# Developmental Disability Coalition 2015 LEGISLATIVE AGENDA





Virginia Down Syndrome Alliance

### 1. Reduce waiting lists by streamlining the management and delivery of cost-effective I/DD services.

Issue: The Commonwealth must respond to the 9,400 Virginians with intellectual and developmental disabilities (I/DD) who are currently on waiting lists for community-based services. In order to address the backlog in unmet needs, the state's approach to organizing, financing and delivering HCB waiver services has to be fundamentally revamped. A single agency of state government must be vested with responsibility and accountability for responding to the waiting list crisis.

#### ACTIONS NEEDED:

- Improve system-wide management and accountability by consolidating budget and operational authority for specialized I/DD services in DBHDS, the agency primarily responsible for operating the state training centers, administering and overseeing the quality of I/DD waiver programs, and fulfilling the state's commitments under the U.S. v. Commonwealth of Virginia settlement agreement. This action will allow increased budget transparency, accountability and efficiency within the I/DD service system.
- Endorse a more cost-effective method of service delivery to better serve persons on I/DD waiver waiting lists. As the redesigned waivers are implemented, the average per capita cost per waiver will differ based on the services and supports required to meet individual needs. The new, tiered approach to delivering less expensive waiver options will help the Commonwealth reduce waiting lists for I/DD long-term services and supports and use available resources more efficiently.

-Support the waiver slots requested in the Governor's amended FY 2016 budget.

-Extend I/DD waiver services to 350 wait-listed individuals with modest support needs at an average SGF cost of \$15,000 per person/per year using individual resource allocations that are based on person-centered planning and individual support needs. This would represent a 50% reduction in per-person costs of services, allowing the Commonwealth to serve twice as many people for the same general revenue outlays. These expanded waivers slots would phased in beginning July 1, 2015 (\$5.25 million SGF).

- Set aside 50 I/DD waiver slots in order to respond to emergencies that are likely to occur during the course of fiscal year 2016. This would help ensure that the state has the capability to swiftly respond to situational crises such as homelessness or death of a caregiver in order to prevent unnecessary and more costly institutionalization.

• Support funds provided in the DBHDS budget to develop a waiver tracking system. Require that these funds be used to assess the service and support needs of all Virginians on waiting lists for I/DD waiver services so the Commonwealth can accurately establish enrollment priorities, project service costs and develop the capacity needed to serve such individuals. Planning should account for the number of graduates with I/DD who are exiting secondary education each fiscal year.

Developmental Disability Coalition: a group of self-advocate and family organizations dedicated to advocating for inclusion & full community participation across the lifespan for the DD community.

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## 2. Invest in a service delivery infrastructure that promotes the cost-effective use of public resources & supports Virginia's continued transition to a community-based system.

Issue: The Commonwealth is overly reliant on congregate service models and offers few meaningful options for consumer-direction through its existing waiver programs. Success in fulfilling the objectives of the US DOJ settlement agreement and complying with CMS' new regulatory definition of home and community-based services is closely tied to transitioning from the congregate-based I/DD services that exist today to an approach that emphasizes personal choice and control through individualized support strategies. As Virginia moves forward with Training Center closures and the redesign of the I/DD Waiver program, it is essential that cost-savings associated with these reforms be protected and reinvested in the I/DD service system to support capacity building activities needed to make this transition.

#### **ACTIONS NEEDED:**

 Amend DBHDS "Trust Fund" language to ensure that all cost savings associated with the provision of I/DD services remain within the I/DD system and are reinvested in systemic improvements and service expansions. Specifically, the Commonwealth should:

- Strike language requiring that deposits to the DBHDS Trust Fund be "swept" back into the General Fund.

- Amend DBHDS Trust Fund language to require that I/DD cost savings, including cost savings associated with Training Center and I/DD Waiver operations, be used exclusively to strengthen and enhance community-based services.

- Amend DBHDS Trust Fund language to authorize up to \$30 million in expenditures to facilitate restructuring of the I/DD service system in order to promote cost-efficiency, successfully implement the DOJ settlement agreement and comply with the CMS HCBS rule.

- Oppose the Governor's proposal to limit consumer-directed employees to only one employer of record. Many individuals and families rely on consumer-directed employees who support multiple individuals/families. The proposed policy has the potential to limit access to essential, cost-effective services and supports. DMAS also should be required to grant exceptions to maximum work hours and travel time polices in instances involving extenuating circumstances.
- Proceed with the Commonwealth's plan to close three of the four remaining state-operated training centers.

#### 3. Improve access to early intervention services.

Issue: Funding for the Part C program has not kept pace with the growing demand for early intervention services over the past year (an increase of 4.8% from previous year). As a result, there will be a funding shortfall during this current biennium. There is no funding formula to ensure that the state's contribution to Part C costs corresponds to the increase in the number of eligible children. Under federal law, early intervention services are an entitlement for families of children with disabilities and developmental delays. Waiting lists and/or inappropriate service delivery due to lack of funding could jeopardize federal funds.

#### **ACTIONS NEEDED:**

• Provide \$4 million (\$2 million in FY15 and \$2 million in FY16) to close the Part C funding gap and help provide services to children not receiving Medicaid.

#### 4. Implement reforms to keep students with disabilities safe from seclusion & restraint.

Issue: Seclusion and restraint are dangerous procedures exercised in Virginia schools and in schools nationwide that can inflict injury and trauma on students. According to national data collected by the U.S. Department of Education, Office of Civil Rights from 2011-2012, over 110,000 students were subjected to these unsafe intervention techniques. The use of these unsafe methods has a disproportionate impact on students with disabilities. Students with disabilities make up 13% of Virginia's student population, but 76% of students who were subject to restraint had a disability. Despite the evidence that the unregulated use of seclusion and restraint can be harmful to students, Virginia does not offer protections for public school students.

#### **ACTIONS NEEDED:**

 Require the Virginia Board of Education to promulgate regulations on the use of seclusion and restraint in public schools, consistent with the recommendations of the Commission on Youth (COY). These regulations should be consistent with the principles promulgated by the U.S. Department of Education and the 2009 Virginia guidelines, which call for limiting the use of seclusion and restraint to situations involving an imminent threat of serious physical harm to the child or others.

### 5. Oppose plan to transition I/DD long-term services and supports to profit-making managed care companies.

Issue: In 2013, the General Assembly adopted budget language that directs DMAS to shift all acute and LTSS to a managed care format over a multi-year period. The Arc is concerned that the Commonwealth may decide to use private, profit-making companies to meet this requirement. Managed care companies have little to no experience in the provision of long-term services and supports to people with I/DD. Moving this type of model would represent a radical (and untested) departure from the way in which services are currently organized and delivered.

#### **ACTIONS NEEDED:**

- Oppose the proposal to fold all I/DD long-term services and supports, including public and private ICF/ IDDs and I/DD waiver services, into a Medicaid managed-care plan operated by private, profit-making companies.
- Work on transforming the delivery and financing of long-term supports for individuals with I/DD should move forward in tandem with efforts to achieve broader health delivery reforms. In particular, the steps necessary to restructure the I/DD service delivery process in keeping with the terms of Virginia's settlement agreement with USDOJ should not be sidetracked by efforts to expand managed care to I/DD long-term services and supports.

#### 6. Improve access to accessible and affordable housing.

**Issue:** Virginians with intellectual and developmental disabilities continue to lack access to affordable and accessible housing. Despite an emphasis on independent living in the DOJ agreement, less than 5% of current recipients of I/DD services are living in their own home/apartment.

#### **ACTIONS NEEDED:**

• Support the Governor's proposal to increase access to rental subsidies and expand use of bond funds that were included in the introduced budget.