



**Remarks to the House Appropriations Subcommittee on Health and Human Resources
January 26, 2016**

Good afternoon Mr. Chairman and members of the Subcommittee. Thank you for the opportunity to provide comment on the redesign of Virginia's I/DD Waiver program. My name is Jamie Liban and I serve as the Executive Director of The Arc of Virginia, a statewide organization for people with developmental disabilities and their families.

Since today marks the four year anniversary of when Virginia first announced the settlement agreement with the U.S. Department of Justice, I would be remiss not to thank you for your support of Virginia's transition to a community-based system thus far. The reforms that have already taken place have greatly improved the lives of many Virginians with I/DD.

Since 2012, thanks to your leadership, two Training Centers have closed and 693 former residents of Training Centers from across the state are now living successfully in the community. The stories we hear from these individuals and their families as a result of this transition are overwhelmingly positive and families have reported increased satisfaction with services and improved quality of life for loved ones. Furthermore, the cost savings achieved from these transitions have allowed the Commonwealth to create 1,075 I/DD Waivers for individuals and families on waiting lists, preventing unnecessary institutionalization and helping the Commonwealth respond to some of the unmet need.

While we celebrate these achievements, we also recognize there is some more work to be done in order to complete Virginia's transition to a truly integrated, community-based system for people with I/DD. We have an opportunity to make major progress this year with the redesign of the I/DD Waiver program and a proposed, historic reduction of the I/DD Waiver waiting list.

The Arc of Virginia's Position on I/DD Waiver Redesign:

The Arc of Virginia strongly supports the proposed redesign of the I/DD Waiver program (Item 306.CCCC in the proposed budget). The I/DD Waiver program must be overhauled in order for Virginians with intellectual and developmental disabilities (I/DD) to have the opportunity to truly experience "A Life Like Yours" in the community. Individuals with I/DD and their families from across the Commonwealth continue to face great difficulty accessing services in the most integrated settings. Examples of barriers to inclusion include long waiting lists, inadequate reimbursement rates and a lack of providers who are able to offer services in the most integrated settings.

Virginia must address these barriers in order to facilitate compliance with the community integration mandate of the ADA, the 2012 DOJ Settlement Agreement and the CMS rule governing the provision of home and community-based services. The redesign of the I/DD Waiver program is the

Commonwealth's primary strategy for achieving compliance with these federal requirements, as it will provide greater access, increased independence and community inclusion for people with I/DD across the Commonwealth.

Why We Support I/DD Waiver Redesign:

- The Arc of Virginia supports the proposed I/DD Waiver program because it will provide a more cost-effective way to address the backlog of unmet needs. There are now more than 10,300 Virginians with I/DD who are on waiting lists for home and community-based services. The redesign will create a new Individual and Family Support Waiver, which will have an average cost that is half the cost of the existing Intellectual Disability (ID) Waiver. By using this new Waiver to focus on providing cost-effective family support, the Commonwealth can now serve more people and will be better positioned to offer services in a timely manner. (I will discuss this in greater detail later on in the presentation.)
- The new I/DD Waiver program will improve access to services and facilitate easier system navigation by streamlining eligibility. Last year, the General Assembly approved legislation adopting a new functional definition of the term "developmental disability." Consistent with this statutory shift, the redesigned I/DD Waiver program creates the following: a single point of entry to services; a unified eligibility determination process; and a consolidated waiting list for services for all people with developmental disabilities, regardless of IQ score. Converting to a true "DD" system will eliminate silos within the current system and help individuals and families better navigate through the program. The new functional assessment, VIDES, has been revised to reflect this change; training and reliability standards will be incorporated in the roll-out.
- The proposed I/DD Waiver program will increase reimbursement rates for several services provided in the most integrated settings. Subcontractor Burns and Associates conducted a study of the current reimbursement rates and the cost of providing services. A new rate structure is proposed that better reflects the cost of providing services, and in some cases, creates financial incentives for providers to offer services in integrated settings, a critical step toward achieving compliance with the aforementioned federal rules.
- Rates are based on the support needs of the individual. Individuals with higher medical and behavioral support needs will receive higher reimbursement rates for certain I/DD waiver services than those determined to have less intensive support needs. The tiered structure will ensure individuals with the most complex support needs are able to be served in the community.
- New services in the I/DD Waiver program will promote greater community integration. The new I/DD Waiver program will include the coverage of non-medical transportation, "smart home" technology, private duty nursing, community access and dental services. These new services will expand opportunities for community integration for people with I/DD and will ultimately assist in reducing the average cost of services.

Further Action is Required:

While the I/DD Waiver Redesign provides the framework to reduce the I/DD Waiver waiting list, the number of I/DD Waivers actually included in the proposed budget is grossly insufficient to meet the Commonwealth's needs. Funding only the minimum slots required under the DOJ Settlement

Agreement has proven inadequate and has resulted in the unnecessary institutionalization of children and adults with I/DD. The waiting list has grown by 3,000 since we first entered into the agreement and if Virginia continues to provide only the minimum number of I/DD Waivers required by the agreement, the waiting list will continue to grow.

We support the solution proposed in amendments offered by Delegate Cox and Delegate Landes, which would expedite access to critically needed services. These amendments would cut I/DD Waiver waiting list in half by phasing in 5,000 I/DD Waivers, for a fraction of the cost it would have been under the previous ID Waiver program. While this would be an unprecedented outcome, it would not be an unprecedented expenditure. This is how...

- The IFS Waiver will reduce average costs for new participants by 50%. Under the existing ID Waiver, the average cost is approximately \$72,000 per person, per year. Services under the new Individual and Family Support Waiver are expected to cost, on average, \$32,000 per person, per year, or \$16,000 state general fund/year. Delegate Landes' amendment proposes phasing in 800 IFS Waivers each year, with the first 100 designated for people with the lowest numbers on the DD Waiver waiting list. This is important to ensure a smooth transition when the lists are merged. The General Assembly, on average, has provided approximately 400 ID Waivers/year in the past. The 800 IFS Waivers/year can be provided for the same cost, doubling the impact and reaching more of those in need.
- Since the majority of costs necessary to fund the IFS Waivers for EDCD recipients are already in the Medicaid budget, only minimal investment is required for additional support needs. We know that 3,400 individuals on the I/DD Waiver waiting list are currently enrolled in the EDCD Waiver program. Most of them are children and while they are getting some of the services they need, they are lacking supports that are more specific to the I/DD Waiver population. The average cost to create these IFS Waivers is estimated to be \$5,000 per person, per year—again a fraction of the cost it was before (\$36,000/person).
- I/DD Waiver waiting list families are not asking for much, they just need a little help. The vast majority are requesting modest in-home supports. More than 75% are requesting less than 45 hours of support per week. What is great about the aforementioned amendments is that we can provide this cost-effective help to families earlier, instead of waiting until they are in crisis, which reduces costs to the Commonwealth in the long term.

While we are in agreement with DBHDS that there is a point where our system will reach stability and priority needs will be addressed in a timely manner. We do have concerns, however, about some of the numbers reported for the Priority categories in the presentation that was given to the Appropriations Committee earlier this week. The presentation does include a note that assumptions will be revisited though. We raise this because Priority 1, people who need services today, appears to have been underestimated because it does not include any children.

Take NP for example, a parent mentioned in the DOJ brief. NP's 8 year old son was institutionalized last year due to a lack of I/DD Waiver supports. She requested help when she was recovering from multiple, major surgeries. Her son was eloping from the house and presenting behavioral challenges. She was in crisis. Her family was in crisis. While this implicated the children's crisis system, crisis could have been averted with the provision of an IFS Waiver slot. Under the current assumptions, NP's son would not be in the priority one category.

Additional Recommendations:

While our primary concern is the lack of I/DD Waivers, The Arc of Virginia has additional recommendations for implementation of I/DD Waiver Redesign which we believe would help achieve the goals of the settlement agreement and facilitate access to the most integrated services. These include:

- Closely monitor implementation of the new rate structure for all services and adjust rates as necessary to ensure they adequately cover the cost of providing truly integrated services, including services for individuals with the most complex support needs. Since adequate reimbursement and financial incentives for providers are necessary to facilitate the system change envisioned by the DOJ Settlement Agreement, and existing regulations will need to be revised to parallel the new rate structure, it is imperative for DBHDS to establish formal mechanisms to properly monitor implementation of the new rate structure and make adjustments to ensure all individuals, regardless of their support needs, are able to be served in the most integrated setting.
- The redesign of the I/DD Waiver program should include a comprehensive implementation plan that addresses stakeholder communication. The implementation plan outlined in the report focuses exclusively on the near-term steps necessary to activate the three amended I/DD Waivers and when the proposed changes to the I/DD Waiver program will go into effect, which is July 1, 2016. Lacking from the implementation plan is a clear and robust communication strategy for stakeholders, including individuals with I/DD, family members, providers, case managers, advocates, etc.
- The redesign implementation plan should provide technical assistance and bridge funding to help service providers successfully transition from congregate service models to more integrated support models. Resources will be needed to increase capacity to serve individuals in fully integrated community settings, and build the infrastructure necessary to administer and oversee the quality and the restructured service delivery process.
- DHBDS should establish formal mechanisms to receive feedback from various stakeholders, especially self-advocates, families and family organizations, at predetermined and ongoing public forums. The Department should be proactive in receiving feedback in order to ensure the Waiver Redesign is successful in accomplishing its intended objectives.
- The Commonwealth should expand consumer directed options to a broad range of services and allow individuals and families to exercise both employer authority and budget authority over their services. The Arc of Virginia, along with many individuals and families, has urged DBHDS and DMAS to expand consumer directed options for services such as in-home residential, integrated day and non-medical transportation in order to facilitate more person-centered services and improve community engagement. Employer authority will give the waiver recipients and their families the ability to hire, fire and direct personal support workers. Budget authority will allow waiver recipients and their families to customize their support services within predetermined budget limits. Expanded consumer directed service options allow recipients to have more control and personalization of their support services, which helps the Commonwealth in meeting its targets for community inclusion.

Conclusion:

In conclusion, we urge you to support the I/DD Waiver Redesign, as well as the proposed amendments that would cut the I/DD Waiver waiting list and provide the infrastructure needed for systems change. Again, thank you for your leadership on these issues and for your steadfast support of Virginians with I/DD.