

# Pennsylvania Message

## Uncertainty Lingers with Implementation of Healthy PA

Healthy PA, the Corbett administration's alternative to Medical Assistance (MA) expansion, took effect in Pennsylvania on January 1, 2015. Changes to MA benefit limits for people with disabilities and access to insurance through the Healthy PA private coverage option also took effect January 1. Approximately 600,000 additional Pennsylvanians are estimated to be eligible for private coverage through Healthy PA. Enrollment in Healthy PA is currently open (<https://www.compass.state.pa.us/compass.web/cmhom.aspx>), and there is no deadline for enrollment. Program implementation continues to be a source of uncertainty. Governor Tom Wolf plans for full expansion of Medicaid as permitted under the Affordable Care Act. It is unclear how quickly Governor Wolf's administration will be able to change the current Healthy PA and move towards straight MA expansion. Officials have pledged that no one will lose coverage in any transition.

As a result of Healthy PA, all current MA benefits are streamlined into the "Healthy" and the "Healthy Plus" packages. People with disabilities should automatically be assigned to the "Healthy Plus" benefits package, which offers the most coverage. The PA Department of Human Services (DHS, formerly the Department of Public Welfare) is deciding which benefits package people fit into based on their own data. Individuals who feel that they have been incorrectly assigned to the "Healthy" package can contact DHS directly.

Benefit limit changes to "Healthy Plus" and the new option for private coverage, available to individuals who don't qualify for MA, were approved by the Federal

government. Benefit limits for the "Healthy" plan have not been approved, so people who would have been assigned to the "Healthy" plan are keeping their traditional MA benefits. The Federal government has until March to decide about benefit limit changes for the "Healthy" plan. This means that people in the "Healthy Plus" plan currently have some benefits, such as medical equipment, that are actually more restricted than individuals in the "Healthy" plan, despite the intention to serve people with higher medical needs under the "Healthy Plus" plan.

The Arc of Pennsylvania and other advocacy groups remain concerned at the lack of detail regarding benefits limits for Healthy PA. Please let us know if you encounter issues with individuals being assigned

to the incorrect benefits package or failing to receive services they have a right to access. The best way to stay current on Healthy PA is to sign up for In Touch, our new e-newsletter published monthly or more frequently as important policy updates dictate. (To sign up for In Touch see Page 6).

Additional Resources:

- [www.HealthyPa.com](http://www.HealthyPa.com)
- Contact Sheet: <http://www.thearcpa.org>
- For a comparison of benefit limits:
- [http://www.dhs.state.pa.us/cs/groups/webcontent/documents/document/c\\_120843.pdf](http://www.dhs.state.pa.us/cs/groups/webcontent/documents/document/c_120843.pdf)
- PA Health Law Center: <http://www.phlp.org> ; (800) 274-3258 for questions/ to report problems.

*Achieve with us.*



**Healthy PA**

ACCESS • AFFORDABILITY • QUALITY

# President's Message - Jeanne Downey



*The snow glows white on the mountain tonight  
Not a footprint to be seen  
A kingdom of isolation,  
And it looks like I'm the queen.  
"Let It Go"*

Frozen is the blockbuster Disney movie, spanning all groups. You can't go anywhere without hearing a child (or adult) singing "Let it Go..." But initially, I wasn't a fan of the story—the parents hiding away their one daughter, Elsa, who was "different"; Elsa being isolated because she thinks she is some kind of monster; and her sister, Anna, who just wants to play with her, seeing Elsa resist because she was afraid of hurting her. I felt this is what happens to many families who have children with disabilities and it made me sad. But after watching the movie several times, I saw a different parallel to the lives of people with disabilities—there are ups and downs in our lives and sometimes we just want to run away; we should try to accept and help people who are different from us, even if those differences can be a little scary; there are battles that we must fight; and true love is what helps us rise above it all and live!

*It's time to see what I can do  
To test the limits and break through  
No right, no wrong, no rules for me  
I'm free*

Over this past year, our advocates have waged some significant battles and have WON! They have "broken through" in many ways. These battles have included:

**ABLE ACT:** Sara Wolff, Self-Advocate & Arc of PA Board Member, has been a tireless advocate and she even testified in Washington DC before the US Senate Finance Subcommittee in July 2014. Achieving a Better Life Experience (ABLE) Act creates tax-favored savings accounts for people with disabilities that would not count toward the \$2,000 individual asset limits that apply to the Supplemental Security Income (SSI) and Medicaid programs. Sara's passion changed "the way things are" in terms of future planning for people with intellectual and developmental disabilities!

**CHLOE'S LAW:** Kurt Kondrich, father of Chloe & Arc of PA Board Member, passionately spearheaded advocacy efforts that led to the passage of Chloe's Law, the Down Syndrome Prenatal Education Act.

This legislation, which was signed in to law by Governor Corbett in October 2014, mandates that medical practitioners give expectant or new parents "informational publications," relating to Down syndrome. Kurt's true love of his daughter led him to challenge current medical practices and change "how it's always been done" to families expecting a child with Down syndrome.

In 2015, let us ALL make a commitment to impact and improve the lives of people with intellectual and developmental disabilities. It may be at your local schools, places of worship, transportation systems, employers, medical professionals, law enforcement agencies, volunteer groups, sporting events, travel and entertainment activities, etc. There may be something bothering you and as you pursue it, you will probably find that it also bothers many other people. That's what grass roots advocacy is all about—not settling for "the way things are" and turning away when we are told "because that's how it's always been done". We make these efforts because of our true love for our family members and friends, and the results impact those that we've never even met. Let's energize our advocacy efforts—we need to turn away from systems and practices that result in isolation and slam the door on limitations placed on people with intellectual and developmental disabilities.

*Let it go, let it go  
Can't hold it back anymore  
Let it go, let it go  
Turn away and slam the door!*

A handwritten signature in black ink that reads "Jeanne C. Downey". The signature is written in a cursive style.

*Jeanne Downey is from Erie County, Pennsylvania.  
She began her 2-year term as President of  
The Arc of Pennsylvania in June 2013.*



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# Executive Director’s Message Maureen Cronin

## The Arc of PA Seeks Elimination of Waiting List in FY 2015-16 Budget



As we enter into 2015, with a new governor and administration, it is made increasingly more complex by an estimated \$2.3 billion deficit budget. The enormity of the work before The Arc of Pennsylvania and our 34 chapters does not escape me. But with hard work comes the opportunity to educate and advance our cause to better serve persons with intellectual and developmental disabilities and their families. The truth is, I am eager to get to work and encourage you to renew your commitment in this New Year and join me. Over the course of the next few months we will provide you with many opportunities to engage your legislators. As an organization we are counting on you for your continued and enhanced support of our shared mission and rely on you for your participation.

Our first priority is to address the 2014-2015 budget that only provides funding for 400 adults in emergency situations and 700 high school graduates - and for the most part not until May or even June 2015, leaving thousands of others with disabilities with unmet needs each and every day this fiscal year. Basic services such as transportation to the doctor’s office; support for finding a job; or aid to make a home safely accessible are not currently being provided to those waiting.

From there, we will call on Governor Tom Wolf to prioritize accessibility to quality of life programs and to assure that the 2015-2016 budget prioritizes funding for the 14,000 individuals who are presently eligible for services but not receiving them, so they will no longer languish on the waiting list. One-third of the people on the waiting list are enduring what are considered “emergency” situations, meaning they risk becoming segregated and institutionalized if the state does not provide support near-term.

The Arc of Pennsylvania firmly believes that the budget should be the Commonwealth’s moral testament to a progressive and inclusive vision for society. In partnership, we will work with Governor Wolf and his administration to present a 2015-2016 budget that properly equips the most vulnerable in our communities. Let’s resolve to help homebound people with disabilities have a chance to participate in their communities or find employment; let’s assist high school students in finding meaningful, sustainable work; and let’s provide respite care for caregivers.

As we advocate with and for persons with I/DD, we need your voice to be heard.

Send Maureen your comments at [mcronin@thearcpa.org](mailto:mcronin@thearcpa.org).

# SAGA: Systems Advocacy & Government Affairs

## State Budget

Pennsylvania faces an estimated \$2.3 billion structural deficit in the 2015-2016 state budget. A structural deficit means that the government is not bringing in enough money in revenue to support its spending obligations. Without significant policy changes such as increasing taxes or decreasing government spending, Pennsylvania's structural deficit is expected to grow to approximately \$2.5 billion in a few years. Legislators, policy makers, and Governor Wolf have proposed different ways to address this deficit, including a tax on natural gas extraction; pension reform; and liquor privatization. The Arc of Pennsylvania is concerned about cuts or freezes to budgets of disability services, particularly in light of the continued waiting list for intellectual disability services and need for more autism services. The Arc of Pennsylvania is advocating for these and other priorities of people with I/DD and their families by meeting with Governor Wolf's administration, legislators, and numerous policy makers.

## Paul's Law

The Arc of Pennsylvania continues working with Representative John Sabatina (D-Philadelphia) on Paul's Law, which was introduced as HB 1474 in the previous legislative session. Paul's Law prohibits organ transplant discrimination against people with disabilities on the sole basis of their disability. We expect Representative Sabatina to re-introduce Paul's Law early in this legislative session—stay tuned for an Action Alert that will let you know when you can ask your local representative to support Paul's Law.

## Employment for Young Adults with Disabilities

The Arc of Pennsylvania is a member of the Campaign for What Works and its I Want To Work advocacy campaign. As part of this advocacy coalition and alongside other disability rights organizations, we are advocating for funding for the Office of Vocational Rehabilitation at a level that draws down the full amount of the available match in federal funds, focused employment support for youth transitioning out of high school, and employment in community settings for young adults with disabilities. The I Want To Work advocacy campaign is being led by young adults with disabilities, including Josie Badger and Alexa Brill. In the upcoming legislative session we will focus on reintroducing and passing HB 2405, which was introduced by Representative Tom Murt (R-Montgomery) in July 2014 and SB 1497, introduced by Senator Lisa Baker (R-Luzerne) in October 2014. These bills reflect some of our employment legislative priorities, including funding the Office of Vocational Rehabilitation, work experiences

for high school youth with disabilities, and connections to community employment. Contact our office or the I Want To Work campaign if you are interested in joining our advocacy efforts.

## LEARN MORE / DO MORE

Stay Informed with PIE - The Policy Information Exchange (PIE) covers policy issues for Pennsylvanians with disabilities, their families, and advocates. The Arc of Pennsylvania manages PIE for the PA Developmental Disabilities Council.

Email us at [pie@theacrpa.org](mailto:pie@theacrpa.org) to receive electronic alerts and the quarterly newsletter.



On February 5, 2015, Rita Cheskiewicz and Pam Klipa from The Arc of Pennsylvania will be joined by Dr. Steve Bagnato from the University of Pittsburgh Early Childhood Partnerships to present information on our Include Me program at the Pennsylvania Department of Education Bureau of Special Education annual statewide conference. Include Me provides inclusive education training and consultation to volunteer school districts and families. Inclusion consultants are on-site, in classrooms acting as a resource to teams supporting students with complex needs in general education settings. Include Me provides support to identified teams for students in kindergarten through twelfth grade.

The conference, to be held in Hershey, is designed to highlight effective instructional strategies and interventions designed to make an educational difference for all students. Dr. Bagnato will present an overview of the independent evaluation outcomes data for Include Me's 2013-2014 year that indicates that students with disabilities participating in Include Me show statistically significant improvements in behavioral and social skills, as well as improvement in communication and adaptive skills. Rita and Pam will share examples of students participating as members of their classrooms, inclusion assemblies and parent testimonials about the impact of inclusion. For more information on Include Me, contact Rita Cheskiewicz, Program Director, at [ritac@includemepa.org](mailto:ritac@includemepa.org).

# Making Life Better for People with Special Health Care Needs



## Special Kids Network

*Making Connections for Pennsylvania's Children with Special Health Care Needs*

Do you have or know a family that has a child with a special health care need, such as autism, an intellectual disability or one who uses a wheelchair? Are you struggling to find information, to understand and navigate the system and make sure the child has everything he or she needs? If the answer to any of these questions is “YES,” then the Special Kids Network (SKN) can help. SKN is a program funded by the Pennsylvania Department of Health (PADOH) and managed by the PA Elks Home Service Program (Elks). The purpose of SKN is to make life better for families and children, especially those with special health care needs.

The SKN program began as an information and referral helpline in 1996 through its toll-free number: **800-986-4550**. Today, SKN offers three primary components that focus on children and youth with special health care needs (CYSHCN), as well as their families:

1. A toll-free helpline, **800-986-4550**;
2. In-home service coordination provided at no cost to families; and
3. A system of community and regional support.

The first component, the toll-free helpline, is available Monday through Friday, 8:30 a.m. - 4 p.m. and is answered by trained staff. The helpline connects families to resources and refers families for individual and family-centered service coordination, if needed.

The second component, in-home service coordination, is provided by the Elks, a statewide, non-profit organization with over fifty years' experience helping to improve the quality of life for children and adults. A referral can be made to an Elks nurse when the family needs assistance in obtaining information and services. The nurse will come to the family's home, not as a nurse offering medical care, but as someone who coordinates home-based support services.

The third component, a system of community and regional support, is provided by six regional coordinators. The coordinators, who are parents of children with special health care needs, have experience advocating for their children. The coordinators organize and facilitate meetings for families, providers and communities to improve the system of care for CYSHCN.

## Senator Casey's ABLÉ Act is Law

On December 19, 2014, President Barack Obama signed the Achieving a Better Life Experience Act (ABLE Act) into law, paving the way for people with disabilities to open tax-free savings accounts. Modeled after 529 college savings plans, under the new law qualified persons can save up to \$100,000 without risking eligibility for Social Security, Medicaid, and other government programs. Funds can be used to pay for community living expenses including education, health care, transportation, housing and other expenses.

To be eligible, individuals must have a disability that occurred before age 26 and each person may only open one ABLE account. Under current gift-tax limitations, as much as \$14,000 could be deposited annually.

Regulations for The ABLE Act are expected from the US Department of Treasury by June 19, 2015 and each state will have to choose whether or not to offer ABLE Accounts. The Social Security Administration will be developing more details on who qualifies for ABLE Accounts and those eligible should be able to sign up under any state's plan. The Arc of Pennsylvania is working with legislators to enact the ABLE Act in Pennsylvania and ensure people with disabilities have access to the accounts.

The bill was first introduced in 2008 under the name of the Disabilities Savings Act, and in subsequent sessions was introduced by Senators Casey and Burr as the ABLE Act. In a published statement, Senator Casey recognized the leadership and support of The Arc of Pennsylvania and other disability rights organizations in moving this legislation as well as our Board Member, Sara Wolff, who was one of the bill's most vocal advocates.

# Telephone Access for Transitioning Youth with Disabilities

By Diana Jurist, Consumer Educator, PA's TDDP



All young people experience changes after High School graduation. Protected by the comforts parents and schools provide for us, it is a shock when we graduate and for the first time, we may need to find our own way. Students with disabilities experience the same new challenges after graduation, but often to a

higher degree. Whether it is the need to make our own appointments with doctors, find travel accommodations or just connect with a friend, we must be sure we have the proper tools in order to accomplish these activities independently (or in some cases as independently as possible). In Pennsylvania, the "transition process" begins at age 14. Career planning, job skills, college accommodations, and independent living skills are just a few of the topics discussed during these transition years. I wonder, however, if teams discuss another important transition topic, Telecommunication Access. Are teams reviewing the many telephones and accessories designed to accommodate communication needs in the home and at work? Do they know where to send families to learn more about Pennsylvania's Telecommunication Device Distribution Program (TDDP)?

The Telecommunication Device Distribution Program (TDDP) is a statewide program which provides FREE, specialized telecommunication devices (telephones and accessories) to eligible Pennsylvanians who have disabilities which impede independent access to telephone services. Implemented by Pennsylvania's Initiative on Assistive Technology (PIAT), and funded by the PA Office of Vocational Rehabilitation and the PA Public Utility Commission, TDDP is one of the many programs at the Institute on Disabilities at Temple University.

While the program is operated out of Philadelphia, you don't have to live near Philadelphia to access TDDP and the specialized telecommunication equipment. There are seven Assistive Technology Resource Centers located throughout the state to answer your questions, provide demonstrations of the program's equipment, and even help you apply. To acquire information about the TDDP and adding telecommunication access to your transition plan, acquiring equipment for yourself, or a loved one please contact us at 800-204-7428 (voice), 866-268-0579 (TTY), 215-204-6336 (fax), or by email at [TDDP@temple.edu](mailto:TDDP@temple.edu). More information about the program can also be found on our website: [www.disabilities.temple.edu/tddp](http://www.disabilities.temple.edu/tddp).

## Advocacy & Policy Day

Plan now to participate in The Arc of Pennsylvania's 2015 annual conference in Harrisburg. Conference updates and registration information will be communicated in upcoming editions of In Touch.

4/20/15

The Arc of PA's Advocacy & Policy Day

4/20/15

The Arc of PA's Legislative Reception

4/21/15

The Arc of PA PCE Meeting

4/21/15

The Arc of PA's  
Board of Directors Meeting

4/21/15

The Arc of PA's  
Annual Membership Meeting

## Our New E-Newsletter Has Launched!



We are offering a new monthly e-newsletter in order to keep you more regularly informed on disability policy, advocacy issues and provide you with additional detail on what is going on at your state chapter in Harrisburg. We will continue to publish the print and electronic versions of Pennsylvania Message three times annually. For a limited time, you can sign up for In Touch without having to pay a membership donation. To register to receive this new publication email Amy at [ahouser@thearcpcpa.org](mailto:ahouser@thearcpcpa.org) before February 20.

# New Governor



On January 20, Tom Wolf was inaugurated as the 47<sup>th</sup> governor of the Commonwealth of Pennsylvania. In a separate swearing-in ceremony, Michael J. Stack III became Lieutenant Governor. Supporting this transition are new Cabinet members and review teams that will work with the outgoing administration to better understand the issues and challenges that face the executive branch. Especially noteworthy is that Maureen Cronin, Executive Director, The Arc of Pennsylvania, was named to the Aging Transition Committee.

As The Arc of Pennsylvania begins a new season of advocacy on behalf of persons with intellectual and developmental disabilities, we welcome our new slate of lead legislators:

## House Republicans:

Speaker of the House: Mike Turzai (R-Allegheny)  
Leader: Dave Reed (R-Allegheny)  
Whip: Bryan Cutler (R-Lancaster)

Appropriations Chairman: William Adolph (R-Delaware)

## House Democrats:

Leader: Frank Dermody (D-Allegheny)  
Whip: Mike Hanna (D-Clinton)

Appropriations Chairman: Joe Markosek (D-Allegheny)

## Senate Republicans:

President Pro Tempore Designee:  
Joe Scarnati (R-Jefferson)

Leader: Jake Corman (R-Centre)

Whip: John Gordner (R-Columbia)

Appropriations Chairman: Pat Browne (R-Lehigh)

## Senate Democrats:

Leader: Jay Costa (D-Allegheny)

Whip: Anthony Williams (D-Philadelphia)

Appropriations Chairman:

Vincent Hughes (D-Philadelphia)

## Governor Wolf has announced the following nominations and appointments:

Sharon Minnich - Secretary, Office of Administration

Teresa Osborne - Secretary, Department of Aging

Russell Redding - Secretary, Department of Agriculture

Robin Wiessmann - Secretary, Department of Banking and Securities

Randy Albright - Secretary, Office of the Budget

Cindy Dunn -

Secretary, Department of Conservation and Natural Resources

John Wetzel - Secretary, Department of Corrections  
Gary Tennis - Secretary, Department of Drugs and Alcohol

Pedro Rivera - Secretary, Department of Education

Richard Flinn -

Director, Pennsylvania Emergency Management Agency

John H. Quigley -

Secretary, Department of Environmental Protection

Timothy Solobay - Commissioner, Office of Fire

Curt Topper - Secretary, Department of General Services

Dr. Karen Murphy - Secretary, Department of Health

Ted Dallas - Secretary, Department of Human Services

Grayling Williams - Inspector General

Teresa Miller - Secretary, Department of Insurance

Kathy Manderino - Secretary, Department of Labor and Industry

Major General James R. Joseph -

The Adjutant General, Department of Military and Veterans Affairs

Colonel Marcus L. Brown - Commissioner, Pennsylvania State Police

Dr. Rachel Levine - Physician General

Leslie Richards - Secretary, Department of Transportation

*Government is a trust, and the officers of the government are trustees; and both the trust and the trustees are created for the benefit of the people.*

*Henry Clay (1777-1852) - Speech at Ashland, Ky., March, 1829.*

## North Schuylkill Friends Forever Program



*"The only way to have a friend is to be one."*  
— Ralph Waldo Emerson

We're excited to share this wonderful example of inclusion at the high school level with you. As their 2015 legacy project, North Schuylkill High School students Paul Dean, Brett Budwash, and David Zienkiewicz developed a student program that recognizes that not all friendships develop naturally and that sometimes students need corroboration in fostering healthy and rewarding peer relationships. "Friends Forever" creates a culture of change that supports interpersonal relationships with the goal of providing all students with the opportunity to build lasting friendships.

The Friends have been taught special skills to create an environment of respect and acceptance and they plan peer-to-peer supervised gatherings to create different opportunities for friendships to develop such as movie and game nights or attending after-school club, cultural or sporting events. This program serves as a wonderful example of how to support the social, emotional and intellectual development of students.



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Harrisburg, PA  
Permit No. 649

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The **Pennsylvania Message** is published by The Arc of Pennsylvania.  
The Arc of Pennsylvania is affiliated with The Arc of the U.S. and 34 local chapters serving 56 counties and 8,000 members.

## Include Me Welcomes Senator Casey to Mikayla's Voice School Assembly

The Arc of Pennsylvania's Include Me program sponsored a Mikayla's Voice school assembly on December 19 at the Neil Armstrong Elementary School in the Scranton School District with special guest, Senator Bob Casey. We have been partnering with Mikayla's Voice for four years now as part of our message of inclusion. The program, focuses on changing a child's possible feelings of fear or intimidation when meeting a child with disabilities to one of understanding and acceptance. Senator Casey met with the students and was the guest reader of the book *My Friend Mikayla*, a story about having a friend with a disability, published by Mikayla's classmates in 2006 when she was in the third grade. A copy of the book was donated to every public school in Pennsylvania in 2012. The assembly program can be adapted for elementary, middle, high school and college levels.



Senator Casey greets Mikayla Resh, her mother Kim Resh, and Maureen Cronin before the Include Me program assembly at Neil Armstrong Elementary School.

### 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.*