

## **WAITING LIST**

### **ISSUE**

The wait for desperately needed community based services for people with intellectual disabilities (ID) is impacting almost 16,000 Pennsylvania families.

### **SUMMARY**

The wait for community based services for people with intellectual disabilities is a national crisis and is the most urgent and critical issue for them and their families. Current figures on the number of people waiting for services can be found at The Pennsylvania Waiting List Campaign's website ([www.pawaitinglistcampaign.org](http://www.pawaitinglistcampaign.org)). The waiting list has three levels: emergency, critical and planning which are defined as follows:

- **Emergency:** individuals who must be served immediately
- **Critical:** individuals who will require support within two years
- **Planning:** individuals whose anticipated needs are more than two years but less than five years.

### **BACKGROUND**

The waiting list continues to exist for the following reasons:

First, each year between 400-600 young people who have had the entitlement of special education through the age of 21 leave school with few, if any, supports and find themselves on the waiting list. Without the supports needed to gain employment, for transportation, respite for the family, and other community services, they lose the skills they had while in school and their support needs eventually increase and become more costly.

Second, about 60% of people with an intellectual disability (adults and children) live with family members. These families have taken care of their family members for decades but eventually need services and find themselves on the waiting list.

- Many are supported by family members age 70 and older. A large number of these elderly caregivers are widowed, caring for sick spouses and battling their own health issues.
- Without respite, in-home care and home modifications, many family caregivers are not able to provide adequate support for their loved one.

## **The Arc of Pennsylvania Position Statement**

- Many single parents need day support so they can work to pay bills that keep their homes and family together.
- When the last caregiver in the family dies, a crisis emerges for the individual in need of supports and a place to live. Sadly, families will often not receive appropriate supports until their situations have become impossible to manage or they die.

Third, a lack of adequate rates or COLAs (Cost of Living Adjustment) for service providers to account for inflation results in service capacity being lost.

### **POSITION**

The Arc of Pennsylvania supports a significant and sustained effort to end the emergency and critical waiting lists. The Governor and Secretary of Public Welfare must work with the General Assembly and stakeholders of the community ID system to develop and implement a waiting list plan that commits to ending the emergency waiting list in two years, and ending the critical waiting list in five years. The reduction and gradual elimination of the ID Waiting List can best be achieved through the joint collaboration of self-advocates, families, advocates, service providers, and government representatives. The Arc of PA and its members stand ready to work with all stakeholders to eliminate the waiting list and thereby to make Pennsylvania a better place for people with an intellectual disability and their families to live, work, and play.

Approved by The Arc of Pennsylvania Board of Directors January 26, 2013