase the opportunities for Pennsylvanians with disabilities to thrive in their communities.

Department of Human Services

$26.2 million increase for offering new Community Living waiver services for 1,000 individuals with intellectual disabilities from the waiting list and 820 Person/Family Directed Support waivers for recent high school graduates. This is the most significant waiting list funding in nine years.

The increased waiting list funding is part of the overall $195.9 million increase, or 14.7%, to provide home and community based services to more than 55,000 individuals with intellectual disabilities, including residential, transportation, and habilitation support. This overall increase includes $54.7 million to provide rate increases from the renewal of the waiver program and $109.7 million to provide for increases in utilization and costs. This includes funding to increase the wages of Direct Support Professionals, who currently make $4/hour less than living wage for working families in Pennsylvania and face a high turnover rate. Additionally, the administration is requesting supplemental funding to close the deficit the Office of Developmental Program is facing in this fiscal year.

Community Base funds have an increase of $784,000. $230,000 of this is to provide Targeted Services Management State Plan (TSMSP) Services for 455 people with intellectual disabilities on the waiting list.

A $2 million increase for Autism Intervention and Services. $783,000 of this will provide TSMSP Services to 1,545 individuals with autism currently on the interest list. $642,000 of this increase will provide waivers to 50 adults with autism.
President’s Message - Ken Oakes

THE ARC... NOW MORE THAN EVER

Every decade since the first group of parents met to organize, The Arc has been challenged by local, state and federal governments to protect and advocate for the rights of children and adults with intellectual and other developmental disabilities and their families. Every step of the way, The Arc has boldly risen up and made our collective voice heard demanding change. Denial of a public education, de-institutionalization, community living, quality special education, the death penalty, employment, Early Intervention, transition, inclusion, extended school year, and countless other issues have moved The Arc to take action and lead the way. Thousands of Pennsylvanians that we will never know have benefited from the work of The Arc. Many without even knowing there was an Arc.

The Arc, as you know, is the largest and oldest advocacy organization for people with intellectual and other developmental disabilities in the country. The Arc in Pennsylvania is a leader in local communities, Harrisburg and Washington DC. We have the collective power to fight for and fight back when the people we love are denied services and supports. We know how to organize and mobilize when our children, siblings, neighbors and friends are targeted with cuts to those programs that have so greatly improved their lives.

Today, the political world seems upside down. This means that The Arc is more important than ever. For example, locally, more kids are included, special education is getting better, Early Intervention prepares little ones for school, neighborhoods are welcoming, more and more people are working in real jobs in their communities, and more. None of this happened by itself, and none of it was easy. It took years of advocacy by countless volunteers and staff to make it happen.

At the state level, several years of flat funding or slow growth has put more people on the waiting list for services. This trend may be turning around as we see in Governor Wolf’s proposed budget. This budget includes: the closing of another state institution, funding for 1,000 people on the waiting list, funding for 820 high school graduates, increases in special education, OVR, Early Intervention, preschool, autism services and supports, and expanded waivers, moving 40 more people from state institutions. The work advocacy gear and help do all we can to ensure that this budget gets approved and life continues to improve for folks with disabilities.

Most likely, some of the most difficult work will happen in Washington. After many years of advocacy, we are now preparing for some very uncertain times. I recently attended my first board meeting of The Arc US, and the report from the Public Policy staff made it perfectly clear that we will likely be facing cuts and changes at the federal level like we have not known before. Fortunately, our Arc staff and leadership in Washington DC and Harrisburg are up for the challenge, as are you! Whatever comes our way from the Executive or Legislative branches of government, The Arc needs to be ready to be the loudest and strongest voice, showing our collective power as self-advocates and on behalf of those we love, care for, live next door to, teach, and work with.

I want to thank you all for the work you have done, and challenge you to face what may come. I am very serious when I say that we need The Arc now, more than ever. Onward!

Ken Oakes
President

STATE BUDGET DETAILS continued from cover

$7.3 million increase in Infant/Toddler Early Intervention.
$4.9 million decrease for State Centers.
$544,000 to transition 40 individuals currently residing in state intellectual disabilities centers to the community. This is part of the Benjamin Settlement.

Department of Education
$25 million increase to special education.
$11.7 million increase in funding for Preschool Early Intervention to serve approximately 1,100 new children.
$544,000 to transition 40 individuals currently residing in state intellectual disabilities centers to the community. This is part of the Benjamin Settlement.
Executive Director’s Message
Maureen Cronin

The Arc’s Advocacy Works

If you’ve been following state budget news for the past few years, it has been a rough time for disability services in Pennsylvania. State budget deficits coupled with political disagreements continued the underfunding of disability services. Two years ago, Pennsylvania had a budget impasse that put providers of disability services in a tight spot as payments were delayed. Last year’s budget did not address the 5,000 people on the emergency waiting list and did not serve all graduating high school students with intellectual and developmental disabilities.

We are thrilled to share that this year, after numerous meetings with the Governor and his staff and the Office of Developmental Programs, Governor Wolf proposed a strong budget for Pennsylvanians with intellectual and developmental disabilities.

The rest of our newsletter gets into the details of why we’re supporting this budget - from the robust investment it makes in new waivers to the sorely needed funding to stabilize providers’ services.

I want to focus on thanking you. For your advocacy, for your donations that make our work possible, for showing up at our yearly rally - your presence, you making yourself heard makes an impact. Advocacy is frustrating work because we don’t always (well, almost never) see the impact right away, but times like this remind us that showing up makes a difference.

Our work isn’t done. The Arc of Pennsylvania is, even as I’m writing this, gearing up for meetings with legislators to show them why this disability funding is so important for Pennsylvania. I hope you’ll be part of this effort - we’ll be in touch with opportunities.

Thank you, again, for being part of this movement. The Arc wouldn’t exist without you.

To whom much is given, much is required — not expected, but required.
— Andrew Young
The new year brings the start of another legislative session and dozens of new legislators. At the beginning of each legislative session The Arc of Pennsylvania sets budget and policy priorities to be the focus of our advocacy work during the next two years.

**2017-18 Budget Priorities:**

**END THE I/DD WAITING LIST**

Nearly 5,000 Pennsylvanians with intellectual and developmental disabilities continue to struggle on the intellectual and developmental disabilities waiting list, living in heightened crisis situations without access to the supports they have a right to use. The Arc of Pennsylvania calls for funding to support all people with intellectual and developmental disabilities who are waiting for critical services. Rep. Tom Murt (R-Montgomery) has circulated various cosponsor memos that address funding for the waiting list. Below is the list of bills The Arc of Pennsylvania supports:

- Requiring each slot machine licensee to collect a $2 per patron admission fee to establish the Intellectual Disabilities and Autism Waiting List Account in State Treasury.
- Imposing an additional $0.04 tax on cigarettes sold in Pennsylvania to fund the Adult Intellectual Disabilities and Autism Waiting List Account.
- Restoring the 14% tax on table games from 12% to fund programs and services for adults with intellectual and developmental disabilities.
- HB 414 - Establishing a bill of rights for individuals with intellectual disabilities and requiring the Department of Human Services to develop and submit a plan to address the waiting list for community-based services to people with the same.

**EARLY INTERVENTION FUNDING**

Pennsylvania’s Early Intervention Program plays a critical role for children with disabilities from birth to age five. Studies have shown that learning and development are at their highest rate in the infant, toddler and preschool years and it is essential that we provide our children the proper resources to succeed. Early Intervention is designed to lay a foundation that will improve the lives of children and offer greater opportunities for future education and employment. Funding rates for Early Intervention have not increased in eight years. The Arc of Pennsylvania is calling on the General Assembly to provide adequate funding that will cover growing costs to provide these critical services.

**2017-18 Policy Priorities:**

**SUPPORT FAMILIES OF PEOPLE WITH DISABILITIES**

The Arc of Pennsylvania supports the Office of Developmental Program’s increased focus on shifting our service system to make it as streamlined as possible and empowering families to support their loved ones with disabilities at home. All child-serving systems should adequately fund and coordinate supports so that every child is growing up with a family, rather than in a facility. Maximizing family supports generally keeps people connected in their communities, allows a greater degree of independence and choice, and increases the cost effectiveness of supporting individuals. The Arc of Pennsylvania affirms that people with disabilities are best served: in their community, alongside their peers with and without disabilities, and in a range of settings including living with family, shared living, and living with roommates.

**CLOSE STATE CENTERS**

The 1999 Supreme Court decision (Olmstead) affirmed a person’s right to receive community integrated services rather than segregated institutional living. A 2015 LBFC study demonstrates the need for transitioning individuals from segregated settings to the community, and includes recommendations to phase out the remaining state centers. The Arc of Pennsylvania calls on the Department of Human Services (DHS) to end admissions to state centers, publicly post a quarterly list of the numbers of admissions and transitions, and close the five remaining state-run institutions by relocating all residents to community living. To note: DHS announced that they will close Hamburg State Center within 18 to 24 months.

**EMPLOYMENT**

The Arc of Pennsylvania has been implementing ADEPT, an employment project using the Discovery process for students with significant disabilities, with support of the Office of Developmental Programs and the Office of Vocational Rehabilitation since 2013. The Arc of Pennsylvania applauds Pennsylvania becoming an Employment First state and looks forward to improvements expected by the Workforce Innovation and Opportunity Act that will create greater access to employment for people with disabilities in Pennsylvania. We urge the Department of Human Services and the Department of Labor and Industry to continue connecting with stakeholders in implementing an Employment First policy. Various pieces of legislation have been circulating throughout the House and Senate that are focusing on I/DD employment. The Arc of Pennsylvania supports the following bills:

- Rep. Jake Wheatley (D-Allegheny) has circulated a cosponsor memo that would provide tax deductions to employers hiring veterans and other individuals with barriers to employment, including recipients of SSI.
- SB 159, introduced by Sen. Christine Tartaglione (D-Philadelphia), would amend the State Civil Service Exam and give people with disabilities additional points on the State Civil Service Exam, which will improve state employment eligibility.
STATE POLICY PRIORITIES continued from page 4

IMPROVE SCHOOL CLIMATE FOR STUDENTS WITH DISABILITIES

The Arc of Pennsylvania supports efforts to improve school climate through expansion of Statewide Positive Behavior Supports (SWPBS) that helps reduce bullying, passage of regulations to end unnecessary restraints and seclusion, and promotion of effective technical assistance, training, and least restrictive environment compliance programs. The Arc of Pennsylvania will like to see the definition of bullying updated to include cyberbullying, standardized anti-bullying policies in schools, and protect educators who report incidents of bullying.

ORGAN TRANSPLANT DISCRIMINATION

Discrimination against people with intellectual and developmental disabilities being considered for life-saving transplant procedures happens across the United States and in Pennsylvania. Transplant centers can wrongly use neurodevelopmental status as criteria for determining transplant eligibility, even when a person’s disability creates no medical impact on transplant candidacy. New Jersey, California, and Maryland have passed laws banning organ transplant discrimination against people solely on the basis of their disability; similar legislation is currently being considered in Delaware and Oregon. Sen. John Sabatina (D-Philadelphia) reintroduced Paul’s Law, SB 108, which would prohibit discrimination against individuals with disabilities in need of organ transplants.

BURDEN OF PROOF ON SCHOOL DISTRICTS, NOT PARENTS

Pennsylvania has no statute or regulation that assigns the burden of proof to school districts. Surrounding states (New York, New Jersey, West Virginia, Connecticut, and Delaware), DC and six other states have legislatively assigned the burden of proof to school districts. Few parents go into this process with the resources or knowledge to properly present their child’s case against seasoned professionals representing school districts. The Arc of PA supports legislation which would place the burden of proof in special education matters on school districts.

DIRECT SUPPORT PROFESSIONALS

Direct Support Professionals (DSPs) provide in-person supports that empower individuals with intellectual and developmental disabilities to live, work, and thrive in the community; this includes employment, self-care, household maintenance, and transportation support. Despite the level of responsibility and impact involved in the work of DSPs, their average hourly wage is $11.54 per hour. The intellectual and developmental disabilities service industry is struggling because at this wage rate it cannot attract or keep quality DSPs, which makes Pennsylvanians with disabilities and their families vulnerable to crisis situations. Without an increase in service payment rates in the state budget, providers are unable to raise wages. The Arc of Pennsylvania supports a wage increase in the state budget for over 35,000 DSPs that serve Pennsylvanians with intellectual and developmental disabilities each day.
WELCOME NEW DIRECTOR OF ADVOCACY AND PUBLIC AFFAIRS

Please join us in welcoming Anne Yanikov, our new Director of Advocacy and Public Affairs at The Arc of Pennsylvania. Anne graduated from West Chester University with a bachelor’s degree in Political Science and two minors History and Criminal Justice in 2009. After graduation, she obtained a Legislative Assistant position at the Pennsylvania House of Representatives working for Majority Chair of Labor and Industry, Mauree Gingrich, for six years. During her tenure at the House, Anne completed her Master of Public Administration at Villanova University in 2016, was elected as the York Township Republican Committeewoman in 2014 and graduated from the Anne B. Anstine Excellence in Public Service Series Program in 2013. Outside of politics, Anne enjoys traveling, going to “Diners, Drive-ins and Dives” restaurants and the arts. The Arc of Pennsylvania is thrilled to have Anne as part of our advocacy team.

“HEY ALEXA, WHAT’S AN ECHO?”

Amazon Echo ($180), Tap ($130) and Echo Dot ($50) are all personal assistant internet devices that use the Alexa Voice Technology to make life easier at home. You speak and they will follow some directions. First, you need to let it know that you want it to listen to you. You can do this by saying “Alexa” (or touching the Tap). Then you can say something like, “What is the weather?”, “Set a repeating alarm for weekdays at 7 a.m.”, “What’s on my calendar for tomorrow?”, “Connect to my phone” and even “Tell me a joke.” You can even tell it to brew coffee if you have a “smart” coffeemaker.

Alexa Voice Technology is being used by people with disabilities in helpful ways. Darnel, a 43-year old young man diagnosed with Down syndrome, recently moved from his family’s supportive home into his own apartment. Darnel needs assistance so he can access places in the community. Darnel’s family helped him set up an account with Uber and using his Amazon Echo from his home, he can ask the device, “Alexa, ask Uber for a ride.” The ride fare is automatically deducted from the Uber account and Darnel does not have to worry about not having enough money in his pocket for the ride.

Shaylee, a 22-year old woman with intellectual disabilities, uses the technology to schedule recurring appointments. Shaylee tells her Amazon Dot to set an alarm for 8:00 am every morning. Setting up recurring appointments was difficult for her in the past, but her personal assistance device makes it an easier process.

UPDATE ON REGULATIONS AND WAIVER RENEWAL

It isn’t glamorous but it is important. The Arc of Pennsylvania reviewed, analyzed, and commented on the Office of Developmental Programs’ proposed Home and Community Based Services and Licensing Regulations and Waiver Renewal. The proposed regulations included changes that would impact providers of residential, day, and employment services. The proposed waiver renewal included numerous changes to the services people with disabilities use - including expanding access to the Consolidated and Person/Family Directed Services waiver to people with autism, increased flexibility in waiver services through new definitions, and a focus on supporting families. The Arc of Pennsylvania supports The Office of Developmental Program’s increased efforts on community integration but was concerned about the proposed percentage targets for time in the community and timeline of implementation. In response to overarching concern about this portion of the proposed waiver renewal, ODP has released a modified proposal. The Office of Developmental Programs must address all the submitted comments before sending their final plan to the Centers for Medicare and Medicaid.

Appendices I and J of the waiver renewal were released in late February. They include updates to rates and a new proposed limit on the P/FDS waiver of $33,000 per year, with further $15,000 allowed for Advanced Supported Employment activities. The Arc of Pennsylvania staff is currently working on comments.

The Amazon Echo (and Tap and Dot) are speakers with microphones that connect to the internet, allowing them to follow some simple directions and answer some questions. They can also serve as a home automation or “smart home” hub and control lots of appliances, thermostats, doors, and more. This is all part of the “internet of things” - or machines communicating with other machines.

Each task these devices can make happen are called “skills”. People are creating new skills for Alexa Voice Technology all the time. Currently, over 10,000 skills for Alexa have been developed. Many of the developed skills are for fun but others have profound capabilities.

Many of the giant tech companies are getting into the personal assistant game. Google Home is another option to consider. Logitech has some solutions also. Inventors and developers are quickly coming up with new ways to create personal assistant that can help people. The possibilities are endless!

If you are interested in learning more about how these technologies might be useful, please reach out to your local Assistive Technology Resources Center - you can find yours at http://bit.ly/pa-atrc.

Kim Singleton- Director of Assistive Technology Programs
Jamie Arasz Prioli- Assistive Technology Specialist
Institute on Disabilities @ Temple University
In January 2017, the Department of Human Services announced their decision to close Hamburg State Center and help current residents transition to community-based living. The Arc of Pennsylvania supports the Department’s decision to move away from a segregated, state-center model of living. The transition plan includes meeting several times with current residents and their families to explore community living options and demonstrates the Commonwealth’s commitment to invest in the lives of people with disabilities.

Since The Arc of Pennsylvania’s inception, inclusive and authentic community living has been a core priority. These core values were the platform for The Arc to file its first litigation case in the 1970s against the state for the Right of Education for children with disabilities. Subsequently, by citing *Brown v. Board of Education* the courts decided that the state was in violation of the 14th Amendment of the U.S. Constitution, which prompted the beginning process of transitioning individuals from state facilities to community-based living. The Arc led the movement to close state facilities by filing litigation for two more cases: *Halderman v. Pennhurst* and *Richard C. v. Western State Center*. Pennhurst was ordered to close due to its findings that violated the civil rights of the residents and required the State to place all Pennhurst residents in community programs.

Since the Court’s decision to close Pennhurst State Center, The Arc of Pennsylvania has remained committed to support the closure of all state facilities located across the Commonwealth. Forty years later, this has remained a top priority of The Arc.

While The Arc of Pennsylvania recognizes that state facilities have vastly improved since the terrible human rights abuses brought to light in the 60s, these facilities remain a segregated model of support for people with disabilities. We understand that the transition process is never easy because our staff has helped numerous individuals and their families transition into community-based living. The Arc supports the Department of Human Services plan to meet with individuals, conduct the proper assessments, and talk through the options with families and the individuals to create a successful transition into the community. We recognize that families are integral to a successful transition and we are committed to supporting these individuals and their families in whatever we can to make this a successful move into community-based living.

The Arc of Pennsylvania believes that all individuals in the Commonwealth have the right to live in the community, including those who currently reside in a state-owned facility. All residents in the Commonwealth should be able to have the same shared experiences, such as going to coffee shops, obtaining employment, or being able to choose their housemates. We’ve witnessed countless instances where people with disabilities - whom lived their entire lives in state-owned facilities - flourish when they moved into the community.

The Arc of Pennsylvania appreciates the efforts of our administration - particularly Ted Dallas, Secretary of Human Services and Nancy Thaler, Deputy Secretary of the Office of Developmental Programs - for their continued leadership and commitment to ensure all Pennsylvanians have the same opportunities to a quality life.

The Arc of Pennsylvania supports closure of Hamburg State Center

The beginning process of transitioning individuals from state facilities to community-based living. The Arc of Pennsylvania appreciates the efforts of our administration - particularly Ted Dallas, Secretary of Human Services and Nancy Thaler, Deputy Secretary of the Office of Developmental Programs - for their continued leadership and commitment to ensure all Pennsylvanians have the same opportunities to a quality life.

**THE ARC OF PENNSYLVANIA SUPPORTS CLOSURE OF HAMBURG STATE CENTER**

Hooverville Elementary School in Waynesboro came together on Wednesday, February 15th to meet a new friend and learn about her life. Mikayla Resh and her mother, Kim, presented two assemblies to the Kindergarten through 6th grade students, staff, teachers, and district representatives to teach them about disabilities and inclusion. Each assembly began with a teacher reading the book “My Friend Mikayla” aloud to the students. Mikayla herself has significant disabilities and this book was written by her third-grade class to explain why it is wonderful to have a friend with a disability. After the book reading, students were given the opportunity to ask Kim questions about Mikayla’s life. Through their thoughtful questions, the students showed their curiosity and caring towards Mikayla. They wondered “How does she talk?”, “How does she eat?”, “What happened to her?”, and “Is she in pain?”. Kim answered all questions openly and honestly and demonstrated how she lifts Mikayla into bed as well as how Mikayla presses her switch to get attention. Kim explained to the students why Mikayla is not able to talk and asked them to be Mikayla’s Voice since she cannot use her own. The students agreed enthusiastically to share how cool it was to have a friend with a disability. As the assembly ended, the students met Mikayla, shaking her hand or giving her a fist-bump before heading back to class.

The Arc of Pennsylvania is honored to continue our partnership with Mikayla’s Voice and offer these inclusion assemblies free of charge to public schools. Over the seven years that Include Me has been providing inclusive classroom support for students with disabilities, The Arc of Pennsylvania has seen how these inclusion assemblies make a direct impact on students and teachers. Having a safe space to ask questions about disabilities reduces stigma and promotes honest conversation. For more information on Include Me, visit www.includemepa.org.
MISSION STATEMENT

The Arc of Pennsylvania promotes the human rights of people with intellectual and development disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.