The 2014 Gubernatorial Candidates
HOW THEY WILL WORK FOR PEOPLE WITH DISABILITIES

As your lead policy advocate, The Arc of Pennsylvania represents the interests of the intellectual and developmental disabilities community at every level of government, working hard to ensure that our constituency remains relevant in our legislators’ agendas. With the governor’s election pending this fall, we reached out to Governor Tom Corbett and his Democratic opponent, Tom Wolf, to ask them to weigh in on topics that matter to our community. We hope this Q&A helps you to ascertain which of the two candidates will best serve you and your family.

Question 1 - What has been/what will be your governing philosophy when it comes to issues impacting citizens with intellectual and developmental disabilities and their families? And, how have you made sure/how will you make sure your decisions on those issues are informed by people with disabilities and their families?

Tom Corbett

I believe that residents with intellectual and developmental disabilities should have the same opportunities as other residents to lead fulfilling lives. That includes attending high quality publicly funded education programs that meet their needs and prepare them for meaningful employment, and the opportunity to live at home and in the community. As governor, I will work with key stakeholders, including self-advocates and their families, when exploring relevant policy.

With the guidance of Chloe and her family, one of my proudest accomplishments as Governor has been to work with the state legislature to lead Act 130 of 2014 - widely known as Chloe’s Law - to my desk for signature. I signed Chloe’s Law this past July 18th, which will ensure that expectant families are provided with up-to-date evidence-based information about Down syndrome that has been reviewed by medical experts and national Down syndrome

Governor Tom Corbett

As Governor of Pennsylvania, my philosophy has been guided by a desire to ensure that every Pennsylvanian is afforded an opportunity to succeed. Over the past several years, I have been fortunate to develop a friendship with a young girl named Chloe Kondrich. Chloe - who was born with Down syndrome - is an active eleven year old who excels at school and loves volleyball. Chloe is my inspiration. She demonstrates that every individual is capable of accomplishing remarkable achievements if given the resources necessary to succeed.

Additionally, I will name an individual as Secretary of the Department of Public Welfare who shares my values on the importance of supports and services for all persons with intellectual and developmental disabilities. I will work with the Secretary to assure that people with intellectual and developmental disabilities have respect, are integrated into their communities, and have meaningful choices of work.

Tom Wolf

I believe that residents with intellectual and developmental disabilities should have the same opportunities as other residents to lead fulfilling lives.
President’s Message - Jeanne Downey

Mother said: “Stand up straight. Don’t let your classmates make, you feel like you don’t belong. So not like the rest of them, someday, the best of them, will realize they were wrong.”

Standing Out in a Crowd - Trisha Yearwood

By this time of year, students are back in school. For some students and their families, it can be a very challenging time. Wanting to fit in, learning new things, and making friends are things that all students want, whatever their age! And for students with intellectual and developmental disabilities, fitting in is very important! Many times, they don’t want to stand out for being “different”.

Entering the educational arena is emotional because it means parents need to let go a little. This is true for all families of three year olds, but even more so for families whose children require additional supports and services. Not knowing if your child will fit in, be able to do the work, and most importantly, be happy, are all concerns that parents of preschoolers have as their child starts their educational journey. Learning educational acronyms and processes are new lessons that families of children with disabilities experience.

When children transition from the preschool to kindergarten, families have a somewhat different set of emotions and lessons. Depending on their experiences in preschool, this transition can be fairly smooth or very rocky. The expectations of teachers and school administrators are key to making all students successful and this is especially true for children with intellectual and developmental disabilities. Having the best resources available can make these school experiences positive for students and their families.

The Arc of Pennsylvania has started another school year offering the Include Me program, designed to promote and expand inclusive practices for students with significant disabilities, grades K-12. (www.includemepa.org). Students in over 30 school districts across Pennsylvania are currently receiving Include Me services, with some districts increasing the number of students involved. The Arc has recently received additional funding to expand the program for Include Me School Age. These two outstanding initiatives involve consultants who provide onsite support and training for school personnel/student teams, as well as family members of children with disabilities. These resources are not only beneficial to the students who are directly involved, but they provide the help to build inclusion capacity within all schools. For students and their families, these opportunities, are priceless! It creates a culture of inclusion in the entire school community. The students involved with Include Me now “stand out” because they ARE fitting in, they ARE learning new things, and they ARE making friends!

“It’s funny how now, it’s not such a bad place to be. Standing out in a crowd.”

Jeanne Downey is from Erie County, Pennsylvania. She began her 2-year term as President of The Arc of Pennsylvania in June 2013.
The U.S. Census estimates there are 56.7 million Americans, about one in five, with a disability or chronic condition. Last year, the Youth Transitions Collaborative conducted a survey that studied the voting patterns and political views of people with disabilities and chronic conditions, their families and caregivers. Because they were largely unknown, some interesting and powerful information was gleaned from the survey, “Power in Numbers: A Profile of American Voters with Disabilities.”

We learned that as a disability community, we are politically diverse; we care deeply about issues impacting the community and will vote on these issues. The best current Census estimates place voter registration for our community at 69%, as compared to 72% of the overall population. More than 80% of those polled indicated that a candidate’s record on supporting services and programs for people with disabilities is “somewhat” or “very important.” Approximately the same number indicated that they would consider voting against a candidate they otherwise supported who was in favor of cuts to services. Similarly, they would actively support a candidate working to strengthen government services and supports for people with disabilities.

The two findings that are especially good news for The Arc are:

- 12% of those surveyed indicated that they are part of an organized group or movement today that helps Americans with disabilities or other chronic conditions AND an additional 19% want to be.
- Younger members (18-30) of the disability community will act even more strongly on issues affecting our community and are even more apt to vote.

This indicates that we have an opportunity to engage more people in our efforts and we should be steadfast in identifying new, creative and innovative ways to engage them in The Arc.

The collective strength of the disability community at the polls is significant and with so much at stake we need to mobilize our membership, family and friends to keep our issues front and center this November. What’s in store for the next four years may very well be a matter of your having voted...or not!

Every vote counts. Let yours be heard!

Send Maureen your comments at mcronin@thearcpga.org.
I support the principles enunciated in the Oberti decision and embodied in the Gaskin settlement. Pennsylvania has made great strides since the early nineties, when it ranked near the bottom of all states in terms of inclusiveness. However, clearly there is more work to be done.

As governor, I will promote efforts to improve school climate for students with disabilities. I believe we need to provide adequate state funding for education programs so that students with special needs have access to appropriate supports and programs. I will also support a special education funding formula so that every child in the Commonwealth has access to the tools and resources to be successful.

Lastly, I will work to bridge the transition between school and the workforce so that students have opportunity to transition into meaningful employment opportunities.

Question 3 - Since passage of Act 70 of 2010, The Adult Protective Service (APS) Law, Pennsylvania has been working to institute a system that protects adults with intellectual and developmental disabilities between 18-59 years of age from abuse and neglect. However, this desperately needed system has not received sufficient funding and has not been implemented effectively.

Protecting vulnerable Pennsylvanians who cannot protect themselves is a primary responsibility of state government. As Governor/if elected, how will you support full implementation of the APS system?

Act 70 was an important step in ensuring that adults with disabilities are protected from abuse and neglect. As implementation of this law continues, I remain committed to providing increased resources to the Department of Public Welfare, the Area Agencies on Aging, and county and local agencies to ensure complete and thorough implementation.

I believe that great strides have been made since Act 70 was enacted, and it is my hope that as implementation continues, Act 70 will provide a comprehensive system to ensure that persons with disabilities are protected from abuse and neglect.

As governor, I will work with key stakeholders including self-advocates and families to carefully review and monitor APS implementation to ensure that the system is appropriately funded and achieving the critical goal of protecting vulnerable Pennsylvanians.
Question 4 - Fifteen years ago, the U.S. Supreme Court ruled in its Olmstead decision that unnecessary institutionalization of citizens with disabilities violates federal law, yet Pennsylvania still operates five state centers and approximately 1,000 Pennsylvanians are housed in them. Research has demonstrated that individuals with intellectual disabilities thrive in the community as compared to institutions when they receive appropriate supports and services.

As Governor/if elected, will you commit to close the remaining five state centers and ensure 1,000 individuals receive support to live full lives in their communities?

I take very seriously compliance with the Olmstead decision. There are fewer than 1000 Pennsylvanians residing in our state centers while tens of thousands of Pennsylvanians are being served successfully in the community. The Department of Public Welfare is working to transition to the community state center residents who have expressed an interest in doing so. In fact, my budget for the current year includes new funding to make that a reality for an additional 50 individuals. We plan to do the same in subsequent budget years as well. Asking someone to move from a place where they have lived for decades can be a very sensitive issue, and care must be taken to do it properly. I also believe we must work hard to ensure that community services are of high quality and offer individuals with intellectual disabilities an “everyday life”, and my administration has been committed to doing so. Finally, in addition to enabling individuals to return to the community from state centers, we must do all we can to serve individuals who have no services. To that end, I have increased funding to help people with disabilities come off of waiting lists and stay in their homes and communities.

I firmly support the Olmstead decree and will work with DPW to create and implement an Olmstead plan. As governor, I will work with families, providers, and counties to ensure that they understand the research and importance of community versus institutional living.

Question 5 - As of May 31st, 13,855 Pennsylvanians with intellectual and developmental disabilities were on the state’s waiting list for services, over 4,000 are waiting for emergency services. Some of these Pennsylvanians face dire medical situations, are supported by aging caregivers, and have been desperately waiting for services for years.

As Governor/if elected, how have you addressed/how will you address this critical issue facing individuals and families? Describe your commitment to bring supports and services to these Pennsylvanians.

During the early days of my administration, I had the privilege of meeting several families in the Philadelphia region who had loved ones on the waiting list. When I left that meeting, I was a changed person. The care and support of individuals with significant disabilities should be our number one priority. That is why I have made reducing the waiting list a budget priority. To date, my Administration has invested an additional $199 million in total state and federal dollars to reduce the intellectual disability waiting list, providing home and community-based services for an additional 3,310 individuals and their families.

But there is more to be done, and I will continue to make this a budget priority so that all Pennsylvanians with intellectual disabilities and their families have the supports they need to live an everyday life.

My administration will work to decrease the waiting list in all categories. The waiting list initiative will work with all stakeholders including providers, counties, advocates, families, and self-advocates to identify untapped funding sources and federal opportunities for funding. In addition, DPW will continue to explore managed long term care options for people with intellectual and developmental disabilities.

Take up your right to vote and go to the polls on November 4 or file your absentee ballot by October 31.
Launched by The Arc of Pennsylvania in 2010, Include Me has evolved into a robust program that works towards including all students with significant disabilities into general education classrooms early, making it less likely that they will be segregated by building sustainable inclusion practices and capacity within school districts.

Include Me drives the conversation about the value to children with intellectual and developmental disabilities (I/DD) and those without I/DD of being in the classroom together. Include Me brings school administrators, teachers, parents and students together to establish best practices and define common goals.

The program now includes two components; Preschool and School Age. This school year, Include Me Preschool’s Inclusive Education Consultants and Early Intervention Teams will support eight Intermediate Units across the state with on-site technical assistance, parent and teacher training and other capacity building projects so that young children with disabilities are better prepared to enter kindergarten.

The School Age program provides the same services with a goal of reaching 170 students this year. On average, Include Me consultants provide 37 hours per month of in-person mentoring, training and consulting to teachers. Last year, Include Me provided mentoring, trainings, and consultation to approximately 180 teachers, 120 students with significant disabilities, and 240 parents in 30 school districts. Include Me is funded by the Pennsylvania Department of Education, the Harry and Jeanette Weinberg Foundation and the Donald B. and Dorothy L. Stabler Foundation and offers support at no cost to schools.

The University of Pittsburgh Early Childhood Partnerships provides an independent evaluation of the impact of Include Me and has determined that the program has continued on a positive, results-oriented path of inclusively educating students with complex needs into regular education classrooms. Students with disabilities show statistically significant improvements in behavioral and social skills, as well as improvement in communication and adaptive skills.
The Arc of Pennsylvania’s DISCOVERY Focuses on Employment

Use of the customized employment process called Discovery is a new initiative of The Arc of Pennsylvania that supports transition students with disabilities after graduation and is an alternative to traditional vocational assessments. Discovery focuses on the abilities and interests of the student, taking into account the activities they already enjoy and pursue, to connect the student with successful, sustainable, and living-wage employment. The Discovery Profile, developed and offered by Marc Gold and Associates, a nationally recognized leader in customized employment, is unique because it first focuses on understanding the identity of the job seeker.

The Arc of Pennsylvania works with 15 consultants who are being trained to obtain a national certification in the Discovery process which will prepare them to train other consultants in future years. This certification is the first of its kind in the United States and eight consultants have already received their certification. Consultants meet with a student on a weekly basis and learn about them through observations, interviews, research, and participation in activities and at times also meet with their families, friends, educators, and other mentors. The PA Office of Developmental Programs and the Donald B. and Dorothy L. Stabler Foundation fund the program.

For more information contact Rita Cheskiewicz at ritac@includemepa.org.

“The Arc of Pennsylvania’s Discovery program responds to the desperate need for better transition services in school age services and better post-school employment options for youth with disabilities. Parents who have worked hard to have their children included in regular education are not interested in pursuing sheltered workshop or segregated day programs after their children age out of the school system.”
Rita Cheskiewicz, Include Me Project Director

Selfies to Put a Face on the “I Want to Work” Campaign

The I Want to Work Campaign (of which The Arc is a partner) is leading a selfie campaign the week of Oct. 20. The idea is for youth still in high school to schedule appointments with their legislator(s) and pose with their legislators holding the I Want to Work poster. Pictures can then be posted on Facebook and other social media outlets. This campaign is to gather support for additional funding in HB 2045 for students to have OVR support while still in school so that they can have part time jobs just as students without disabilities. These part time jobs lead to full employment after graduation.

The Arc of Pennsylvania will be joining DPW Secretary Beverly Mackereth at the Capitol on October 23 for selfies. For a list of key Senators and Representatives that are on the Labor and Industry House and Senate committees visit our website, www.thearcpa.org.

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.
HEALTHY PA APPROVED BY CMS

Healthy Pennsylvania, Governor Corbett’s alternative to Medicaid expansion, has been approved by the federal government. Many details of Healthy PA remain in negotiation, including: potential limits on benefits such as durable medical equipment; potential health assessments to qualify for the high-risk benefit plan; and the process of obtaining exemption from monthly premiums. Stakeholder input influenced what was changed and approved in the Healthy PA plan. As a refresher, Healthy PA makes changes to the current Medicaid system and creates a private coverage option for people at or below 133% of the federal poverty level.

Details of the approved plan include:

No work search requirement: Work search activities for Medicaid enrollees will not in any way impact eligibility or coverage. The Corbett administration had proposed that a work search requirement be tied to health coverage under Healthy PA, though they later softened this stance; CMS (Centers for Medicare and Medicaid Services) did not approve this.

Premiums: Monthly premiums will be charged for individuals who are not exempt from paying them. People with disabilities are considered exempt from premiums, though it is unclear how this exemption will be determined.

Low and high benefits plans: The details of benefit limits are still being negotiated. It is reported that the high-risk benefit plan, which people with disabilities would be covered under, is comparable to commercial plans. It is still unclear what mechanism, such as a health assessment, will be used to determine which plan an individual enrolls in.

Copayments: Copayments will remain at the current rate during 2015 and will continue being charged through the end of the demonstration project for those at or below the federal poverty level. People can be denied coverage by a physician in the private option if they do not pay copayments.

Disenrollment for failure to pay premiums: Failure to pay Medicaid or private premiums for three consecutive months will result in being un-enrolled from coverage. Individuals can apply to re-enroll and must be accepted. CMS did not approve the Corbett administration’s proposal that failure to pay premiums would result in being dropped out of Medicaid and being locked out from re-enrolling for a time period.

Some of these details may change as the state and federal government finalize their negotiations. Healthy PA will begin on January 1, 2015 and we will be monitoring its implementation closely. You can visit www.healthypa.com to read more.

ELECTION 2014

The election for Pennsylvania Governor, the state House of Representatives, and half of the state Senate will take place on November 4, 2014. The deadline to register to vote so that you can vote in this election is October 6, 2014. To register to vote and find out where you can go to vote, visit www.votespa.com.

VIDEOING IN GROUP HOMES SURVEY

Disability advocacy organizations, including The Arc of Pennsylvania, ask for your participation! We created surveys to find out how video cameras are currently used in group homes and what people think about the topic. Please participate and let us know what you think about the use of video cameras in group homes. If you are a person with a disability or family member, visit www.surveymonkey.com/s/PZSRKGK to fill out the survey. If you are a provider, visit www.surveymonkey.com/s/PFRZMNR to fill out the survey.

REFORM SPECIAL EDUCATION FUNDING

House Bill 2, that was signed into Law and became Act 3, 2013, had the recommendations of the Special Education Funding Commission that included a funding formula. It became part of the School Code Bill that was passed with the budget in June 2014. Highlights included the funding formula recommended by the Special Education Funding Commission, which weights factors for distribution of money including student needs, levels of poverty in area, property tax effort, and rural and small school districts. The formula only applies to new dollars and also contains a hold harmless clause. The formula will not affect charter and cyber charter schools, which will be addressed in the newly formed Basic Education Commission.

STATE TASK FORCE

The Arc of Pennsylvania, led by representative Ken Oakes, facilitated the efforts to develop a Parent...
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Email us at pie@theacrpa.org to receive electronic alerts and the quarterly newsletter.

LEGISLATIVE VISITS

Government Relations and Advocacy Director Pam Klipa, Self-Advocate Engagement Consultant Matt Stinner, Policy Director Ashlinn Masland-Sarani and Executive Director Maureen Cronin made visits to the following Legislators in September: Representatives Tom Murt, Gene DiGirolamo, John Sabatina, and John Payne. Visits are also being planned with Representative Sturla and Senator Vance. Their visits were focused on the mission of The Arc and continuing to build relationships.

ADVOCACY TRAININGS

Pam Klipa traveled to The Arc of Blair County on September 19th, to co-present a training class for the Altoona Chamber of Commerce on Legislative Advocacy. Plans are under way for future trainings across the Commonwealth in conjunction with the Include Me School Districts.

PA State Budget 2014-2015 Highlights

During the budget process, The Arc of Pennsylvania staff, board members and self-advocates met with legislators to keep the needs of the intellectual and developmentally disabled in the forefront. While we didn’t secure all of the benefits of the Governor’s original spending proposal, the $29.1 billion balanced budget encompasses the retention and increased funding for significant programming for people with disabilities and their families; services that are not only critical to meeting daily needs but those that also will lead to improved education, employment and independence.

The budget includes $20 million in additional funding for special education; $10 million for early childhood education and $40 million in additional funding for students with I/DD who age-out of the school system so they will be eligible for community waivers which will provide them with necessary on-going services. Increased funding to reduce the waiting list for services and expand programming in home and community-based settings is also included.

We are especially grateful to the following legislators for their work:


Satisfaction survey, to be used by Local Task Forces (LTF) - starting in the School Year 14-15. It was piloted via Survey Monkey, edited and will be ready for release to the LTF’s for use in September. The State Task Force met on September 23rd for the first time in the 14/15 School Year. Plans for the upcoming year’s agenda and introductions of new members is scheduled.
Sara Wolff, Self-Advocate & Board Member, National Down Syndrome Society, Board Member of The Arc of Pennsylvania, and a Law Clerk, testified before the Senate Finance Subcommittee on Taxation and IRS Oversight on July 23rd regarding the Achieving a Better Life Experience Act, best known as the “ABLE Act”. Sara has worked closely with Senator Bob Casey, Chairman, to call on leaders in Congress to ease financial strains faced by individuals with disabilities by making tax-free savings accounts available, the same types of flexible savings tools that all other Americans have, to cover qualified expenses such as education, housing, and transportation. The bill would supplement, but not supplant, benefits provided through private insurances, the Medicaid program, the supplemental security income program, the beneficiary’s employment, and other sources. In her testimony, Sara recounted the regulation that restricts persons with disabilities to have no more than $2,000 in assets - or risk their government benefits. Americans with disabilities need to be able to participate in the workforce and save for their futures without the threat of losing necessary supports that enable this participation.

Recently, some changes have been made to the bill to bring the cost down. While the bill remains generally intact, some changes include: only one ABLE account allowed per person; to have an ABLE account a person must have had their disability before the age of 26; and a limit on how much can be put into the ABLE account each year. Once legislators have finalized how the bill will be funded, we expect it to move quickly. We will keep you updated on any significant changes or need for action.

Update on the ABLE Act

Successful Name Change - DPW to Be Called DHS

For many years, The Arc of Pennsylvania and its members have worked to have the name of the Department of Public Welfare changed to the Department of Human Services. We are excited to share that advocacy to change the name has been successful! Many thanks to Representative Tom Murt and Senator Bob Mensch, self-advocates like our board member Joshua Stranix who spoke out against the stigma of the word “welfare”, and the coalition of advocacy organizations who helped make this happen. The House passed the DPW Name Change HB 993 bill on September 17th and was signed by Governor Corbett as Act 132 of 2014 on September 24th.
The Knights of Columbus “Measure Up” Again in 2014

The Pennsylvania Knights of Columbus have raised more than $5.7 million for the state and local chapters of The Arc over the past 36 years through their “Measure Up “Campaign. Council members across the Commonwealth distribute plastic rulers between April and July to generate donations. This year, the Knights raised $112,281 to support our mission statewide!

Of these funds, seventy-five percent stays in the county where it is raised for local chapters, and the other twenty-five percent is donated to The Arc of Pennsylvania to assist people where no local chapter exists and to advocate for state program funding and better laws to protect people with disabilities.

Maureen Cronin commented on the campaign by saying “The ongoing support of the Knights of Columbus is significant to our mission to provide advocacy and resources for citizens with intellectual and developmental disabilities (I/DD) and their families so that they can meet their goals. We are so grateful for the Knights’ continued partnership and commitment that helps us to provide critical benefits for people with I/DD and for helping to raise awareness for The Arc of Pennsylvania and our local chapters.”

New Labor Regulation Expands Employment Opportunities

A new regulation has been instituted by the U.S Department of Labor that requires companies that do business with the federal government to set a goal of having individuals with disabilities comprise a minimum of seven percent of their workforce. This is a significant policy change and should make a positive impact for people with disabilities who are seeking employment. This regulation puts responsibility on the employer to focus on a person’s ability not disability.

Governor Tom Ridge spoke of this sweeping policy change at the Pennsylvania Disability Summit organized by the PA Governor’s Cabinet for People with Disabilities. Representing the National Organization on Disability as its board chairman, Ridge noted that people with disabilities are twice as likely to be unemployed as those without disabilities. His organization works towards narrowing that gap by highlighting what the disability community can contribute and how it can add value to businesses. He highlighted stories from employers who found that hiring a person with disabilities added to the productivity of other workers. For more information visit www.nod.org.

The Arc of Pennsylvania Past President, Joe Angelo, past Board Director John Angelo, Department of Public Welfare Secretary Beverly Mackereth, Governor Tom Ridge and Deputy Secretary Steve Suroviec at the PADES Conference.

Good Times at the Capitol Rotunda!

The Arc of Pennsylvania Past President, Joe Angelo, past Board Director John Angelo, Department of Public Welfare Secretary Beverly Mackereth, Governor Tom Ridge and Deputy Secretary Steve Suroviec at the PADES Conference.

ART: The Universal Language - Winners will be announced on October 8th at a reception at the Capitol Rotunda. Be sure to visit our website, www.thearcpa.org for information and pictures of the winning entries!
Chloe’s Law

Pennsylvania’s legislation for Chloe’s Law was introduced in March by Representative Jim Marshall (R-Beaver Falls) and passed with almost no opposition. Kurt Kondrich, a Board Director for The Arc of Pennsylvania was a major impetus behind the Down Syndrome Prenatal and Postnatal Education Act, inspired by his daughter Chloe. The law requires that medical practitioners provide expectant parents who have received a Down syndrome diagnosis for their baby with unbiased and accurate information on Down syndrome. The law was signed by Governor Corbett - and Chloe - on July 18 and will be effective October 1. Medical practitioners will be mandated to give expectant or new parents informational publications to be provided online by the state health department. The Pennsylvania Department of Health is now working to select appropriate publications, which must include “physical, developmental, educational, and psychosocial outcomes” and contacts for support services. A small but growing number of states have similar laws.

October is Down Syndrome Awareness Month.