

The Arc of Virginia

Remarks to Joint Commission on Health Care

September 4, 2008

Good morning. My name is Howard Cullum. I'm the current President of The Arc of Virginia. We appreciate the opportunity to comment on the Medicaid Mental Retardation Waiver and the Individual and Family Developmental Disabilities Support Waiver. Hopefully, this will be one of the last presentations you receive with the term "mental retardation" as the Commonwealth shifts its language to the term "intellectual disability".

I'll cover three areas. First, the important numbers. Second, state policy and funding direction. Third, wait list operational management.

First the key numbers for The Arc are:

- Over 26,000 persons with intellectual disabilities served by CSBs last year
- Only 7,400 of these persons were served through the MR waiver
- Only 600 people with related developmental disabilities are served by the IFDDS Waiver
- 600 new MR waiver slots were approved for FY 09 – thank you
- Demographics are driving wait list growth:
 - o The success of community care for individuals & families
 - o Over 4,000 persons with ID will exit special ed over next 5 years
 - o Over 900 with autism will also exit special ed over the next 5 years
- The most important statistic for The Arc is the following:
 - o There are over 17,821 persons with intellectual or developmental disabilities in Virginia who are living at home with parents over 60 years old

What these numbers mean:

Virginia, like every other state, has large numbers of persons with developmental disabilities exiting special education each year as well as a large cohort of persons still living at home with aging parents or caretakers. These family caregivers have made the state policy of community care work and, by the way, saved the Commonwealth hundreds of millions of dollars by avoiding institutional care. Remember, all Medicaid waiver recipients qualify for institutional care which currently costs over \$131,580 per person annually. However, the rubber will meet the road in terms of what will happen as these family caregivers themselves age out.

These numbers lead us to the second area: state policy and funding direction.

The Arc members believe strongly that it is time for our Commonwealth to take bold action to address wait list demands for the ID/DD populations. There must be a renewed state commitment for community-based care through legislation and a state funding commitment to draw down the waiver wait lists a certain percentage each year.

Virginia is currently ranked 46th for its fiscal effort in community-based funding. Make no mistake about it, you all demonstrated fiscal effort last year to take Virginia out of crisis mode-but this cannot be a one-time effort. Virginia needs a plan with commitment from the Executive and Legislative branches to end the wait list for the MR and DD Waivers so that Virginians with ID/DD have “A Life Like Yours”. I understand there have been issues raised in the past about community capacity. The fact is the system can put on as many slots as you can approve during a fiscal year. Thanks to your support, people with ID/DD can access an array of services under these waivers, which include the trending towards in-home support, consumer-directed services, and respite.

In addition to MR and DD waiver slots, there is also a critical need for state funding for persons who are not waiver eligible and for additional community housing options. The Joint Commission members should note that over 11,000 persons with intellectual disabilities who are not on the MR waiver received services last year from CSBs. State support for this large group has continued to drop each year. As for community-based housing, the state has not put up-front general fund dollars into community housing for 25 years. Meanwhile, hundreds of millions have been spent for state institutions, an outdated model of support. The reality is over 97% of people with intellectual disabilities live in the community, yet 36% of our state’s funding goes to fund institutions-where only 2% of people with intellectual disabilities live.

Bottom line-The Arc would like to see clear and visible legislative “ownership” of funding responsibility for persons with ID/DD.

The third and last area is what I will call wait list operational management. Let’s be clear. The Arc strongly supports the current MR waiver allocation and wait list management system. It is fair and equitable to allocate new slots to CSBs on the basis of their share of the urgent need. Allocations of individual slots are local decisions made by persons who know the consumers and families and not by a mindless chronological system in Richmond looking at paper. As you well know, we have a triage system that focuses on the person and family most in need.

As long as there is a wait list, I’m sure there will always be a few people unhappy about a CSB individual slot allocation decision. However, I am sure Joint Commission members who have taken the time learn about and participate in their local CSB decision-making will vouch that it is an excruciating process. These are literally life and death decisions that are not taken lightly.

Finally, let me be perfectly frank with you about some of the wait list issues that sometimes appear to sidetrack us from the problem at hand. It reminds me of the famous phrase “it’s like rearranging deck chairs on the Titanic”. Hello. Thousands and thousands of families have done their duty, they have made community care work, they have saved the Commonwealth hundreds of millions of dollars but are now starting to sink under the 24/7 of caregiving demands. What will happen to our loved ones when we are unable to provide the care? It is time to make the commitment to consistently fund MR and IFDDS Waivers until we have reached the goal of eliminating the wait list altogether.

Thank you.