

Testimony of Maureen Jordan on Behalf of The Arc of Pennsylvania  
Before PA House Appropriations Committee's Public Hearing on SB850  
Re: General Fund budget bill for 2009-2010  
Harrisburg, Pennsylvania  
May 22, 2009

Thank you Chairman Evans and Minority Chairman Civera for taking the time to hear the thoughts of the people who are impacted by the decisions you are making. I hope it gives you a real-life, "person on the street" view of the impact of the budget as presented in SB850 will have on the community-based services system for adults with intellectual disabilities.

My name is Maureen Jordan and I am the Public Policy Advocate for Adult Issues with The Arc of Pennsylvania, a statewide non-profit organization that provides advocacy and resources for citizens with intellectual and developmental disabilities and their families. The Arc of PA was established in 1949 and is affiliated with 36 local chapters covering 52 counties across Pennsylvania. It is also affiliated with The Arc of the United States based in Washington, D.C. We are a grassroots, membership-driven organization with over 9,300 members in Pennsylvania. Before I joined The Arc, I was the Executive Director of a small group home in rural Juniata County, which provides me with the additional perspective of how challenging it is for providers to operate in a system reliant on public funding. Finally, I am the mother of Elise Westcott, a wonderful woman who helps out on a neighbor's farm, takes horseback riding lessons, spoils her 1 year-old nephew, and has intellectual disabilities. So I have lived the life of a parent, an advocate, and provider, with over 23 years of experience dealing with these issues.

The Arc of PA understands we are facing serious economic and fiscal challenges. However, notwithstanding the slowing revenues coming into the state, we believe budget making is about establishing appropriate priorities. The Arc of PA believes that funding programs supporting Pennsylvanians with intellectual and developmental disabilities is a core responsibility of state government and thus ought to be one of the highest budget priorities of both the Governor's Office and the General Assembly as they finalize budget negotiations.

The Arc of Pennsylvania was not pleased with the Governor’s budget proposal when it was released in February. It included a zero percent rate increase for service providers – an increase that is needed to save jobs, maintain service capacity, and sustain existing levels of service quality. And, the new funding it included would have served only a fraction of the number of people languishing on the emergency waiting list for services. But Senate Bill 850 is far worse than the Governor’s budget proposal. It cuts out all new funding to serve people facing institutionalization because they have nowhere else to turn, AND it cuts people out of existing community-based services to which they have grown accustomed.

### **SB 850 Would Cut Funds and Services under the Consolidated Waiver**

- » More than 15,000 individuals with intellectual disabilities receive services through the Consolidated Waiver, a Medical Assistance-funded program that provides them with habilitation, vocational services, therapies, respite care, assistive technology, and other benefits to enable them to remain in their own homes and communities.
- » SB 850 would **eliminate \$37.72 million in state and federal funds** from the Consolidated Waiver, resulting in **termination of services for 550 people** currently receiving services
- » SB 850 would **eliminate the emergency waiting list initiative** that would have provided services for 180 children in residential care whose services will end when they turn 21, 100 adults in emergency situations, and 500 young people transitioning from special education to adult life.
- » **SB 850’s cuts in the long-run will increase the costs to taxpayers.** Many individuals with intellectual disabilities who cannot access essential home and community-based services will be forced into institutions that cost far more than the services provided through the Consolidated Waiver.

### **SB 850 Would Reduce “Base” Mental Retardation Funding**

- » SB 850 would **cut \$12.117 million in base funds**, eliminating the small amount of services for 3000 families who have been waiting for years for Medicaid Waiver services.

These families are increasingly struggling to maintain their family members at home rather than placing them in institutions at a much greater cost to the taxpayers.

### **SB 850 Would Cut Autism Funds and Services**

- » SB 850 would **cut \$15.286 million** in state and federal funding that would **eliminate services for up to 50 percent of the individuals with autism** who were about to begin receiving services this year after years of waiting.

Numbers on paper are easy to read and even easier to forget. My daughter and I are here today to put a face to the numbers. If Elise lost her Consolidated Waiver, she would no longer have a Habilitation Aide. Unemployment is high in our county and even though one of her goals is to have a job, the reality of it happening is slim. Without a job, the alternatives are sitting at home watching TV or going to a day program. She chooses to create her own program thus her Hab Aide is critical to her being a part of her community and living an “everyday” life - taking her to her horseback riding sessions, going shopping, getting to her doctor’s appointments, attending church, etc. And last year the Medicaid Waiver was critical as she had a severe reaction to a medication and needed to live for a time in a group home with 24/7 staffing support. If the Waiver had not been available, this would have been impossible and institutionalization may have been the only answer for my daughter.

While we are just one family, our story is representative of thousands of other families across Pennsylvania. Elise is independent, and dreams of getting and holding a job and being married, but others with intellectual and developmental disabilities need more supports and care. To them, SB850’s cuts will mean housing not being available and having no other choice but to enter a public or private institutional setting, like an ICF/MR (which can cost twice the amount of community services). Cuts in day programs and the transportation to them would risk making the person more isolated from the community. If respite funds were not available, the families who care for their sons or daughters - at significant cost savings to the taxpayers - would not have the break they need, increasing the stress that already exists on them and their family and possibly resulting in them giving up and having to institutionalize their loved one.

The Arc of PA is not just here to ask for new money. We'd like to put an idea on the table to save money. DPW still operates 5 state-run institutions. Studies have shown that individuals with intellectual disabilities thrive in the community as compared to an institution when receiving appropriate supports and services. What's more, PA's state institutions are expensive to operate. The Arc of PA believes that as much as \$191 million can be saved if the 5 remaining state MR centers were to close. These savings even account for the 1256 individuals living in the state centers being placed in the community with an average-priced residential program. DPW officials have indicated that it costs money in the short-run to close a state institution, but that should not be a barrier now that PA is has 27 months worth of one-time Medicaid stimulus money. This is the perfect use of time-limited Medicaid stimulus funding. The short-term additional cost of closing the 5 state institutions could be covered by stimulus funds, and the long-term savings to the Commonwealth could be \$191 million. Unfortunately, DPW officials have publicly stated that there will be no further closures of state MR Centers during the remainder of the administration. The Arc of PA believes this is short-sighted and a failure to utilize precious and limited taxpayer dollars in a responsible manner.

In closing, I found the following primer on making a budget on CNNMoney.com, and I found their comments very pertinent to what State budget makers will be doing over the next several weeks. It explains to the reader that, to make a budget, one needs to...

- Identify goals that matter, deciding which are most important
- In hard times put less important goals on the back burner
- When deciding which goals are most important, ask "which will cause greater harm if deferred"

I am asking that you make individuals with intellectual and developmental disabilities and their families who need the state's help your top budget priority. Please provide the funding necessary to address the emergency waiting list for services; and, provide a modest rate increase for providers so that service capacity and quality can be maintained. At the very least, please restore the funding proposed in Governor's Rendell's budget for services for adults with intellectual and developmental disabilities.

Thank you for the opportunity to testify before your committee today.