Governor’s Budget Mixed for Pennsylvanians with Disabilities

On February 9, Governor Wolf proposed a $33.3 billion budget for fiscal year 2016-2017. This is a 10.89% increase compared to the $30.03 final 2015-2016 budget.

The General Assembly is currently creating their own budget proposal for the 2016-2017 fiscal year. After it is formally introduced and shared with the Governor’s administration, budget negotiations will begin.

The 2016-2017 Governor’s budget proposal is a mix of positives and negatives for Pennsylvanians with intellectual and developmental disabilities and autism. While it includes increases to special education, funds to offer ABLE Accounts in Pennsylvania, funds to reduce the number of adults waiting for autism services, an increase in base funds, and an increase for the Office of Vocational Rehabilitation to support employment for individuals with disabilities, the budget also proposes the smallest waiting list initiative in five years and continues increasing funding for state intellectual disability centers.

Acknowledging that many of the proposed increases are a restoration of budget cuts made under the previous administration, Executive Director Maureen Cronin notes that “The Arc of Pennsylvania will work diligently to support portions of the budget proposal that are positive for persons with intellectual and developmental disabilities, while pushing for more waiver funding to be made available to individuals desperately waiting for services. We firmly believe that the state’s budget should be the Commonwealth’s moral testament to an inclusive society where individuals with disabilities live and work as independently as possible.”

The Arc of Pennsylvania is paying particularly close attention to the following budget items:

**Department of Human Services**

- $1.2 million proposed increase in Infant/Toddler Early Intervention
- $71.4 million increase, or 5.9%, to provide home and community based services to more than 55,000 individuals with intellectual disabilities, including residential, transportation, and habilitation support.

- **This includes an $11.5 million increase for offering waiver services for an additional 250 individuals with intellectual disabilities (Consolidated waiver) and 500 students with intellectual disabilities graduating from high school (P/FDS waiver).**

- **This is a significant step backwards from the last two years:**
  - Fiscal year 2013-14 - 380 Consolidated waiver spots and 700 P/FDS spots
  - Fiscal year 2014-15 - 400 Consolidated waiver spots and 700 P/FDS spots
  - The Office of Developmental Programs also holds back waiver spots each year for emergency situations that arise, particularly for individuals are referred to waiver services through Adult Protective Services. This means that there will be even fewer new spots to remove individuals from the emergency waiting list. Currently there are nearly 5,000 individuals on the emergency waiting list.

- Currently over 5,000 individuals are on the intellectual and developmental disabilities emergency waiting list.

GOVERNORS BUDGET MIXED FOR PA continued on page 6
President’s Message - Ken Oakes

In the many years that I have been involved with The Arc, and specifically The Arc of Pennsylvania, I have never heard anyone doubt that we have one of the best state Arc chapters in the nation. Remember, The Arc of PA is the birthplace of the right to a free and appropriate public education, the place where some of the first children and adults with intellectual disabilities left state operated institutions and moved in to real homes near their families. Certainly, we are rich in history, but we never rest on our laurels.

Even given our notable past advocacy, I have heard people from local chapters ask...“What do we get from our affiliation with The Arc of PA?” “Why should we continue to financially support a state chapter of The Arc?”. Now, understanding that local Arc chapter budgets are being squeezed by financial needs that exceed state and federal funding, and that fundraising and grant dollars are increasingly more difficult to secure, I can understand why a local Arc board might ask “why?”. Especially if they are new members, or have not had the benefit of reading and hearing of the state chapter advocacy on their behalf.

I will be honest in telling you that when I was the President of my local Arc and we were struggling as an “all advocacy” chapter, to fund our work, we too asked “why?”.

As your President, I wanted to take this opportunity to offer some reasons why every dollar you use to support your state chapter benefits your local Arc and the men, women, children, families and communities you serve. I pledge to you that every dollar is used wisely and often leveraged to secure grant funds. Please allow me to share a few thoughts on why The Arc of Pennsylvania is deserving of your financial support.

- Every two years when new members are elected to the state Senate and House, The Arc of PA staff walk the halls of the Capitol to share informational packets about The Arc movement, our issues and advocacy, the needs we see every day in our towns and cities, and most importantly to tell the stories of the folks we serve. This outreach is also true when there are new members elected to represent our state in the US House and Senate.

- When a new Governor is elected, one of the first disability advocacy groups that he (so far it has only been a he) hears from and meets with is The Arc of PA. This is also true for the members of the Governor’s new cabinet and their Deputy Secretaries.

- When a newswire service, local paper, television or radio station news department needs a comment on a hot issue of the day regarding citizens with intellectual and developmental disabilities, they call The Arc of PA.

- When the Governor, state and US Representatives and Senators need to talk budget issues that affect the lives of our constituents, they call The Arc of PA.

- The same is true when these legislators need to know why and how pending legislation at the state and federal level will impact the lives of folks with intellectual disabilities and families - they call The Arc of PA.

- If the Secretaries of Education, Human Services, or Labor and Industry get a call from The Arc of PA regarding an advocacy issue that will improve the quality of life for Pennsylvanians with disabilities, and strengthen local Arc chapters, without hesitation they agree to a meeting with the state chapter staff and often volunteers.

- You would probably not be surprised to know that The Arc of Pennsylvania is the “go to” organization for information, leadership and advocacy on behalf of many thousands of people with intellectual and developmental disabilities, young and old.

- The prevention of funding cuts to disability services and increases in disability services are a direct results of The Arc of Pennsylvania’s advocacy.

- As we advocate, struggle and yes, even fight to expand Medicaid Waivers, increase special education funding, chip away at the waiting list, ensure that everyone has access to good dental and health care, foster an inclusive education and community for all, guarantee that all students graduating from high school have effective transition plans and are ready for real work, and promise that every child and adult with a disability is respected, treated with dignity, and make their own decisions, The Arc of PA is always there.

So, as I write this, I am not sure that the question is “why?” but “why not?”.

We are in this together and have been for more than 66 years. From The Arc of Centre County on Atherton Street in State College, to Chestnut Street in Harrisburg where our state chapter staff can be in the office of the Governor, any state legislator, or a Commonwealth agency within 20 minutes, we all keep moving forward. Sometimes quietly, but always with a firm belief in the mission statement of The Arc... To promote and protect the human rights of people with intellectual and developmental disabilities and actively support their full inclusion and participation in the community throughout their lifetimes.

How can we put a price tag on that?

Thank you for all of the work you do day in and day out in urban, suburban and rural locations across this amazing and diverse state. I am eternally grateful for being a member of The Arc “family” and how we support each other.

Ken Oakes
President

Achieve with us.
Executive Director’s Message
Maureen Cronin

Moving Forward Together

Pennsylvania is again nearing a critical decision: how and what to fund in our state during the 2016-2017 budget year. At The Arc of Pennsylvania we are purposely non-partisan, because we believe disability issues affect us all and must be resolved with bipartisan work. We strongly advocate for funding services that Pennsylvanians with intellectual and developmental disabilities need - thousands of whom have been waiting years for services - so that they can live and thrive in the community.

While our system is improving, there is no doubt that it is unjust. Because of funding shortfalls, Pennsylvanians with intellectual and developmental disabilities must wait years to receive services they need to live well in the community - yet, if they wanted to give up community living, they are eligible for and could receive services in institutional settings.

Pennsylvanians with disabilities want to live in the community. Their families and friends want them to live in the community. They want this so badly that they endure a long wait for services instead of choosing institutional settings. Families have made a strong choice in choosing to support their sons and daughters at home instead of in institutional settings; in doing so, they have also saved the state and federal government billions of dollars in funding. It is time for Pennsylvania to make critical investments that sustain families and provide a more cost-effective services model.

Pennsylvania can do better than this. This is at the forefront of my mind as The Arc of Pennsylvania advocates for disability services funding. Disability rights are human rights - education, employment, and participation in the community are the rights of Pennsylvanians with and without disabilities. At The Arc of Pennsylvania, this commitment to the rights of people with disabilities drives our budget advocacy. Please join us.

“To whom much is given, much is required — not expected, but required.”
— Andrew Young
The Arc of Pennsylvania’s 2016 Legislative Priorities

The Arc of Pennsylvania policy committee approves legislative priorities for The Arc of Pennsylvania staff to focus on each year. This helps guide our advocacy on behalf of our members across the state. In 2016, The Arc of Pennsylvania is focusing our advocacy efforts on:

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.

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, empowering families support to support their loved ones with disabilities at home. Maximizing family support 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.

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 to end admissions to state centers, publicly post a quarterly list of the numbers of admissions and transitions, report on Money Follows the Person (MFP) progress, and close the five remaining state-run institutions by relocating all residents to community living.

HUMAN SERVICES BLOCK GRANT

The Arc of Pennsylvania remains concerned about the continued pressure to expand the Human Services Block Grant beyond the 30 current counties to all 67 counties in Pennsylvania. The Arc of Pennsylvania applauds the Governor’s proposed 2016-2017 budget for including funds that begin restoring the 2011-2012 10% cut, which significantly hurt human services in Pennsylvania. The Arc of Pennsylvania calls on the General Assembly to 1) Fully restore the FY 2011-12 10% budget cut to human services funding; 2) Compare data from past years to the data presented in the Human Services Block Grant reports to present a more accurate account of the impact of the block grant; and 3) Require greater transparency for counties using the block grant; and 4) Add protections that assure no reduction of I/DD funding occurs in counties using the block grant as long as there is a waiting list for disability services.

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. The Arc of Pennsylvania continues this project in the 2015-2016 school year with diverse funding sources. 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 and opportunities 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. As a coalition member of the I Want To Work campaign, The Arc of Pennsylvania supports HB 400, introduced by Representative Gingrich and soon to be signed into law, which calls for increasing funding of OVR and part-time job opportunities for youth with disabilities in high school.

BURDEN OF PROOF ON SCHOOL DISTRICTS, NOT PARENTS

The Arc of Pennsylvania supports SB 762, sponsored by Senator Browne, which would place the burden of proof in special education matters on school districts rather than parents. Under the Federal Individuals with Disabilities Education Act (IDEA), parents and school districts have the right under due process to an administrative hearing when there is an unresolved disagreement over which special education services students should have to successfully meet their academic goals. Until recently it has been understood, unless otherwise specified in a state’s due process regulations or statutes, that the school district had the burden of proof in due process proceedings. Pennsylvania must take the affirmative step of adopting a statutory provision which allocates the burden of proof in due process proceedings to the school districts. The Arc of Pennsylvania is working with Senator Browne’s office to advance SB 762 in this session.

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 supports HB 156, introduced by Representative Dan Truitt, which expands the definition of bullying to include cyberbullying, standardizes anti-bullying policies in schools, and protects 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 use neurodevelopmental status as criteria for determining transplant eligibility, even when a person’s disability creates no medical impact on transplant candidacy. New Jersey and California have passed laws banning organ transplant discrimination against people solely on the basis of their disability; similar legislation is currently being considered in Maryland and Oregon. The Arc of Pennsylvania supports Senator Sabatina’s SB 902 and Representative Tom Murt’s HB 585 which prohibits discrimination against people with disabilities for organ transplant consideration.

OFFER ABLE ACCOUNTS IN PENNSYLVANIA

The Achieving a Better Life Act (ABLE) Act was signed into law by President Obama in December 2014, giving people with disabilities the right to open ABLE savings accounts. Pennsylvania unanimously passed Senator Baker’s SB 879 PA ABLE legislation, which became Act 17 of 2016 on April 18, 2016. The Arc of Pennsylvania applauds Senator Baker and the Pennsylvania Treasury Department for their commitment to financial choice and independence for Pennsylvanians with disabilities and their families. An ABLE Advisory Board - which includes Pennsylvanians with disabilities, their family members, and members of disability rights organizations - is currently meeting with the Pennsylvania Treasury Department to create the PA ABLE program. An ABLE account can be used for community living expenses such as housing, transportation, education, and assistive technology; the account does not affect an individual’s eligibility for Social Security (if the amount in the account remains under $100,000) or Medical Assistance. Pennsylvania’s ABLE program is unique in the country - the state has chosen not to enforce the Medicaid payback provision of ABLE, which means that after a person who has an ABLE account passes away his or her remaining money can be distributed according to a will. The Pennsylvania Treasury Department estimates it will take until at least November 2016 for ABLE accounts to be offered in Pennsylvania.

Save the Date for Summer Employment Trainings

The Arc of Pennsylvania is offering two concurrent trainings on June 6-8: Discovery and Customized Employment Job Development.

The Discovery training offers a comprehensive overview of Discovery (an alternative to traditional vocational assessments) and how to complete Discovery. For those seeking to become certified providers of Discovery, this is a required face-to-face training to complete certification. Individuals not seeking certification will gain valuable information and insight and may attend as auditors of the course. More information is available at http://www.thearcpa.org/file_download/39ef70e0-f4ef-4f36-80c2-6079637d1bb9.

At Customized Employment Job Development attendees will learn how to develop and negotiate customized jobs with employers on behalf of individuals with disabilities. This is the pre-requisite face-to-face training to complete certification. More information is available at http://www.thearcpa.org/file_download/81b25d50-d936-4780-8c1c-8619b9d635b1.

Participants seeking certification through The Arc of Pennsylvania are expected to commit approximately 40 hours of fieldwork with/on-behalf of a learning partner under the guidance of Marc Gold and Associates over the course of 4 months. To register or if you have questions, contact Program Specialist Nicole Turman at nturman@includemepa.org or visit http://includemepa.org/certification/.

The Arc of Pennsylvania’s Annual Advocacy & Policy Conference

We hope you are planning to join The Arc of Pennsylvania June 6 - 7 for Advocacy & Policy Conference 2016 at the Hilton Hotel in Harrisburg, PA. This year’s conference is filled with opportunities to learn about policy - you will have to opportunity to discuss policy with House Majority Leader Dave Reed, participate in a disability rights rally, visit with legislators, and attend leadership development sessions hosted by the Pennsylvania Council of Executives as well as a Legislative reception.

Stay tuned for updates from Advocacy & Policy Conference 2016. You can follow us on social media for live updates during Advocacy & Policy Conference - on Twitter @TheArcPA and on Facebook at www.thearcpa.org/TheArcPA.
Pennsylvania’s Assistive Technology Lending Library

by Sandra McNally, Program Director, PA’s Initiative on Assistive Technology (PIAT)

Regular readers of this column are probably already familiar with Pennsylvania’s Assistive Technology Lending Library (the “AT Lending Library”). The AT Lending Library is a free service that provides short-term loans of assistive technology (AT) devices to Pennsylvanians of all ages and disabilities, and is funded by a line item in the Department of Labor and Industry budget.

The AT Lending Library was established via a “Program Revision Request” with the support of five departments - the Pennsylvania Departments of Aging, Education, Health, Labor and Industry, and Public Welfare (now Human Services), recognizing the important role that AT can play in the lives of Pennsylvanians with disabilities. Then (and current) Deputy Secretary Nancy Thaler played an important part in advocating for its establishment, and originally the program was part of the “Office of Mental Retardation” (now Office of Developmental Programs) budget.

Since its beginning in 1997, the AT Lending Library’s goal has been to “assure easy access and availability of assistive technology to all Pennsylvanians with disabilities and older Pennsylvanians” (PIAT Advisory Board, 1997). The AT Lending Library’s “try before you buy” service plays an important role in helping consumers make informed decisions about the devices that will (or will not!) work for them. The AT Lending Library can also be used to fill short-term needs for accommodations, and for professional development.

At the peak of its funding in 2006-2007 (over one million dollars) the AT Lending Library received almost 4400 requests to borrow devices. The program is now in its 18th year of operation and its fifth year at funding at or below $400,000. In the 2014-2015 program year, the AT Lending Library processed 1068 requests to borrow; 445 of those were from first-time borrowers.

The current inventory includes over 3,600 devices housed at the Hiram G. Andrews Center, which serves as the “circulating department” of the AT Lending Library. Devices are shipped to and from borrowers via UPS at no charge. New items are added to the AT Lending Library as funding permits, and include items funded through Pennsylvania’s Initiative on Assistive Technology (PIAT), the Commonwealth’s Assistive Technology Act Program. Examples of some of the new devices added within the past year are: adapted telephones; Clicker 6 (writing software); communication devices (Accent 800, 1000, 1400, Choice Communicator); and Apple iPad 2, iPad Mini 3 and iPod Touch, which are loaned with requested apps pre-loaded.

Several informational (captioned) videos and webcasts introducing individuals to the process of borrowing from the AT Lending Library can be viewed at http://disabilities.temple.edu/atlend.

How to borrow from the AT Lending Library:

1. Visit http://disabilities.temple.edu/atlend to download a Device Loan Request form, or contact the Assistive Technology Resource Center (ATRC) that serves your county to request a form.
2. Search the Equipment Catalog on the website to gather the information about the equipment you want to borrow. Tip: You can also use the “Loan Cart” to enter devices on an online Device Loan Request form.
3. Complete the Device Loan Request form, either by printing and completing the form offline, or by using the Loan Cart on the website to enter information, then print the form.
4. Sign the form where indicated and send the completed form to your regional Assistive Technology Resource Center (ATRC). If you don’t know your ATRC, call our office at 800-204-7428, or visit http://disabilities.temple.edu/programs/assistive/atlend/atrc.shtml.

If you have questions about the AT Lending Library or need assistance in learning about the AT that might work for you, contact PIAT at 800-204-7428 (voice); 866-268-0579 (tty); or ATinfo@temple.edu (email).

Office of Vocational Rehabilitation

$2 million increase for OVR, which would leverage approximately $8 million in federal funds. OVR provides supported employment services to adults with disabilities.

Department of Education

$50 million increase to special education, which would be distributed according to the new Special Education Funding Formula.

No change in funding was proposed for Preschool Early Intervention.

Treasury Department

$4 million to start up the PA ABLE savings account program for individuals who acquired their disability before age 26.

The Arc of Pennsylvania will continue advocating for a budget that empowers people with disabilities in our communities - a budget that helps those with disabilities who are presently confined to their homes get the support they need to seek employment and community connections; a budget that helps high school students find meaningful, sustainable work that prepares them for adult life; and a budget that supports families through providing respite care for caregivers.
Include Me School Age Update

The Arc of Pennsylvania’s Include Me School Age program is finishing another successful year of supporting students, teachers, and schools across the state. Include Me supports effective inclusive education in grades K-12 across Pennsylvania; currently Include Me is working in 30 districts to support 214 students.

Meet Cristobal, who attends Chambersburg Area Senior High School. He is participating in an inclusive classroom with support from his local Include Me consultant, Susan Edney. He has accomplished many things, including recently learning to go order lunch, pay, eat his lunch and return his tray. Cristobal is thriving in this inclusive classroom after being in a more segregated setting.

Include Me is recognized as an inclusion leader across the state. Include Me and leadership from Bangor School District presented at the Pennsylvania Department of Education Special Education conference about the impact of Include Me. Presenters included:

- Rita Cheskiewicz - Project Director, Include Me
- Pam Klipa - Government Relations & Advocacy Directory, The Arc of Pennsylvania
- Stephen J. Bagnato, Ed.D., NCSP Professor of Psychology & Pediatrics Faculty Mentor, Division for Early Childhood Partnerships University of Pittsburgh/Office of Child Development
- Jeanine Tiscio - Assistant Principal Washington Elementary School

Include Me was also recently highlighted by the Bureau of Special Education in The Special Education in Pennsylvania: A focus on Data-Driven Programs and Services 2014-2015 booklet, which reaches every school in Pennsylvania.

Include Me and partner Mikayla’s Voice recently hosted an inclusion assembly featuring Pennsylvania’s Secretary of Education Pedro Rivera. Secretary Rivera read Our Friend Mikayla, a book written about Mikayla Resh by her third grade class. Carter and MacRae Elementary in Lancaster developed a curriculum around the book and were excited to welcome Secretary Rivera and Mikayla.

Include Me is proud to partner with Mikayla’s Voice, founded by Kim and Mikayla Resh. Mikayla was born with disabilities and grew up fully included in her schools and community. Now a young adult, Mikayla and her mother Kim travel around Pennsylvania teaching students about having a friend with disabilities and giving them a safe space to ask questions about people with disabilities through inclusion assemblies.

Join the Disability Advocacy Network

It’s a big election year - subscribe to the Disability Advocacy Network and keep updated on decisions that impact you. http://cqrcengage.com/thearc/app/register?0&m=163962

GO GREEN

The Pennsylvania Message is now available via email. Please send your full name, local chapter, and email address to ahouser@thearcpa.org to receive your electronic copy.
Message from Board Director Mike Marsh on Recent Budget Hearings

As a volunteer for The Arc of Pennsylvania and The Arc Alliance, as I note many on this list are as well, I just want to say THANK YOU to our local chapters, our execs, and The Arc of PA staff. [The amount of coverage intellectual and developmental disability issues received in budget hearings] is nothing short of impressive. Thank you for your leadership, dedication, and focused efforts. No way would there be such a response without intentional efforts by so many. You all are absolutely heroes for so many in our Commonwealth. So many of you are struggling with budgets and to supply the leadership needed to our families and yet you work so hard to inform legislators. These are impressive results.

Fellow parents and volunteers - thank you all as well. I know many of you met with legislators, staffers, wrote letters or emails, made phone calls and made sure vital stories are told. Without your ongoing work to help make the needs real, no progress can be made. Investments are easier to make when there are real people impacted. You all help to give voice to those who don't have a voice and encourage those who do to tell their story.

Thank you to our self-advocates for speaking up for what you need and know to be right and for so many others who don’t yet know how to get their message across. Each of you are strong individuals who contribute a lot to our Board(s), communities, and families. Thank you very much for sharing your gifts and talents.

-Mike Marsh, parent/volunteer

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.