2018 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 licensed by the Virginia Department of Behavioral Health and Developmental Services (DBHDS). ServiceSource 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 2018 annual report, which focuses on 2 specific areas of concern which had also been identified in the 2017 annual report.

- 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.

In addition, ServiceSource identifies a serious provider barrier, in terms of adequate compensation, that restricts the ability of all Virginia providers to adequately support the complex needs of individuals with developmental disabilities.

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 discussed in the 2017 annual report, 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.

Specifically, during the period of the Settlement Agreement, the wait list has more than doubled, from 5,790 in 2011 to 12,812 as of January 2019. Within this current total, there are 3,238 identified as Priority One (indicating the most urgent and critical need). Alarmingly, there are 43 individuals out of the 12,812 who are over age 70.

This issue of unmet need is particularly evident in Fairfax-Falls Church where there are now 2,292 individuals on the wait list (also reported in January 2019) while the number in the urgent Priority One category has increased to 576.

Provider Barriers

Virginia has a well-established network of community providers, most of which are non-profit agencies. These partner providers work in tandem with local CSBs, DMAS, DBHDS and DARS, to address specific needs within their communities. Since 1991, when Medicaid Waiver funding was initiated in Virginia, these providers have needed to become increasingly more dependent on reimbursement from DMAS for
services (as other funding sources have diminished) and these Medicaid reimbursement rates, which were never established to provide full compensation, have not been adjusted to match increasing expenses incurred by these providers. From 1991 through 2016, there were very nominal adjustments and there were many years without any adjustments.

There had been a DBHDS commissioned rate study leading to a rate adjustment effective in 2016 but the data used to calculate those rates was based on data from 2013. Since then, these rates have not increased so while costs have continued to increase, providers have not been relieved by adjusted reimbursement. In 2018, providers were invited to discuss this issue with State officials for an ad hoc group identified as Provider Issue Resolution Workgroup (PIRW). The PIRW met over a multi month period and generated a report with specific recommendations proposing both an annual rate refresh (using current data while maintain the rate calculation formulas) AND a regular rate rebase (re-evaluating and adjusting the rate formula every 6 years) but neither of these recommendations were included in the DBHDS or DMAS budget requests submitted to the Governor’s Office nor included in the Governor’s advertised budget. Providers have interpreted this as a lack of commitment by Virginia to fair reimbursement. With assistance from concerned elected officials, patrons introduced legislation during the 2019 Session to address these issues, but the bills did not receive sufficient support to result in any changes.

**Addressing Extraordinary Undermet Needs**

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 42% while for the 22 former NVTC residents who continue to be supported by ServiceSource (suggested as a sample), only 4% score in level 2 and none score at level 1.

- Assignment to levels 3 and 4 are also disparate with 45% of the former NVTC residents assessed at levels 3 or 4 compared to a State-wide distribution of 36%.

- 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 supported by ServiceSource, 50% score at these levels.

- The prevalence assessed at level 6, indicating extreme medical support needs, is particularly troubling when reviewing data published in the 2017 Annual Mortality Review, published by DBHDS where it was reported that while only 6.3% of Waiver recipients Statewide were assessed at level 6, the percentage of deaths among those assessed at level 6 was 23%. This startling reality strongly supports the need for adequate rate compensation for providers to safely support our most vulnerable individuals.
While the current Medicaid Waiver rates allow for increased compensation for individuals assessed at higher levels, ServiceSource and other providers contend that even the increased rates are inadequate to safely address those with complex medical or behavioral support needs. Rates must be regularly adjusted to match increasing expenses incurred by providers and this is particularly problematic in the areas of staff recruitment, retention and training so that complex needs can be supported.

In the previous annual report, ServiceSource noted the introduction of preventative dental care through Medicaid Managed Care. After a year of available preventative dental care, ServiceSource staff was curious if any data was available to illustrate unmet and unfunded dental care that had been identified through the preventative care. Reaching out to DMAS to request these data, staff was informed that DMAS had not assembled these data for analysis and a large FOIA fee would be charged for the request. ServiceSource withdrew its information request.

As noted in the previous annual report, oral care is a significant problem for those who are low income (an estimated 30% of Americans have no access to dental care) and this is exacerbated for individuals with developmental disabilities. Much of what is known about dental care for individuals with developmental disabilities is anecdotal but represent very serious issues. Many family members report that their family members are unable to sit in a dental chair for routine care, and especially for longer procedures, and that the cost of sedation or anesthesia are beyond their means, if they can even find dentists offering this service. This has continued even with the minimal and capped coverage for sedation offered through Medicaid Managed Care. Among the small subset of dentists who do treat individuals with developmental disabilities, many treat only children, meaning that even those who are fortunate enough to receive specialized care will eventually “age out” of that service.

### How Does Virginia Rank?

In any discussion, it is relevant to review comparative data. Fortunately, United Cerebral Palsy (UCP) publishes an annual ranking of States comparing variables related to supporting individuals with developmental disabilities. In the most recent report, Virginia ranked 39th (1st being the best rating and 50th being the lowest). While this is an improvement from ten years ago when Virginia was ranked nearly 50th, it is still a major policy issue. Virginia is one of the most populous (12th), one of the wealthiest (8th), one of the best educated (37% have at least a bachelor's degree) and have favorable ratings for low unemployment and a low poverty rate. With all of these positive demographics, it is clear that a funding commitment to individuals with developmental disabilities is a voluntary policy decision and not one that is based on population or economic variables or restrictions.

As Virginia has closed its State Training Centers (reaching a census of just over 300 compared to nearly 1,200 in 2010, funding has NOT been invested to strengthen community-based services. In fact, the UCP report notes that less than $30,000 per person was expended for community-based services in Virginia in 2016 while the average ICF cost that year was nearly six times greater.

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.