

The Arc Alliance

Paul Stengle, Chief Executive Officer

August 13, 2019

I would like to thank the House Democratic Policy Committee for inviting me to give testimony concerning the waiting list for the home and community based services waiver.

First, and most important, we must find funding for the 13,015 individuals on the IDD waiting list and the 3,716 individuals on the autism waiver waiting list. Waiver funding is allocated by priority of need as waiver slots are available.

Who do those numbers represent? Some of these families have children/adult children who have been on the wait list for years. As you are aware, enrollment into one of the four ODP waivers is determined by level of need. It is then presumed that individuals who are in the most need of service are served before individuals who are in less need of services.

I would to describe individuals who are typically on the waiting list for years. The first group I would like to talk about are those people who are the sole caregiver for their child with disabilities. Many of these individuals are over 70 years old and have increasing health and mobility issues themselves. I know of one such individual who lives with her mother. Her mother has had cancer for years and increasing health issues. But, because she still has a place to live and because of funding, she is considered less of a priority than other individuals. She has been waiting for services for years and each year the struggles increase.

Another group are those families that need assistance in their daily life, to get through the day and to keep their job. For example, I know of a family – a mother, father and child. The father works out of town on a regular basis. During these long periods of time, the mother becomes the sole caregiver to their child. When the father returns, he has significant responsibility to care for his child with disabilities because of his wife's need for a respite. In this situation, the mother is not only providing care for her child with disabilities, she is also employed. Here you have an intact family, a family with a moderate income. It is very unlikely that they will receive services for their child until there is a crisis, such as a death of one of the parents. Services are too expensive to pay out of pocket and quitting their job is just not an option. And even when families face a crisis, the system often moves too slowly to help during these times of crisis.

How we determine who gets services and who does not get services is based almost solely on what families report. In my experience, most families are unwilling to talk about the level of the crisis that their family is experiencing in dealing with their child with disabilities. Families are reluctant to share family problems with others, especially if one parent is drug dependent or using alcohol. Most families are unwilling to talk about the issues that affect their inability to support and raise their children.

Who do those Wait List numbers represent? We must understand when we look at the numbers that of the 13,015 individuals on the waiting list, only 5,331 are in the need of

immediate services. Meaning that they have completed the PUNS and need services today or within the next 6 months. And we know that many of these individuals are not looking for a high cost residential placement – or a group home as we commonly call it. Most families are looking for support so they can maintain their child with disabilities at home. Most individuals and families are looking for services that support their family member to live, work and be part of their community.

Research tells us that individuals with intellectual developmental disabilities benefit from more inclusive and least restrictive settings. Families of children and young adults are requesting and in some cases demanding, to have services that are in the community and inclusive.

I cannot stress enough, about the importance of inclusive integrated programs. When the Right to Education Conset Amendment occurred in the early 70's, it required that children be educated in least restrictive settings. This was because even in 1972, we knew that individuals with special needs did better in inclusive settings rather than in segregated settings. Since that time, there are hundreds of studies that confirmed that individuals do better in least restrictive settings. It should be noted that least restrictive alternatives not only provide for a greater growth in the individual, they are, on average, less expensive than more segregated settings.

What does all this mean? It means we need to support growth in inclusive, less restrictive programs as opposed to the more traditionally segregated programs. Many states have closed all of their public institutions. These public institutions are more expensive on average than community residential programs and in general, community residential programs provide a higher quality of life and skill acquisition of individuals residing in those programs. I also would like to point out that in general that larger institutions are not more cost effective than smaller institutions.

In summary, there are many individuals who are in desperate need of services that are not receiving the support they need and the solution is to increase funding to serve individuals on the waiting list. Furthermore, in order to guarantee a better care at a lower cost, we need to continue to develop opportunities for programs that are inclusive and part of the community. The state is working on achieving this objective with objection from a small percentage of providers and parents.

We need to improve the Prioritization Urgency Need Survey so that it accurately determines the level of need and prioritizes individuals with disability appropriately. I need to be clear that the PUNS does a good job in assessing need of individuals but again, we need to continue to improve how we determine who gets served so that the individual in the most need of services receives the support before individuals of a less need. It means we must support families when the need arises – not only when they find themselves in a crisis.

I would also reiterate that it is vitally important that we limit the availability of segregated programs and increase the availability of community programs. If The Arc believed that people were better served in institutions than in their own community, we would support the institutionalization of persons. However, we know that is not true. We also know that younger parents are not interested in segregated options. They want their children to live in the

community that they were raised in and not shipped to a state institution in the middle of rural Pennsylvania to receive segregated services. I would hope that the Commonwealth of Pennsylvania would follow other states in the closing of their state centers.

Again, I would like to thank the House Democratic Policy Committee for permitting me to make this presentation today and I would be very happy to answer any questions you may have.

Sincerely,

Paul Stengle