

**2017 Annual ServiceSource Report:
*Identifying Extraordinary Unmet Needs of Adults with
Developmental Disabilities in Northern Virginia.***

ServiceSource has been serving citizens of the Northern Virginia area for over 40 years, providing employment and support services to people with disabilities and a valuable labor force to local commercial businesses and government agencies. For nearly all of these 40 years, ServiceSource has been supporting individuals with complex medical and behavioral needs, many of whom had resided at the Northern Virginia Training Center (NVTC) until its closure in 2016. Many of these former NVTC residents have continued to be supported by ServiceSource Long Term Community Integration Services (LTCIS) after they have moved into community housing.

ServiceSource has been a service provider under contract with multiple northern VA CSBs, for the Virginia Department of Medical Assistance Services (DMAS) as an approved Medicaid provider for the Developmental Disabilities (DD) Waivers, for the Virginia Department for Aging and Rehabilitative Services (DARS) as an approved employment services provider and has also partnered with numerous colleague service providers through its active involvement in Virginia Network of Private Providers (VNPP) and the Virginia Association of Community Rehabilitation Programs (VaACCSES) as well as active ongoing support of the Northern Virginia Coalition. ServiceSource is proud of its leadership role in both advocacy and service delivery.

Our vision and mission statements reflect our commitment to our community.

ServiceSource Vision:

We envision communities that welcome, value, and support the full diversity of their members.

ServiceSource Mission:

The mission is to facilitate services and partnerships to support people with disabilities, their families, their caregivers and community members in order to build more inclusive communities.

ServiceSource has also identified the following **Key Initiatives** in its current Virginia Regional Strategic Plan:

- Creating and supporting community-based employment options for individuals with disabilities
- Providing long-term support services for individuals with disabilities and their families
- Development of specialized services to meet gaps in community needs
- Uniting with the community to achieve our common goals.

This commitment as expressed in the vision, mission, and key initiatives is provided as background to this 2017 annual report, which focuses on two specific areas of concern:

- *The wait list for Developmental Disability (DD) Waiver Services;*
- *The prevalence of complex medical needs among ServiceSource recipients, including former NVTC residents and the continuing need for specialized medical supports, such as dental services.*

ServiceSource is committed not only to current service recipients, who rely on supports to enable them to manage complex medical and behavioral needs while living in the community, but also to the large number of individuals in our community who have significant unmet needs and remain on an alarmingly large wait list for critical Waiver services and supports which are not available to them.

Unmet Needs

As historical perspective on this critical unmet need, the wait list for DD Waiver services has exploded during the period of time that Virginia has been both under scrutiny by the U.S. Department of Justice and engaged in a legal Settlement Agreement to correct this serious public health crisis.

In 2004, the **Statewide** wait list was 2,815, yet in late 2017 there are over 2,000 individuals waiting just in **Fairfax-Falls Church** while that state total has increased from under 3,000 to over 12,000.

Specifically, during the period of the Settlement Agreement, the wait list has more than doubled, from 5,790 in 2011 to over 12,000 in 2017.

These data acknowledge that from 2016 to 2017 some increases to the wait list can be attributed to combining two separate wait lists as part of Waiver Redesign, but even after the combination of the wait lists in late 2016, the January 2017 wait list was 11,112 and the October 2017 wait list was 12,221, which is an increase of 1,109 in just 10 months or a 10% increase in 10 months.

As part of Waiver Redesign and combination of waiting lists, priority status was also changed from classifications of Urgent, Non-urgent and Planning to numerical categories of Priority One, Two and Three. This was not just an adjustment of nomenclature---the criteria were redefined to restrict "eligibility" for the most urgent status. The impact was dramatic. In 2015 and 2016, those considered Urgent represented 61% of the total State WL while in the revised classification system the number in Priority One in Oct 2017 is only 27%. This raises serious questions as to whether the new system is accurately measuring the severity of need and this has serious consequences for information dissemination to the General Assembly and the value of this information to legislative decision makers. Without the proper

context, elected officials and the public may be misled to believe that the urgency and criticality of these individuals has somehow been lessened.

This issue of unmet need is particularly evident in Fairfax-Falls Church where there are now over 2,000 individuals on the wait list (2,052 reported in mid-October) representing an increase of 8.3% in just 7 months (1.2% monthly increase) while the numbers in Priority One have increased by 11.2% in 7 months for a monthly increase of 1.6%.

Setting aside percentages, and focusing on personal impact, we are facing a crisis of 12,221 individuals in Virginia in need of critical Waiver services and of these, 2,052 are Fairfax-Falls Church residents.

Other advocacy leaders in Virginia echo these concerns about unmet needs.

Virginia Association of Community Services Boards (VACSB) has identified this critical need in its 2018 Legislative Platform, recommending that Virginia fund 800 additional Family and Individual Supports (FIS) Waivers and 250 Community Living (CL) Waivers. Quoting the VACSB statement, “Receiving a Waiver slot will enable an individual who needs developmental services and supports to live a life that is fully integrated in the community”.

VNPP supports 750 Community Living (CL) Waivers as well as 75 Family and Individual Supports (FIS) Waivers. Additionally, VNPP recommends that an additional 120 slots that had been proposed for reserve/emergency and discharge use be added to these 825 slots.

VaACCSES has not yet published its 2018 Legislative Position but had indicated it will also support addressing this unmet need as it has in previous years.

Similarly, the Arc of Virginia has not yet published its 2018 Legislative Position but has consistently advocated for additional slots to address this crisis.

Fairfax County publishes its own legislative position paper and the 2018 position supports “additional state funding to increase Medicaid waiver rates and slots, to provide appropriate community services and ensure the Commonwealth fulfills its responsibility to implement the federal settlement agreement.”

Addressing Extraordinary Undermet Needs

Virginia Department of Behavioral and Developmental Services (DBHDS), as part of Waiver Redesign, uses a standardized instrument to assess support needs, the Supports Intensity Scale® (SIS). The assessment scores are extrapolated and displayed in a hierarchy of levels and tiers.

Individuals scoring in levels 1 and 2 have the least significant support needs, those scoring in levels 3 and 4 have moderate supports needs while those scoring in levels 5, 6 and 7 have extraordinary support needs, either as an overall measure (level 5), extraordinary medical needs (level 6) or extraordinary behavioral needs (level 7).

Reviewing DBHDS published data that identifies the 2017 distribution of ALL DD Waiver recipients by level AND comparing these data to those collected by ServiceSource, we offer the following observations.

- Overall (Statewide), the distribution of recipients in levels 1 and 2 is 46% while for the 25 former NVTC residents who continue to be supported by ServiceSource (suggested as a sample), only 4% score in level 2.
- Assignment to levels 3 and 4 are comparable, with an increased number of former NVTC residents assessed at the higher level of 4 as compared to the overall distribution.
- The most compelling observation is apparent when reviewing those with extraordinary needs. Statewide, only 16% of Waiver recipients score at levels 5, 6 or 7 yet among former NVTC residents, 58% score at these levels—in fact those former NVTC residents assessed with extraordinary medical support needs score at four times the rate of ALL Waiver recipients statewide.

DBHDS has developed and implemented reimbursement rates based on individual SIS scores and ServiceSource (along with other providers) contends that this current reimbursement protocol is grossly insufficient to address these extraordinary and complex medical and behavioral support needs. Based on comparison with reimbursement rates negotiated contractually with local CSBs for the same intensity of services, the Waiver reimbursement rates are, in these cases, just more than half of rates legally contracted by local CSBs (after rigorous review and approval by County Procurement procedures) for comparable services. In fact, these locally negotiated rates were in effect to support individuals in community day programs while they resided at NVTC and then the rates were abruptly decreased to the insufficient Waiver rates upon transition from NVTC...impacting providers such as ServiceSource to provide the same level of supports for just over half of the previous reimbursement rate.

To enable providers to support the extraordinary and complex needs of those already receiving authorized Waiver services, DBHDS must reform its rate methodology protocol to adequately compensate providers to ensure the delivery of individualized supports in a healthy and safe manner.

ServiceSource also notes serious under met medical supports for Waiver recipients. Due to the manner in which Medicaid services are provided, Medicaid recipients may have medical services available through the “basic” federally mandated insurance, identified as CCC+ as of December 2017, or State Plan Option services (selected by each State as optional services) OR Waiver services. Acknowledging that Virginia has adopted managed care through its CCC+ coverage commencing December 2017, ServiceSource still raises concerns about dental care for Waiver recipients *but is very encouraged about the recent change in CCC+ that covers preventative care*. CCC+ provides preventative dental care (cleaning and x-rays) effective December 2017 but the availability of dental care such as extractions, crown work and sedation for procedures remains unfunded for adults if they rely on Medicaid coverage exclusively. *ServiceSource is supportive of DBHDS efforts to continue to address this under met need.*

Medical research indicates that health disparities exist for individuals with developmental disabilities. *Healthy People 2020*, a national initiative of the U.S. Department of Health and Human Services, reports that local and State policies can directly affect access to and availability of affordable services. ServiceSource contends that dental services for adults with developmental disabilities are critical medical services and that these services should be available to all qualified individuals in Virginia.

Both *Healthy People 2020* and the former U.S. Surgeon General have reported that individuals with developmental disabilities have additional risks of secondary health conditions. Some individuals with developmental disabilities have a predisposition to respiratory infections, pulmonary issues or to cardiovascular diseases.

Comprehensive preventative and responsive dental care can address a number of these risks. Oral health and effective dental care have direct impacts on an individual's total immune system and inadequate or non-responsive dental care can lead to systemic infections that become difficult to manage.

Beyond the serious medical risks associated with inadequate dental care, self-esteem and self-image are often impacted and these important attributes of holistic health are often severely impacted by long-term neglect of dental care.

Since the implementation of managed care (CCC+) is new to Virginia, ServiceSource suggests that DMAS monitor the usage of available preventative dental care for its members with developmental disabilities and use this analysis to advocate for additional dental services to be covered by Medicaid as CCC+ is adapted to be responsive to the needs of individuals with developmental disabilities. ServiceSource supports DBHDS in advocating that additional dental care procedures (and other extraordinary medical supports) can be included in the managed care system rather than be limited to Waiver recipients---thereby offering some relief to those individuals who remain on the Waiver Wait List.

In summary, ServiceSource, as both a leader in service delivery and a partner in advocacy efforts, offers this information with the expectation of its value to help guide both elected and appointed officials to develop and implement policies, procedures and programs, which are fully funded, to address both unmet and under met needs and ameliorate this public health crisis for Virginians with developmental disabilities.