

2018 Issues Facing Pennsylvania Citizens with Intellectual & Developmental Disabilities & Their Families



*Expect, Receive, and
Achieve with us.*

Achieve with us.

**The Arc Alliance
Position Statement**

2018 Issues Facing Pennsylvania Citizens with IDD & Their Families



3075 Ridge Pike
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Achieve with us.®

The Arc Alliance mission is to support people with developmental disabilities by providing exceptional personal services, inspiring hope, potential, and well-being; ensuring valued life experiences and treatment expected by all people.

Funding

- ♦ **Challenge:** The community based programs remain in crisis. State institutions have received cost of living increases while community based programs have overlooked for years.
- ♦ **Action:** Minimally provide adequate funding so that community based programs are not faced with rate reductions.

El Rate Increase

- ♦ **Challenge:** For far too long the fees provided for early intervention services have remained flat, while the costs to provide the services have grown by 15-20% a year.
- ♦ **Action:** Requesting the General Assembly to provide adequate funding that will cover the growing costs to provide critical services.

Burden of Proof In Special Education Due Process Cases Allocated To School Districts

- ♦ **Challenge:** Parents don't have the resources or money to have access to information needed for a fair due process hearing.
- ♦ **Action:** Support legislation supporting burden of proof in due process proceedings to the school district, not the parents.

Waiting List For Community Services

- ♦ **Challenge:** There are 13,732 people on the waiting list in Pennsylvania.
- ♦ **Action:** Increase the budget so it is large enough to end the waiting list and increase funding in the budget to serve individuals on the emergency waiting list. Also, if the emergency list is not being met then the critical waiting list is not even being addressed.

Employment

- ♦ **Challenge:** People with intellectual and developmental disabilities have historically had difficulty getting and maintaining jobs in the community. As a result, they tend to live below the poverty level and are dependent on government programs to survive.
- ♦ **Action:** Support of HB 1641 promoting employment at competitive wages and SB 159 amending State Civil Service Exam improving employment eligibility

State Institutions

- ♦ **Challenge:** Historically, 22% of funds spent supporting people with developmental disabilities are spent in state centers which house 4% of the individuals receiving services. You can provide support for 2.5 individuals to every 1 individual in a state institution.
- ♦ **Action:** Close the state institutions and allocate the funding to community based programs.

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THE ARC ALLIANCE
About Us

The Arc Alliance was founded in 1950 by parents of people with intellectual and developmental disabilities and delays (I/DD). We have been working to remove the barriers that infringe on a person's opportunity to be fully included in society. The Arc Alliance believes and support an individual's right to make their own decisions on the life they want to live. We provide advocacy and training to families navigating the educational and I/DD system so that they know which services and supports they are entitled to in order to make life a little more "do-able".

Because of our unwavering commitment, The Arc Alliance has grown to become a major influence in the counties we serve. Our growth continues as we continue to provide Early Intervention programs through The Arc Alliance Children's Services, to over 1350 children in Montgomery, Chester and Berks Counties. And those numbers grow daily. Early intervention teachers and therapists go into the homes and care settings of children birth to age three with delays in development to promote and assist learning through everyday activities and play. Our professional staff provides an array of family services, information and training.

Our advocacy efforts, through The Arc Alliance Advocacy Services, have also expanded to support families in Montgomery, Berks, and Bucks County. The Arc Advocacy Services provides a variety of services and supports for individuals diagnosed with an intellectual or developmental disability and their families. Our Advocates, Supports Coordinators, and Guardians are also members of local task force groups to provide education, information, and legislative advocacy for the individuals in our community. We also provide training, support groups, educational and legislative advocacy to ensure that everyone has the right to participate fully in their community, to develop relationships, and have the opportunities to pursue their dreams.

With the growing number of families we serve through early intervention and advocacy; our agency works to better the lives of people with intellectual and developmental disabilities through awareness of legislative issues that affect or will affect the rights or quality and quantity of services, supports and benefits. We inform and encourage our special families to contact their legislators, tell their stories, and share their views on critical issues. In addition, The Arc Alliance is a member of The Arc of Pennsylvania (www.thearcpa.org) and The Arc of the United States (www.thearc.org), which primarily focus on state and federal public policy matters.



PA Budget

We remain grateful for your 17/ 18 Appropriation which provided needed funding for ODP priorities including funds for 820 special education students entering the adult service system, 1,000 individuals joining the Community Living Waiver, 50 adults being able to access the Autism Waiver, additional funding for Community participation and other key priorities. We are also grateful that the 17/18 Budget provided \$54 million for rates which for the first time in ten years began the process of addressing significant wage depression experienced by Direct Support Professionals.

Budget Priorities:

- **Funding to address in FY 18/ 19, the 5034 individuals identified by the Office of Developmental Programs as Emergency Needs Category. These are individuals at risk and in need of services and supports immediately.**
- **Funding to add 100 more individuals to be served by the Autism Waiver**
- **\$60 million appropriation for Direct Support Professional wages to support your call for establishing a Path to A Living Wage for DSPs.**

END THE WAITING LIST

Nearly 5,000 Pennsylvanians with intellectual and developmental disabilities continue to endure years on the emergency 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.

Additionally, 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:

- HB 628 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.
- HB 626 - Imposing an additional \$0.04 tax on cigarettes sold in Pennsylvania to fund the Adult Intellectual Disabilities and Autism Waiting List Account.
- HB 818 - 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 Pennsylvania's children with 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. Rates for Early Intervention have not increased in eight years. The Arc of Pennsylvania is asking the General Assembly to provide adequate funding that will cover growing costs to provide these critical services.

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 an increase in the state budget that would fund a living wage for over 35,000 DSPs that serve Pennsylvanians with intellectual and developmental disabilities each day.

CLOSE STATE CENTERS

The 1999 Supreme Court decision (Olmstead) affirmed a person's right to receive community integrated services rather than live in segregated institutional facilities. A 2015 study from Pennsylvania's Legislative Budget and Finance Committee 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 recently announced that they will close Hamburg State Center within 18 to 24 months.

- HB 1650 - Rep. Kerry Benninghoff circulated a cosponsor memo that requires Department of Human Services to develop a plan to close state centers by January 1, 2023. This legislation requires the Department to implement person-centered plans for current residents, hold public hearings for stakeholder input, use any of the savings that result from closures for home and community based services, and continue to address the waiting list.



Rate increase for Early Intervention (Birth – 3)

ISSUE

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BACKGROUND

For far too long the fees provided for early intervention services have remained flat, while typical costs of business operations have dramatically increased. Health care alone has increased at least 20% each year, this being only one of the many areas in which costs have increased.

In addition, therapists are understandably required to stay current on techniques and mandatory training. The system does not seem to take into account the time required for these issues, further creating pressure to schedule increased child visits to maintain a razor's edge billing.

Agencies are requiring increasing numbers of child visits to simply stay solvent. This pressure has naturally reduced the time they have with the family to address critical and in some cases medical issues. They do not have the time or energy to expand their education and attend courses to stay on top of the latest findings.

The billing pressure also has had a negative impact on new therapists entering this valuable field. The salaries cannot compare to the medical market. New graduates require the oversight early intervention cannot afford to provide due to the increase in required billable time of those who would do the oversight. In the near future the state will be seeing a decrease in the number of children served and the potential of a waiting list as our seasoned therapist enter retirement and no new graduates to take their place. These costs will then have a tremendous impact on the school districts as the needs of these children are not caught and addressed early on.

POSITION

With no increases in rates and yet increases in the costs associated with running EI, the following is being affected:

1. Therapists are asked to bill more units which results in less time for them to:
 - a. Do research surrounding the needs of the child they are scheduled to see
 - b. Take the time to call and have the conversations with the service coordinators to

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- gather background information they might not have gotten from the family.
- c. Spend time connecting with the team to see that they are all on the same page and working together to reach the outcomes the family wants and to assure that they are all getting the same information from the family in order to maintain consistency.
 - d. Therapists do not have the time and agencies do not have the funds to further learning and keep their skills on the cutting edge and/or fresh and new. Mandatory training hours are done during last minute cancellations and the minimum down time found in their schedules. This results in training found online or readings they can find at the tip of their fingers and although relevant may not be as in depth as what they could gain from attending a conference or a more inclusive training.
 - e. Therapists tend to get more medical information from the families. They do not have the time to connect with the medical community as they had in the past. This makes the teaming with the medical community more difficult as families do not always understand how the two relate and can work together and often times would benefit from this collaboration.
2. There have been many initiatives therapists and agencies have developed to help with a sense of community for the families we serve, giving families the opportunity to connect while giving additional supports for their children to participate in outside activities. Unless grant funding (which is difficult to obtain) is provided, agencies do not have the funds and therapists do not have the time to see these come to fruition.



BURDEN OF PROOF

ISSUE

The Need for a State Regulation to Allocate Burden of Proof in Special Education Due Process Cases to School Districts

BACKGROUND

In the common law, burden of proof is the obligation to prove allegations which are presented in a legal action. 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.

Schaffer vs. Weast is a landmark decision by the U.S. Supreme Court which determined that the party "seeking relief" has the burden of proof in IDEA due process proceedings. The Plaintiffs in *Schaffer* sued the Superintendent of Maryland's Montgomery County School District (MCSD) for the costs of privately educating their son when the school refused to place their child in an appropriate classroom setting. The Schaffers argued that the placement proposed by MCSD did not meet their son's disability-related needs and therefore did not provide him with a free and appropriate public education (FAPE) as the IDEA requires. The Court highlighted to the Schaffer's that the federal IDEA statute was silent with respect to who has the burden of proof in due process proceedings. Because the two sides were in "evidentiary equipoise", and because the state of Maryland had no statutory provision assigning the burden of proof in due process proceedings, the Court concluded that the Plaintiffs had failed to carry their burden of proof, as they, not MCSD, were challenging the IEP placement.

Prior to the *Weast* decision, Pennsylvania's school districts had the burden of proof, regardless of who requested the due process hearing. Therefore, it was the obligation of the district to present its case first. Such an allocation of the burden made sense, as it is the school district that has the duty to provide FAPE to the child in the least restrictive environment (LRE).

Moreover, it is practical, productive, time-saving, and cost-minimizing to have the school district, which has the easiest access to the student's records and the teachers and experts that work with the child daily, testify first at the hearing.¹ It is a fact that a large percentage of parents are un-represented during due process hearings. Assigned burden to the school districts created predictability in the system; as the district clearly proceeded first and identified the issues in the case to the hearing officer.

¹ In fact, the Supreme Court acknowledged that school districts have a “natural advantage” over the parents in a dispute in that they have the teachers, therapists, nurses, and psychologists to observe the child all day (and testify without charge) write the IEP progress reports, test the students and grade the tests.

Unfortunately, the Court did not foresee the impact of its decision in states such as Pennsylvania that have no assigned the burden of proof in their due process regulations and statutes. Without such clarification, and armed with *Weast*, many school districts across the Commonwealth are taking the position in every case in which a parent requests due process that the parent is the party “seeking relief” and therefore automatically carries the burden of proof. It is not necessarily the case that the parent is the one attempting to change the status quo. Often it is the school district that is seeking a change of placement or modification of the child’s current program or services. A parent’s resistance to such effort should not saddle them automatically with the burden of proof, particularly when it is the school district, not the parent, which is attempting to force a change such as placement.² The Supreme Court specifically rejected this approach. “The rule applies with equal effect to school districts,” it said. “If they seek to challenge an IEP, they will in turn bear the burden of persuasion before an administration law judge.”

POSITION

The Arc of Pennsylvania strongly affirms that many of the rights, benefits, and successes of students in today’s special education programs were driven by parents who were given a voice through due process. 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. This will continue to provide predictability in the system, clarity of the issues, and cost savings during the hearing process so that the goal of achieving appropriate education outcomes for Pennsylvania’s children with disabilities can be maximized in the shortest amount of time.

Without a clear statutory assignment of burden of proof, it is assured that due process will take more time and more money on all sides. Additional pretrial proceedings are no necessary in order to sort through the issue to ascertain who bears the burden of proof. This delays hearings and burdens the system unnecessarily. The hearing process is now more un-navigable than before as parents now must recognize and argue technical legal issues. It is important to recognize that few parents will go into this process without the resources to secure adequate legal representation and expert witness testimonies, sufficient knowledge of the law, and the ability to take time away from their jobs and care of their children. It is a certainty that even parents with meritorious claims, will not pursue due process. Thus, the very legal system put in place to protect Pennsylvania’s most vulnerable children will be incapable of ensuring appropriate education outcomes for them. The Arc of Pennsylvania supports statutory provisioning of burden of proof to school districts in due process proceedings.

Approved by The Arc of Pennsylvania Board of Directors January 25, 2012

² Such an automatic assignment of the burden of proof to the parent is particularly inappropriate if the district attempting to force the student into a more restrictive placement. Such a policy contradicts the specific terms of the IDEA and its implementing regulations which clearly indicate that it is the district, not the parent, which must establish that the more restrictive placement is necessary in order to confer FAPE. 20 U.S.C. § 1412 (a) (5). *See also* 34 C.F.R. 300.550(b): “Each public agency shall ensure that to the maximum extent appropriate, children with disabilities....are educated with children who are not disabled” and that “special classes, separate schooling, or other removal of children with disabilities from the regular education environment occurs only if nature and severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.”



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WAITING LISTS FOR COMMUNITY SERVICES

ISSUE

The care and protection of adults with intellectual disabilities is a core responsibility of state government, yet the community services system is perennially underfunded, evidenced by the fact that the waiting list has not declined. The issue of people with intellectual disabilities waiting for community-based services is one of the most critical concerns of the families and individuals impacted by a disability and the advocacy groups who support them. As of the most recent count approximately 13,732 people are on waiting lists across the Commonwealth for a variety of services. Of this number, 802 live in Montgomery County, 565 live in Berks County and 531 live in Bucks County. That's 13.8% of the total waiting list in 67 counties struggles to live, learn, and work right here in our communities.

It is a fact that 61% of people with intellectual disabilities live with family members. Many are currently cared for by family members in their 70's, 80's, and 90's. Many of these elderly caregivers are widowed, caring for sick spouses or battling their own health issues. Without home modifications, ramps, lifts, beds, and transportation, family caregivers are not able to provide adequate care. Many single parents just need day support so that they can work to pay bills that keep their homes and family together. And when the last caregiver dies, the person with the disability moves up to the emergency list; which is still a list and not a guarantee of adequate supports and services. Sadly, most families do not receive appropriate support until their situations have become impossible to manage.

Our Position

Families whose sons and daughters are on the waiting list are often people who opted to spare their children from the highly undesirable alternative of institutionalization. Support for these efforts is clearly a moral imperative.

The Commonwealth needs a legislative champion to develop and commit to a systematic detailed plan to provide full funding for community-based supports for all people with intellectual disabilities and their families who are in need. An effective plan should include a mechanism for a more rational distribution of existing resources based on individual need as well as means to maximize revenue from the federal government through the Medicaid waiver process. The Commonwealth's own budget initiatives need to be large enough to end the waiting list and increase funding in the budget to serve 4,595 individuals on the emergency waiting list.

Supporting individuals with intellectual and developmental disabilities is a core responsibility of state government. We urge the Governor and General Assembly to make it a priority to make funds available addressing the emergency waiting list.

1Pennsylvania Waiting List Campaign- www.pawaitinglistcampaign.org publishes current numbers based on ODP records of those in each category waiting for services



Employment

People with intellectual and/or developmental disabilities (I/DD)¹ can be employed in the community alongside people without disabilities and earn competitive wages. They should be supported to make informed choices about their work and careers and have the resources to seek, obtain, and be successful in community employment.

ISSUE

Historically, the majority of people with I/DD have been either unemployed or underemployed despite their ability, desire, and willingness to work in the community. Many have been placed in “prevocational” programs and “disability-only” workshops where they are paid below minimum wage and have little expectation of moving into jobs where they work alongside people without disabilities.

People often leave school with little community-based vocational experience or planning for transition from school to work or post-secondary education. Adult service agencies have struggled to move people into the workforce using personnel who often do not have proper training in best practices for either finding or supporting people in jobs. When employed, few people have opportunities to advance, explore new possibilities, or, in their later years, retire.

Barriers to employment include, first and foremost, low societal expectations that foster job discrimination. In addition, unrealistically low limits on assets and earnings make people fear losing vital public benefits if they work too many hours or earn too much. Systemically, public resources fund service hours rather than outcomes and are often neither sufficient nor flexible enough to allow collaboration and blending of employment funding streams. Lack of other services like transportation or of accommodations like assistive technology can also hinder success.

POSITION

People with I/DD should have the supports necessary from individuals and systems to enable them to find and keep community jobs based on their preferences, interests, and strengths, work alongside people without disabilities, receive comparable wages, and be free from workplace discrimination. Requirements related to employment include:

- Opportunities for post-secondary education, including college and vocational training, to gain knowledge and skills to allow people to get better jobs.
- Ongoing planning to promote job advancement and career development.
- Fair and reasonable wages and benefits.
- Opportunities for self-employment and business ownership.
- Opportunities to work with and, in the case of people with I/DD who own small businesses, employ people without disabilities.
- The ability to explore new directions over time and, at the appropriate time, retire.
- Opportunities to work and increase earnings and assets without losing eligibility for

needed public benefits.

Best Practices

- Employment supports and services should use best practices, including assessing skills and interests, working with employers, matching jobs to skill sets and employer needs, providing individualized and ongoing job supports, designing reasonable job accommodations, integrating people into the workforce, building social skills necessary in the workplace, and securing necessary ancillary services such as transportation.
- People with I/DD must have training and information on how to access supports needed to find and keep jobs.

School-to-Work Transition

- Transition planning should start early.
- Transition activities should foster individualized exploration of and experiences with community-based employment options that enable youth to make informed choices.
- Transition activities should include career assessments to identify students' interests and preferences, exposure to post-secondary education and career opportunities, training to develop job-seeking and workplace skills, and participation in multiple on-the-job activities and experiences in paid and unpaid settings.
- Transition activities should not be limited to unpaid internships at pre-set community worksites.
- Students should leave high school with opportunities to pursue post-secondary education and/or with an appropriate job or an action plan for finding one.

Training of Staff and People with I/DD

- Staff of employment and school-to-work transition programs must receive training in best practices to help people find and keep jobs.
- Along with ensuring appropriate on-the-job training, people with I/DD should receive guidance, if needed, in acquiring the social skills necessary in the workplace.
- People with I/DD must have training, including, if desired, driver's education, to allow them to travel in the community so they can get to jobs and enhance their independence.

Systems

For all people with I/DD, publicly funded employment programs should first explore employment alongside people without disabilities at comparable wages, with comparable benefits, before considering other options in the community. Ancillary services like transportation and accommodations like assistive technology must be available to individuals and support agencies. Public policy should encourage employers to hire people with I/DD.

Publicly funded employment programs should also:

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- Be available to all people with I/DD who wish to explore opportunities to work, regardless of the nature and extent of their disabilities.
- Enable people to make informed choices by providing individualized exploration of and experiences with community-based employment and by presenting all information needed to make informed choices in an understandable way.
- Provide sufficient resources to support people to work in the community and be flexible enough to foster collaboration and braiding of employment-related funds.
- Build infrastructure and supports needed to phase out the issuance of subminimum wage certificates, increase opportunities for competitive integrated employment, and put in place safeguards to protect the interests of any people affected by this shift.
- Measure and publicly report on outcomes on an ongoing basis.

Legislation

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:

- **HB 1641** - Rep. Bryan Cutler (R-Lancaster) and Rep. Dan Miller (D-Allegheny) reintroduced their “Employment First” legislation that promotes the employment of people with disabilities at competitive wages by employers in the Commonwealth. Sen. Mensch (R-Berks) reintroduced the companion bill in the Senate, SB 21.
- 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.

¹ “People with intellectual disabilities and/or developmental disabilities” refers to those defined by AAIDD classification and DSM IV. In everyday language they are frequently referred to as people with cognitive, intellectual and/or developmental disabilities although the professional and legal definitions of those terms both include others and exclude some defined by DSM IV.