CORE PUBLIC POLICY PLATFORM

Our Time Has Come for *A Life Like Yours*: Fully Invest in a Community-Based Developmental Disability System

Adopted by The Arc of Virginia Membership on July 31, 2019
August 2019

For years, Virginians with Developmental Disabilities (DD) and their families have waited for a Fully Funded Community Based Service System; however, the Commonwealth ranks 39th in providing integrated, high-quality services to people with DD. With a growing waiting list, increasing cost per waiver due to a system that only responds with services once someone enters crisis, and a DD workforce crisis caused by insufficient reimbursement rates, Virginia continues to fall further and further behind in caring for some of her most vulnerable citizens.

Many strides have been made since the 2012 finding by the United States Department of Justice, that determined Virginia was in violation of the Americans with Disabilities Act by failing to provide services to people with intellectual and developmental disabilities in the most integrated settings appropriate to their needs. However, the system is entering a dire crisis that will only continue to get worse if it is not fully funded. In the Settlement Agreement with the DOJ, Virginia agreed to build a robust system that is integrated and community-based; yet today, more Virginians are waiting for services than when the Agreement was entered, and the waiting list has in fact more than doubled.

The Arc of Virginia and its membership have developed this Core Policy Platform with three central policies:

- Fully Fund the DD Waiver Waitlist
- Increase Waiver Reimbursement Rates to address the existing workforce crisis in DD services
- Fully Invest in the DD system without disrupting the services of those already being served

The time has come for Virginia to Fully Invest in A Life Like Yours for all Virginians.

Sincerely,

Tonya Milling
Executive Director

Kim Goodloe
President, Board of Directors
Medicaid waivers in Virginia are intended to supply a wide range of critical services to meet an individual and family's needs. This can include nursing and/or behavioral supports, residential services, respite, personal care, employment, and assistive technology.

It is important to remember that individuals who qualify for a Developmental Disability (DD) Waiver are individuals who would also qualify for care in an Intermediate Care Facility (training center). These Virginians and their families are instead “waiving” the right to the care they are entitled to in these settings, and instead seeking the services and supports that will enable them to live full, inclusive lives in their own communities. These home and community-based services are designed to meet similar needs required by individuals in the training centers, and are able to provide these supports at a significantly lower average cost.

While Virginia offers multiple Medicaid waiver programs, one of the most commonly used by people with developmental disabilities is the Developmental Disability (DD) Waiver. A DD Waiver serves individuals of any age with a developmental disability and children (birth through age 9) with a substantial developmental delay or specific congenital or acquired condition. The DD Waiver Program provides supports and services options for successful living, learning, physical and behavioral health, employment, recreation and community inclusion. Within the DD Waiver Program, there are three waivers that provide a continuum of services:

- **Building Independence (BI)** - for adults 18 years and older and able to live independently, this waiver usually goes to individuals who own or lease, or otherwise control their own living environment. They do not need supports at all times.
- **Family & Individual Support (FIS)** - for both children and adults who may live with family, friends, or in their own residence. Some individuals may require supports with medical and/or behavioral needs.
- **Community Living (CL)** - for both children and adults who usually require supports in their home at all times. Some individuals may require staff to reside with them in order to receive support with complex medical and/or behavioral needs.

The need for the DD Waiver has consistently been greater than the number of waiver slots the state has funded. For numerous years, there has been a waiver wait list. Anyone found eligible for a DD Waiver is added to the waiting list, and receives a priority status based on urgency of need and risk of institutional placement.

- **Priority One** - determined to need services within one year (the most critical category)
- **Priority Two** - determined to need services within one to five years
- **Priority Three** - determined to need services within five years or longer

While everyone on the waitlist is in need of services, waiver slots are only given to people in Priority One (due to a lack of funding allocated to properly serve all three levels). Individuals in Priority Two and Three can move higher on the waiting list, provided they can demonstrate their need for a waiver slot has become more urgent.
Core Policy #1

Fully Fund the Waiver Wait List -- starting by Funding Priority 1 in the Biennium

Virginia is currently the 39th ranked state for providing integrated, high-quality developmental disability services\(^1\). Correcting this by appropriately recognizing our critically underserviced constituency is both an ethical and a moral imperative. Addressing the urgent Priority 1 waiver wait list is a pro-family, fiscally-sound investment that concretely supports our community-based services system.

- **Years of underfunding the current system has driven people into various states of crisis, including incarceration and institutionalization.** This method costs the Commonwealth more money, both in the short and long term, and guarantees that the waiting list will only continue to grow.

- **Imminent homelessness, incapacity of primary caregiver, behavioral, medical, financial, or similar crises, are currently the primary functional means by which waivers are obtained** – meaning some of Virginia's already most vulnerable citizens must face inordinately dire straits before receiving appropriate and adequate services and supports. Virginia would be far better served by appropriately investing in community-based services earlier in a person's life before individuals, families, and communities are strained and fractured from the multifaceted weight of being underserved.

- **The average cost per waiver for community-based services is demonstrably lower in states with little to no waiting list.**\(^2\) By eliminating the wait for citizens in Priority 1, we can begin to focus on serving people on the waiting list whose service costs are lower – bringing balance and efficiency to our system.

In 2012, Virginia entered into a Settlement Agreement with the DOJ over the lack of Integrated Community Services. There were 6,000 people on the waiting list then. Today, there are over 13,000 waiting.

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\(^1\) The Case for Inclusion, *Data by State*. Accessible online at: http://caseforinclusion.org/data/state-scorecards

Core Policy #2

Increasing Waiver Reimbursement Rates

Appropriately investing in home and community-based services (HCBS) includes appropriate service supports for Virginians with disabilities and their families. In some cases, individuals have waited years in order to receive their waiver - only to then discover they are unable to obtain services on that waiver due to the low rates. Sufficient reimbursement rates that allow for better Direct Support Professionals (DSP) wages, are essential in limiting turnover amongst providers and ensuring individuals have access to the quality supports and services made possible by their waivers.

- Current rates for waiver services are based on outdated information from a 2013 study by the Human Services Research Institute (HSRI)\(^1\) – recommendations from the study were never fully adopted, and the rates provided do not sufficiently fund professionals to offer needed waiver services.

- Virginia’s current rates were designed to yield a mere full-time salary of just $22,600 for DSPs -- well below the federal poverty line for a family of four. These low rates were not designed to provide a living wage, and frequently require DSPs to work multiple jobs or to leave the profession to support their families. An increase in reimbursement rates would have an immediate and direct impact on the financial security of these professionals and their families.

- The often taxing workloads for DSPs, coupled with the low rates of pay, contribute directly to a very high rate of turnover; nationwide, annual turnover amongst Direct Support Professionals is 45%, meaning that approximately half of these care providers leave the field within a year - often disrupting quality of life for waiver recipients even in cases where replacement support is immediately available. In cases where replacement support is not readily accessible, this turnover often leads to more expensive crises for care recipients and their families.

- The disparity between estimated cost to provide necessary services, and the actual rate provided to DSPs, leaves Virginians who require nursing in a vulnerable and often dangerous position, in terms of nursing retention and quality.\(^1\)

- On the economic front, small business Waiver Providers are also suffocating. These Virginia businesses often find they are unable to operate and provide the level of service necessary with the reimbursement rates available. Additionally, an increase in reimbursement rates would allow and encourage further growth and investment in local economies via increased spending right in their own communities.

Virginia is ranked #1 for Business.
But Reimbursement Rates for DD Waiver services continues to yield low wages for one of our most vital workforces.

Core Policy #3

Safeguard Necessary Supports for All Virginians with Disabilities

A full investment in appropriate disability services should not be provided for by making changes to the quality care and services that are currently being provided to individuals. Virginia must prioritize ensuring that those already receiving waiver services do not experience interruptions or changes to those services, at the same time it is actively investing in providing sufficient waiver slots for those still on the waitlist.

- Virginia is currently the 9th wealthiest state in the nation1 and is ranked as the #1 business-friendly2 - yet between 2012 and 2016, Virginia spent far below the national average on home and community-based support for our citizens, and was ranked 42nd among states in per capita Medicaid spending to support people with disabilities.

- Additionally, Virginia invested significantly less in quality supports and services than several of our neighboring states. This includes states with high rankings in terms of business-friendliness, and where a higher population of citizens are receiving home and community-based care and support – showing that appropriate investment can be made without reducing existing services or curtailing funding.

- Virginia has demonstrated her resiliency and viability in economic terms. Promoting our Commonwealth as the best place to live, work, own a business, and raise a family requires full investment for the over 13,000 individuals currently waiting for a waiver – while keeping our commitment to continue the same quality care for Virginians already receiving waiver services in their communities.

![Per Capita Spending](http://caseforinclusion.org/data)


Brandon (Age: 14), Hanover
Brandon requires constant, 24/7 monitoring of his oxygen levels due to seizures – some of which last more than twenty minutes, with his oxygen levels dropping to 50%. One parent has to stay awake throughout the night to monitor him, as he is often up during the night. He copes with a myriad of other physical conditions, and is also non-speaking. Brandon has been on the waiting list for nine years. In 2019, both parents were diagnosed with cancer; Brandon’s mother had to have surgery, limiting her ability to physically care for him. Additionally, the parents are currently legally separated. The impact of these events – on top of Brandon’s need for 24-hour care – has left his parents mentally and physically exhausted. Brandon is in need of in-home residential and nursing services, assistive technology, and a personal care attendant. His parents need respite services, so that they can attend to their own critical health issues.

Parents of Elliott (Ages: mid-60’s), Chesterfield
We are parents in our mid-sixties who do not envision retirement anytime soon, if ever, because our 28-year-old son, Elliott – who has been on the waitlist since 2007 – will always need caregiving. Elliott has intellectual disability and profound hearing loss. His strong work ethic landed him a part-time position at his former high school. Two days a week, we pay out of pocket for day programs for him, at a cost of at least $320/month. As it stands now, Elliott’s only likely chance of getting the support he needs via a waiver will be when one of us can no longer take care of him because of illness or death.

Henry (Age: 70), Halifax
Henry’s sister moved to live with Henry and their frail mother in 2015. All of Henry’s care comes from his sister, who is 66; their mother died about three years ago. He has been on the waiting list for several years, but is not considered Priority 1. Henry has prostate cancer, diabetes, and needs a great deal of personal care from his sister (who has fibromyalgia, which renders her bedridden 4-8 days each month). Henry’s involvement in the community is through church and visiting elderly neighbors. He is in need of personal care, environmental modifications, and community activities for socialization. His sister needs help with caring for Henry, so that she can address her own health problems.

All names have been changed to protect privacy.
The Arc of Virginia promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.