



**State Disability Services**

# **2022 TREND REPORT**

## **COMMUNITY SUPPORTS**



**Virginia Board for  
People with Disabilities**

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**PROJECT LIVING WELL**



## COMMUNITY SUPPORTS

### *First Edition*

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# BACKGROUND

Community supports are services that help people with disabilities live self-determined lives in the community. Historically, people with disabilities lived in segregated institutional settings with little control over their day-to-day life experience. People with disabilities did not choose to live in an institution; they were placed there by family members who were told by doctors and medical professionals that it was for the best. It was the advocacy of parents of children with disabilities that ignited a movement to reverse institutional bias and develop a system of community-based services and supports. While the services and supports established during the parent movement moved out of large, hospital-like institutions, people with disabilities continued to be isolated from the broader community with little attention to individual choice and autonomy. Many people with disabilities still lived in large congregate settings, including 12-person group homes, or settings in which they experienced little autonomy. Many also spent their days only with other people with disabilities and paid support providers.

Today, Virginia's disability services system is changing to modernize community-based services and supports. This modernization



is rooted in the principles of individual autonomy, equal rights, and full participation in all aspects of community living. Virginia's disability services system is still evolving to improve the accessibility and quality of services, as well as how the system supports people with disabilities to achieve the quality of life they envision for themselves.

Detailed below are four of the most notable actions which have called for substantial changes in the Virginia disabilities services system. They include the 1981 passage of the Social Security Act Section 1915(c), the 1990 U.S. Supreme Court ruling in *Olmstead v. LC*, the 2012 Settlement Agreement with the Department of Justice (DOJ), and the Centers for Medicare and Medicaid Services (CMS) home and community-based services (HCBS) settings requirements per 42 CFR 441.301.

- Spurred by the disability rights movement in the 1960s and 1970s, Congress passed the Social Security Act Section 1915(c) in 1983. This legislation allows states to use Medicaid funds for HCBS instead of reserving them for institutional services. These Medicaid funds are often called Medicaid HCBS waivers. In Virginia, they are referred to as the Developmental Disability (DD) waivers. Because demand is greater than available funding, many people are placed on a wait list.
- In 1990, Congress passed the Americans with Disabilities Act (ADA), the most comprehensive disability rights legislation of the century. In 1999, the U.S. Supreme Court ruled in the case of *Olmstead v. LC* that the ADA requires that people with disabilities be served in the most integrated setting that meets their needs. The case triggered widespread enforcement actions by the U.S. Department of Justice (DOJ) to ensure

people with disabilities have community-based service options.

- In 2011, the DOJ concluded an investigation of Commonwealth of Virginia's state institutions and disability system with the determination that the Commonwealth was not in compliance with the ADA and the *Olmstead* ruling. In 2012, DOJ and the Commonwealth entered into a Settlement Agreement, with stipulations that the Commonwealth would, among other things, reform the disability services system to prioritize community-based services.
- In January 2014, CMS issued a final rule for HCBS that requires states to review and evaluate home and community-based (HCB) settings, including residential and non-residential settings. This rule reflects CMS' intent to ensure that individuals receiving services and supports through Medicaid's HCBS programs have full access to the benefits of community living and are able to receive services in the most integrated setting.

System reform in Virginia has manifested in multiple ways. In 2013, the Department of Behavioral Health and Developmental Services (DBHDS) instituted the Individual and Family Supports Program (IFSP) to provide various forms of aid or relief to individuals on the wait list and their families, such as temporary financial assistance through the IFSP Funding Program; public education, information, and referrals through the online tool My Life, My Community; family mentoring through the Virginia Commonwealth University's Family to Family (F2F) Program; peer mentoring through the Arc of Virginia's Peer to Peer program; and community coordination through IFSP Regional Councils. In 2016, the Virginia Medicaid HCBS waivers underwent redesign. Changes were effective July 1, 2016, and included the development of one uniform set of



# BACKGROUND

eligibility criteria for all DD applicants, the renaming of three DD waivers, and the reconfiguration of services offered with each waiver. Additionally, existing services were modified, and new services to facilitate greater community inclusion and access were created, such as community coaching and community engagement. The Commonwealth is still working towards meeting Settlement Agreement requirements.

DD waiver services are only one method for people with disabilities to access community supports. Others turn towards community organizations. The Centers for Independent Living (CILs), authorized by the Rehabilitation Act of 1973, for example, are independent non-profit organizations that offer services to people with disabilities such as information and referral; peer counseling; independent living skills training; advocacy; and transition services for youth, people living in institutions, and services that prevent institutionalization. In practice, CIL support service activities may include helping a client set and achieve goals related to community participation or to obtaining access to transportation. Because each CIL is an independent non-profit organization, the full menu of services and programs offered by each CIL may differ, and each CIL may differ in final determinations of who is eligible for specific services.

There are a few challenges that Virginia has yet to fully address and will continue to affect the future provision of community supports. One challenge is the direct support professional crisis, in which high turnover rates among direct support professionals has resulted in instances of instability and quality reduction in services for people with disabilities. A second challenge is the increasing population of aging caregivers. As more people with disabilities

are living longer, family caretakers are more likely to provide care as they themselves age. Eventually, both the adult children with disabilities and their family caretakers will be in need of services, and Virginia must prepare for that influx.



# STATEMENT OF VALUES

The Virginia Board for People with Disabilities (VBPD), as Virginia's Developmental Disability Council, advises the Governor, the Secretary of Health and Human Resources, legislators, and other groups on issues important to people with disabilities in the Commonwealth. The Virginia Commonwealth University Partnership for People with Disabilities (VCU PPD), as Virginia's University Center for Excellence in Developmental Disabilities, connects academic research and service delivery systems to improve the quality of life for people with disabilities in the Commonwealth.

As the product of organizations that are tasked to advocate for people with disabilities, help improve the service system, and advise the structure that governs it, this trend report is driven by a core set of beliefs and principles, which can be distilled into three categories:

## QUALITY

People with disabilities should receive quality services and supports which enhance their lives. Quality services and supports should indicate a recognition that

- all people have ***inherent dignity*** regardless of gender, race, religion, national origin, sexual orientation, or disability status;
- people with disabilities should be ***presumed capable*** of obtaining a level of independence and make informed choices;
- people with disabilities have the right to ***self-determination*** and should be included in the decision-making processes that affect their lives; and
- all people, including people with disabilities, are valued for contributing to the ***diversity*** of the Commonwealth.

Additionally, quality services and supports

- should be provided in the most ***integrated*** setting appropriate to each person's needs and desires;
- should provide ***freedom from abuse and neglect***; and
- should be ***fiscally responsible***.

## SATISFACTION

Enhancing the satisfaction and wellbeing of people with disabilities should be a central goal of the disability services and supports system. Wellbeing includes feelings of happiness and feelings of autonomy. Because people with disabilities are experts in their own wellbeing, personal satisfaction metrics should be considered whenever possible in system evaluation efforts. Satisfaction of family members who act as caretakers or legal guardians should also be considered when available.

## ACCESSIBILITY

Essential services and supports must be physically and programmatically accessible to people with disabilities, regardless of characteristics such as, but not limited to, the nature of their disability, their income, or where they live.

## COMMUNITY SUPPORTS TRENDS

Increased emphasis on community-based services and supports has led to widespread reform in Virginia's disability services system. Providing community services and supports is not only important to support a person's autonomy, but also to prevent institutionalization. The Department of Behavioral Health and Developmental Services (DBHDS) and Centers for Independent Living (CILs) are two of many organizations that oversee or provide services to meet the needs of people with disabilities living in the community. Services include financial aid, and support in self-determining the action steps necessary to achieve the life people with disabilities envision for themselves.

KEY	
↑ Increase that is desirable	↑ Increase that is neutral
↓ Decrease that is desirable	↓ Decrease that is neutral
↑ Increase that is undesirable	↔ Little to no change
↓ Decrease that is undesirable	N/A No data available

*When interpreting this trend summary, it is important to note that all trends are based on the most recent data available at the time of trend report development. As a result, some indicator trends may be based on data that is older or newer than other indicator data. Data, years for which data was available, and further discussion of each indicator's trends are included on the indicator summary pages in the trend report. Additionally, the trend arrows are based on the percentage change over time. Please note that changes less than 1% are deemed "about the same" and indicated with "↔." This threshold does not indicate statistical significance, so it is possible that fluctuations greater or less than 1% were due to random chance. More information on how the trend summary was determined is included in the Data Sources & Limitations section. Additionally, because the list of indicators for this trend report is extensive, not every indicator is discussed in this trend summary. For more information on indicators not discussed, as well as their data sources, please see their indicator summary.*



# State Disability Services TREND SUMMARY

## QUALITY

Less than one third of eligible Virginians with developmental disabilities (DD) enrolled in new DD waiver community services. The Individual Family and Supports Program continued to support Virginians on the DD waiver wait list, but spent less on direct financial relief than in previous years. Virginians with disabilities set the most goals in self-advocacy, self-care, mobility, and personal resource management at Centers for Independent Living (CILs). This suggests that state resources should be focused on these areas.

QUALITY INDICATOR	1 YEAR TREND	4 YEAR TREND	8 YEAR TREND
Eligible People Enrolled in Community Engagement or Coaching	↑	↑	N/A
Individual and Family Supports Program (IFSP) Spending on Direct Temporary Financial Relief	↓	↓	N/A
Self-Advocacy Goals Set	↑	↑	↑
Self-Care Goals Set	↑	↓	↓
Mobility/Transportation Goals Set	↑	↑	↓
Personal Resource Management Goals Set	↓	↑	↑

# State Disability Services TREND SUMMARY

## SATISFACTION

A majority of Virginians receiving Developmental Disability (DD) waiver services reported that staff training has met their needs, though the portion reporting this has slightly decreased. Community group participation remains low at about 40% among Virginians with DD waivers. A majority of Virginians with DD waivers reported having friends outside of staff and family, at rates higher than the national average.

SATISFACTION INDICATOR	1 YEAR TREND	4 YEAR TREND	8 YEAR TREND
Staff Have Right Training to Meet Person's Needs	↓	↓	N/A
Community Group Participation	↓	↓	N/A
DD Waiver Recipients Who Have Friends Who Are Not Staff or Family Members	↓	↑	N/A

# State Disability Services TREND SUMMARY

## ACCESSIBILITY

The percentage of family caregivers who are aged 60+ decreased recently, but the overall number of aging family caregivers continues to increase. The increased aging caregiver population signals a growing need for accessible services and supports for family caregivers and their adult children with developmental disabilities (DD). Additionally, the continued increase of the DD waiver wait list and the inadequate salaries of direct support professionals (home health aides, personal care aides, and nursing assistants) bring to light system capacity concerns. While direct support professional salaries are increasing over time, they are not enough to meet basic family expenses, contributing to direct support professional turnover.

ACCESSIBILITY INDICATOR	1 YEAR TREND	4 YEAR TREND	8 YEAR TREND
Aging Family Caregivers	N/A	↑	↑
Family Caregivers Aged 60 and Older	N/A	↓	↑
Average Home Health & Personal Care Aide Salary	↑	↑	N/A
Average Nursing Assistant Salary	↔	↑	N/A
People Who Use Center for Independent Living (CIL) Services Who Are a Racial/Ethnic Minority	↑	↑	↑
Developmental Disability (DD) Medicaid Waiver Wait List	↑	↑	↑

**COMMUNITY SUPPORTS**  
**Quality Indicator**  
**SUMMARIES**

# **QUALITY INDICATORS**

## **Related to Medicaid Waiver Redesign**

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Medicaid waiver redesign in response to the Department of Justice Settlement Agreement has resulted in, among other things, the creation of new community-based services and the Individual and Family Supports Program (IFSP). The following quality indicators track just two aspects of Medicaid redesign performance:

- Eligible People Enrolled in Community Engagement or Coaching
- Individual and Family Supports Program (IFSP) Spending on Direct Temporary Financial Relief



# Eligible People Enrolled in Community Engagement or Coaching

## WHO:

Percentage of Developmental Disability (DD) waiver recipients who enrolled in community engagement or coaching services.

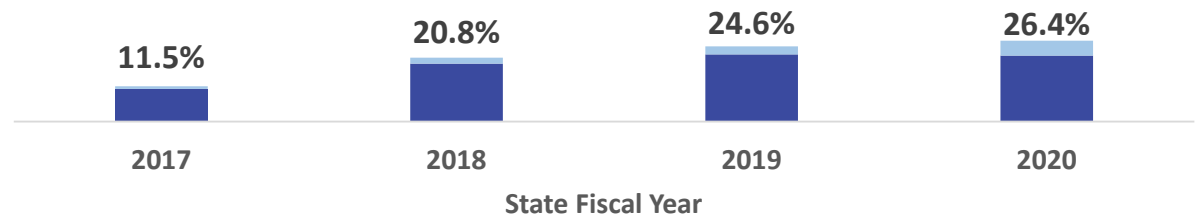
Community engagement services support people with DD in increasing independence and autonomy, forming relationships, improving employment skills, and building natural supports within the community. Activities include but are not limited to volunteering, education or training, and cultural activities.

Community coaching services support people with DD who need one-to-one support to address barriers to participating in community engagement. Activities include but are not limited to skill building for participation in public events and education, public transportation usage, routine supports for personal care, safety supports, and health monitoring.

## HOW:

All people with DD waivers are eligible to receive community engagement or coaching services. The Department of Medical Assistive Services tracks waiver service expenditures.

## DD Waiver Recipients Enrolled in Community Engagement or Coaching



	2017	2018	2019	2020
Community Engagement Recipients	1,333	2,564	3,002	3,155
Community Coaching Recipients	114	262	361	708

Source: Department of Medical Assistive Services. Cumulative Reconciliation of Waiver Slots Data. Richmond, 2021. Produced by Department of Medical Assistive Services.

## WHEN:

Data is reported by state fiscal year.

## WHAT ARE THE TRENDS?

Since the 2016 Medicaid redesign, more Virginians with DD waivers have enrolled in the new community engagement and coaching services, but the portion enrolled was less than 30% of the eligible population each state fiscal year. The percentage of eligible waiver recipients who enrolled in these services ranged from 11.5% in 2017 to 26.4% in 2020. From 2019 to 2020, the percentage increased by 1.8 percentage points (or +7.3%). While the number of community engagement recipients increased from 3,002 people in 2019 to 3,155 people in 2020 (an increase of about 150 people), community coaching recipients almost doubled from 361 people to 708.

## Individual and Family Supports Program (IFSP) Spending on Direct Temporary Financial Relief

### WHAT:

The total amount of money, by the millions, spent on temporary financial relief to individuals and families on the Medicaid Development Disabilities (DD) waiver wait list through the Individual and Family Supports Program (IFSP).

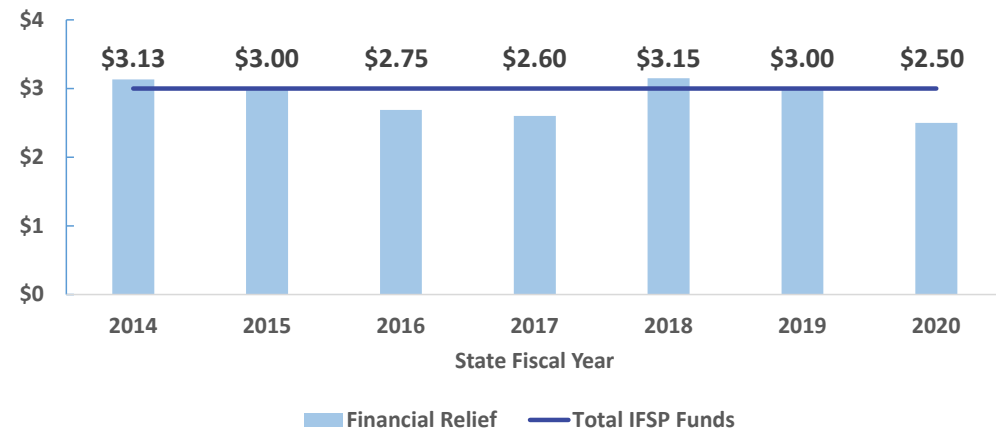
### HOW:

Since 2014, the Virginia General Assembly designates and approves about \$3 million in funding for IFSP each year. Any funding not spent in one year is carried over to the next year. The Department of Behavioral Health and Developmental Services (DBHDS) oversees IFSP, which was created in response to the Department of Justice Settlement Agreement. In addition to providing direct financial relief, DBHDS uses IFSP funding for the Family to Family (F2F) Program, Peer to Peer programs, the My Life, My Community tool, community coordination, and more.

### WHEN:

Data is reported by state fiscal year.

### IFSP Expenditures on Temporary Financial Relief to Individuals and Families on the DD Wait List, by Millions



Source: Department of Behavioral Health and Developmental Services. Individual and Family Supports Program Data. Richmond, 2020. Produced by the Department of Behavioral Health and Developmental Services.

### WHAT ARE THE TRENDS?

Temporary financial relief to individuals and families on the DD waiver wait list has comprised the majority of IFSP expenditures since state fiscal year 2014. From 2014 to 2020, temporary financial aid ranged from \$2.5 million in 2020 to \$3.15 million in 2018. During this same period, the number of individuals and families who received aid ranged from about 1,200 in 2015 to about 3,200 in 2018. From 2019 to 2020, the amount of spending reduced by about half a million dollars (or -16.7%), while the number of recipients reduced from about 3,000 to about 2,500.

## **QUALITY INDICATORS**

### **About Virginians with Disabilities Using Center for Independent Living Services**

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The following quality indicators are based on Virginians with significant disabilities who had consumer service records at Centers for Independent Living (CILs), and received CIL Independent Living Program services funded by the Department for Aging and Rehabilitative Services (DARS). CILs may provide other services outside of the Independent Living Program to people who do not have a significant disability, but such individuals may not be included in this data.

These indicators illustrate areas in which people with significant disabilities have self-determined they would like increased independence. Thus, these indicators illustrate areas in which other state programs may want to increase support as well:

- Self-Advocacy Goals Set
- Self-Care Goals Set
- Mobility/Transportation Goals Set
- Personal Resource Management Goals Set

# Self-Advocacy Goals Set

## WHAT:

The number of self-advocacy goals set by individuals with significant disabilities at Centers for Independent Living (CILs), compared to the total number of people with consumer service records at the CILs. For CIL eligibility in the Independent Living Program, a person with a significant disability has a mental, physical, cognitive, or sensory impairment that restricts their independence and employment opportunities, and whose independence and employment abilities would benefit from independent living services.

Self-advocacy goals are goals to improve the person's ability to represent themselves and their own needs in the public arena, to make their own choices, and more.

## HOW:

A person may set more than one self-advocacy goal. CIL participants (people with significant disabilities) discuss their needs with a CIL Independent Living Specialist in a face-to-face or phone interview. The specialist helps them set and record their goals in a Consumer Service Record. The participant determines five to 10 steps with concrete deadlines needed to achieve their goal with support from the CIL. Goals are achieved when the participant has completed the action steps and believes they have achieved their goal. This data is sent to the Department for Aging and Rehabilitative Services (DARS) for federal reporting.

## Self-Advocacy Goals Set by CIL Independent Living Program Participants in Virginia



Source: Department for Aging and Rehabilitative Services. Centers for Independent Living Data. Richmond, 2019. Produced by the Department for Aging and Rehabilitative Services Independent Living Services.

## WHEN:

DARS reports this data by federal fiscal year.

## WHAT ARE THE TRENDS?

CIL participants have set the greatest number of goals in self-advocacy every year. This suggests that people with disabilities perceive the greatest need for support in this area, and that the focus of state resources and activities should follow accordingly. More than 5,700 self-advocacy goals were set each year since federal fiscal year 2011. Number of goals set ranged from about 5,740 goals in 2014 to about 7,090 in 2018. This could signify that more than half of CIL participants are setting self-advocacy goals, although it could also indicate that thousands of participants are setting multiple self-advocacy goals. The number of total self-advocacy goals has generally increased from 2011 to 2018. From 2017 to 2018, goals increased by almost 400 (or +5.9%).

## Self-Care Goals Set

### WHAT:

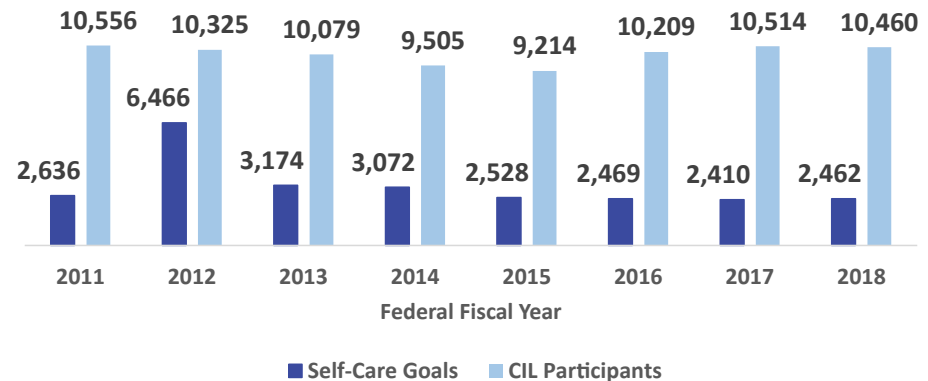
The number of self-care goals set by individuals with significant disabilities at Centers for Independent Living (CILs), compared to the total number of people with consumer service records at the CILs. For CIL eligibility in the Independent Living Program, a person with a significant disability has a mental, physical, cognitive, or sensory impairment that restricts their independence and employment opportunities, and whose independence and employment abilities would benefit from independent living services.

Self-care goals are goals that help the person maintain or increase their level of independence in activities of daily living. Activities of daily living relate to a person's personal health and safety, such as food preparation, personal hygiene, and shopping.

### HOW:

A person may set more than one self-care goal. CIL participants (people with significant disabilities) discuss their needs with a CIL Independent Living Specialist in a face-to-face or phone interview. The specialist helps them set and record their goals in a Consumer Service Record. The participant determines five to 10 steps with concrete deadlines needed to achieve their goal with support from the CIL. Goals are achieved when the participant has completed the action steps and believes they have achieved their goal. This data is sent to the Department for Aging and Rehabilitative Services (DARS) for federal reporting.

### Self-Care Goals Set by CIL Independent Living Program Participants in Virginia



Source: Department for Aging and Rehabilitative Services. Centers for Independent Living Data. Richmond, 2019. Produced by the Department for Aging and Rehabilitative Services Independent Living Services.

### WHEN:

DARS reports this data by federal fiscal year.

### WHAT ARE THE TRENDS?

Self-care is the area in which CIL participants have set the second greatest number of goals. This indicates that self-care is a high priority concern for people with disabilities living in the community. Generally, up to about 25-30% of CIL participants have set self-care goals each year since federal fiscal year 2011. From 2011 to 2018, the total number of self-care goals set ranged from 2,410 in 2017 to about 6,470 in 2012. In 2012, up to about 60% of participants set self-care goals, though it is possible that some participants set multiple self-care goals. From 2017 to 2018, the number of total self-care goals set increased by 52 goals (or +2.2%).



## Mobility and Transportation Goals Set

### WHAT:

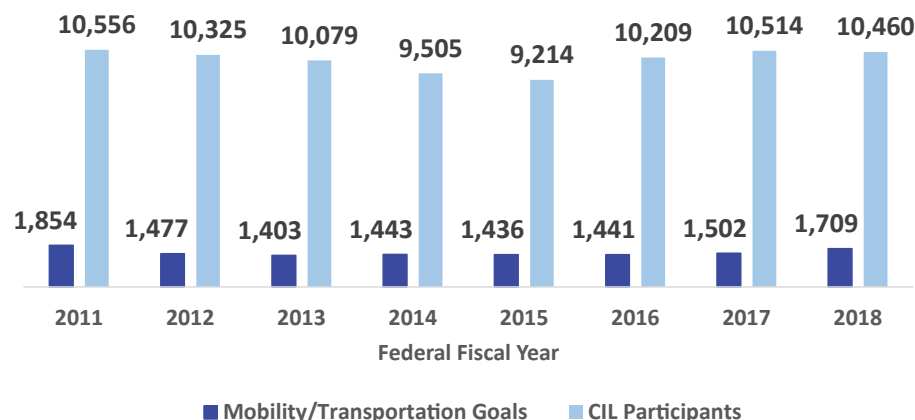
The number of mobility and transportation goals set by individuals with significant disabilities at Centers for Independent Living (CILs), compared to the total number of people with consumer service records at the CILs. For CIL eligibility in the Independent Living Program, a person with a significant disability has a mental, physical, cognitive, or sensory impairment that restricts their independence and employment opportunities, and whose independence and employment abilities would benefit from independent living services.

Mobility and transportation goals involve access to the community and home, and may include obtaining assistive technology, learning to use public transportation, obtaining personal transportation, and more.

### HOW:

A person may set more than one mobility/transportation goal. CIL participants (people with significant disabilities) discuss their needs with a CIL Independent Living Specialist in a face-to-face or phone interview. The specialist helps them set and record their goals in a Consumer Service Record. The participant determines five to 10 steps with concrete deadlines needed to achieve their goal with support from the CIL. Goals are achieved when the participant has completed the action steps and believes they have achieved their goal. This data is sent to the Department for Aging and Rehabilitative Services (DARS) for federal reporting.

### Mobility/Transportation Goals Set by CIL Independent Living Program Participants in Virginia



Source: Department for Aging and Rehabilitative Services. Centers for Independent Living Data. Richmond, 2019. Produced by the Department for Aging and Rehabilitative Services Independent Living Services.

### WHEN:

DARS reports this data by federal fiscal year.

### WHAT ARE THE TRENDS?

People with disabilities set the third highest number of goals in mobility and transportation with CIL support. Since federal fiscal year 2011, more than 1,400 mobility and transportation goals were set by Virginians with disabilities. From 2011 to 2018, the number of goals set ranged from about 1,400 in 2013 to about 1,850 in 2011. Up to about 16% of CIL participants set goals to increase mobility and access transportation each year. From 2017 to 2018, the number of goals set increased by about 200 goals (or +13.8%).

## Personal Resource Management Goals Set

### WHAT:

The number of personal resource management goals set by individuals with significant disabilities at Centers for Independent Living (CILs), compared to the total number of people with consumer service records at the CILs. For CIL eligibility in the Independent Living Program, a person with a significant disability has a mental, physical, cognitive, or sensory impairment that restricts their independence and employment opportunities, and whose independence and employment abilities would benefit from independent living services.

Personal resource management goals involve increasing knowledge and maintenance of fiscal and non-fiscal resources. Goals may include but are not limited to personal or family budgeting, ABLE account access, loan access and management, and obtaining housing subsidies.

### HOW:

A person may set more than one personal resource management goal. CIL participants (people with significant disabilities) discuss their needs with a CIL Independent Living Specialist in a face-to-face or phone interview. The specialist helps them set and record their goals in a Consumer Service Record. The participant determines five to 10 steps with concrete deadlines needed to achieve their goal. Goals are achieved when the participant has completed the action steps and believes they have achieved their goal with support from the CIL. This data is sent to the Department for Aging and Rehabilitative Services (DARS) for federal reporting.

### Personal Resource Management Goals Set by CIL Independent Living Program Participants in Virginia



Source: Department for Aging and Rehabilitative Services. Centers for Independent Living Data. Richmond, 2019. Produced by the Department for Aging and Rehabilitative Services Independent Living Services.

### WHEN:

DARS reports this data by federal fiscal year.

### WHAT ARE THE TRENDS?

Virginians with significant disabilities have consistently set the fourth highest number of goals in personal resource management. More Virginians have set goals regarding personal resource management in recent years than in previous years. Total personal resource management goals set ranged from 1,240 goals in federal fiscal year 2014 to about 2,400 goals in 2017. Up to about 10-20% of participants set goals in this area during the reported years. From 2017 to 2018, the number of goals decreased by almost 750 (or -30.7%).

**COMMUNITY SUPPORTS**  
**Satisfaction Indicator**  
**SUMMARIES**

# **SATISFACTION INDICATORS**

## **About Virginians with Developmental Disabilities**

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The satisfaction indicators are based on the personal experiences or perceptions of Virginians aged 18 and older receiving Medicaid Developmental Disability (DD) waiver services. Virginians with DD are a subset of all Virginian with disabilities, and Virginians receiving DD waiver services are a subset of Virginians with DD.

These indicators give insight into a few aspects of life which have some impact on quality of life and satisfaction, and which state services may be able to influence:

- Staff Have Right Training to Meet Person's Needs
- Community Group Participation
- DD Waiver Recipients Who Have Friends Who Are Not Staff or Family Members

## Staff Have Right Training to Meet Person's Needs

### WHO:

Percentage of Virginians receiving Developmental Disability (DD) waiver services aged 18 or older who said that staff have the right training to meet their needs.

The national average is a weighted average of data from all states that participated in the National Core Indicator (NCI) In-Person Survey. The number of states contributing to the weighted average ranged from 35 to 38 during the time period analyzed. The national average is weighted to take into account each participating states' sample and state population sizes.

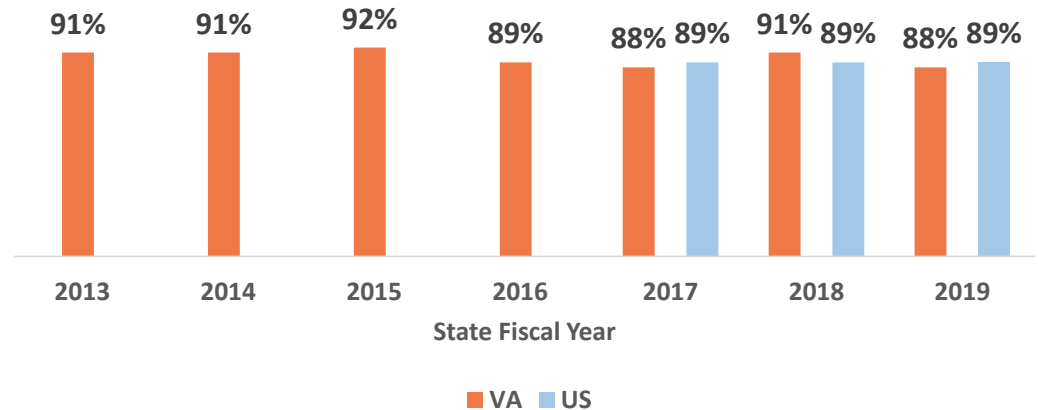
### HOW:

Participants were asked, "Do you feel staff have the right training to meet your needs?" Family members or friends close to the participant were allowed to answer this question. To be included in the survey, the Virginian with DD had to be receiving at least one publicly-funded Medicaid waiver service (other than case management). The data was then submitted to the Human Services Research Institute Online Data Entry Survey Application system to be compiled into an NCI Report.

### WHEN:

States voluntarily report NCI data annually. Results are reported by state fiscal year.

### Virginians with DD Waivers Who Think Staff Have Right Training to Meet Their Needs



Source: Human Services Research Institute and the National Association of State Directors of Developmental Disabilities Services. National Core Indicators (NCI) In-Person Survey. Cambridge: Human Services Research Institute, 2014-2020.

### WHAT ARE THE TRENDS?

Since state fiscal year 2013, about 90% of Virginians receiving DD waiver services said they believe staff have the right training to meet their needs. Participants who said this ranged from 88% in 2017 and 2019 to 92% in 2015. From 2018 to 2019, the percentage who said staff had the right training declined by 3 percentage points (or -3.3%). From 2017 to 2019, responses for Virginians with DD were similar to people with DD nationally.



## Community Group Participation

### WHO:

Percentage of Virginians receiving Developmental Disability (DD) waiver services aged 18 or older who participated as a member in an integrated community group. Community groups include sports teams, book clubs, religious groups, and more.

The national average is a weighted average of data from all states that participated in the National Core Indicator (NCI) In-Person Survey. The number of states contributing to the weighted average ranged from 35 to 38 during the time period analyzed.

The national average is weighted to take into account each participating states' sample and state population sizes.

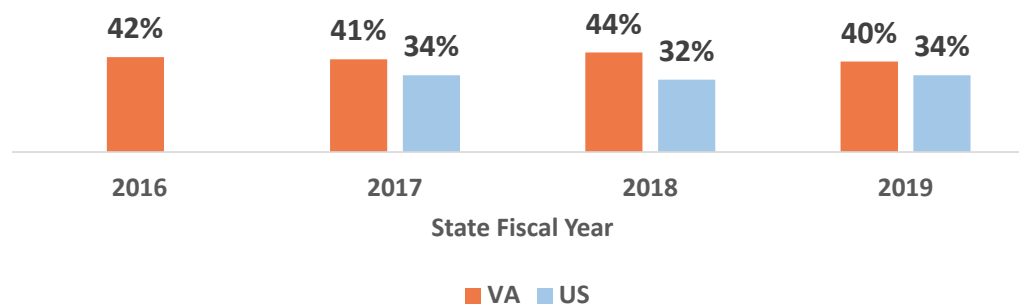
### HOW:

Participants were asked, "Do you participate as a member of community groups in your community?" Family members, friends, or staff close to the participant were allowed to answer this question. To be included in the survey, the Virginian with DD had to be receiving at least one publicly-funded Medicaid waiver service (other than case management). The data was then submitted to the Human Services Research Institute Online Data Entry Survey Application system to be compiled into an NCI Report.

### WHEN:

States voluntarily report NCI data annually. Results are reported by state fiscal year.

### Virginians with DD Waivers Who Participate in Community Groups



Source: Human Services Research Institute and the National Association of State Directors of Developmental Disabilities Services. National Core Indicators (NCI) In-Person Survey. Cambridge: Human Services Research Institute, 2017-2020.

### WHAT ARE THE TRENDS?

Less than half of Virginians receiving DD waiver services participated in integrated community groups. Participation ranged from 40% in state fiscal year 2019 to 44% in 2018. A greater percentage of Virginians receiving DD services were in community groups than people with DD in other states during the years indicated. From 2018 to 2019, community group participation for Virginians receiving DD waiver services decreased 4 percentage points (or -9.1%).

## DD Waiver Recipients Who Have Friends Who Are Not Staff or Family Members

### WHO:

Percentage of Virginians receiving Developmental Disability (DD) waiver services aged 18 or older who have friends who are not staff or family members.

The national average is a weighted average of data from all states that participated in the National Core Indicator (NCI) In-Person Survey. The number of states contributing to the weighted average ranged from 35 to 38 during the time period analyzed.

The national average is weighted to take into account each participating states' sample and state population sizes.

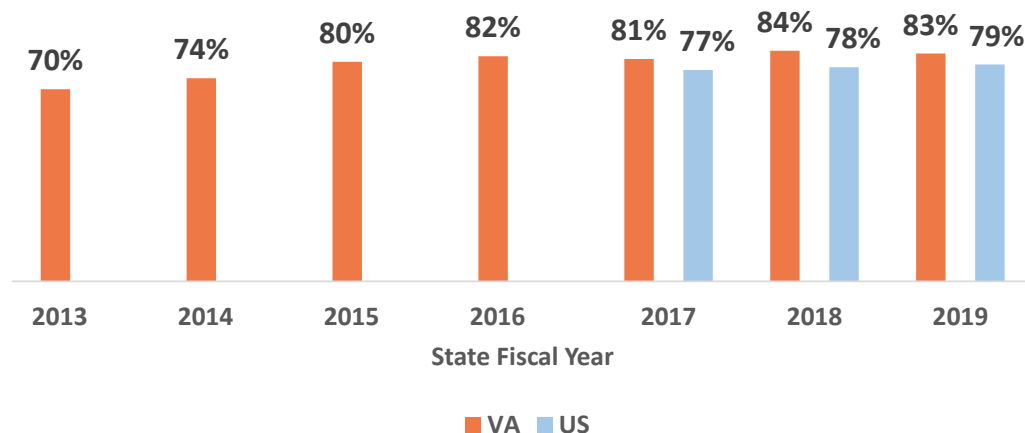
### HOW:

Participants were asked, "Do you have friends you like to talk to or do things with [other than support staff and family members]?" To be included in the survey, the Virginian with DD had to be receiving at least one publicly-funded Medicaid waiver service (other than case management). The data was then submitted to the Human Services Research Institute Online Data Entry Survey Application system to be compiled into an NCI Report.

### WHEN:

States voluntarily report NCI data annually. Results are reported by state fiscal year.

### Virginians with DD Who Have Friends Who Are Not Staff or Family Members



Source: Human Services Research Institute and the National Association of State Directors of Developmental Disabilities Services. National Core Indicators (NCI) In-Person Survey. Cambridge: Human Services Research Institute, 2014-2020.

### WHAT ARE THE TRENDS?

More Virginians receiving DD waiver services have reported having friends who are not staff or family members in more recent years. The percentage of Virginians with DD who had these friends ranged from 70% in 2013 to 84% in 2018. From 2018 to 2019, the percentage decreased by 1 percentage point (or -1.2%). In 2017 through 2019, Virginians receiving DD services were more likely to have friends outside of staff and family than people in other states.

**COMMUNITY SUPPORTS**  
**Accessibility Indicator**  
**SUMMARIES**

# ACCESSIBILITY INDICATORS

## About Aging Caregivers

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The following accessibility indicators describe family caretakers of Virginians with developmental disabilities (DD). They do not include spouses or other non-family caretakers of people with other disabilities.

These indicators show one area in which accessibility of services will be a state concern in the future:

- Aging Family Caregivers
- Family Caregivers Aged 60 and Older

## Aging Family Caregivers

### WHO:

Estimated number of family caretakers for Virginians with developmental disabilities (DD). This caretaker may be a parent or other family member, excluding a spouse.

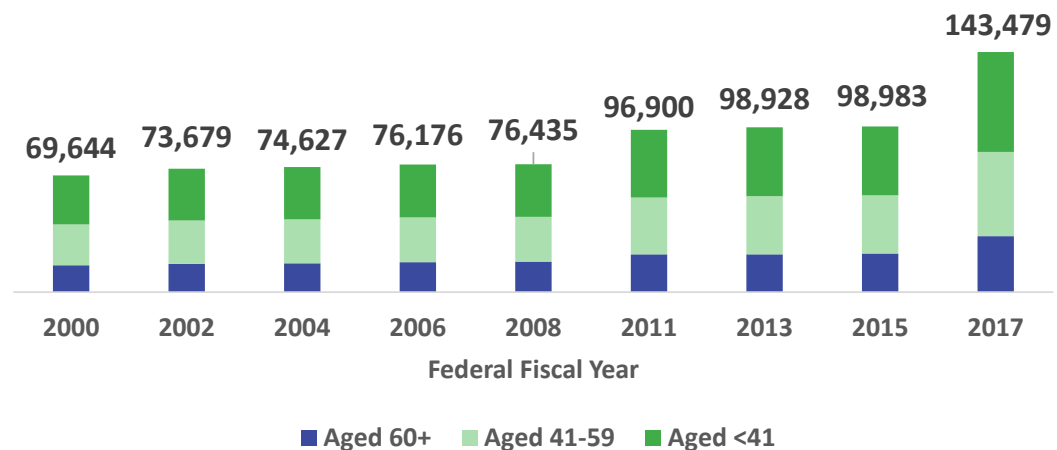
### HOW:

Researchers from the State of the States in Intellectual and Developmental Disabilities Project at the University of Colorado estimates the number of aging family caretakers based on DD prevalence and other factors. The DD prevalence rate used in calculations was 1.58% for years 2000 through 2015 and 2.28% in 2017.

### WHEN:

The data is typically published every other year and is reported by federal fiscal year.

Family Caretakers, By Age Group,  
for Virginians with DD



Source: Tanis, Emily S., Amie Lulinski, Jiang Wu, David L. Braddock, and Richard E. Hemp. *The State of the States in Intellectual and Developmental Disabilities*. Aurora: University of Colorado Anschutz Medical Campus, 2020.

## WHAT ARE THE TRENDS?

The estimated number of family caretakers is increasing each year as Virginians with DD live longer and more Virginians are diagnosed with DD. The estimated number of caretakers more than doubled from almost 70,000 in federal fiscal year 2000 to more than 140,000 in 2017. From 2015 to 2017, family caretakers increased by almost 44,500 (or +45%). The substantial increase from previous years to 2017 is attributable to the change in estimated DD prevalence rate from 1.58% to 2.28%. The change in prevalence rate and consequential jump in estimated caretakers means that the growing need for increased services is a greater concern than previously believed.



## Family Caregivers Aged 60 and Older

### WHO:

Percentage of family caregivers aged 60 or older for Virginians with DD. This caretaker may be a parent or other family member, excluding a spouse.

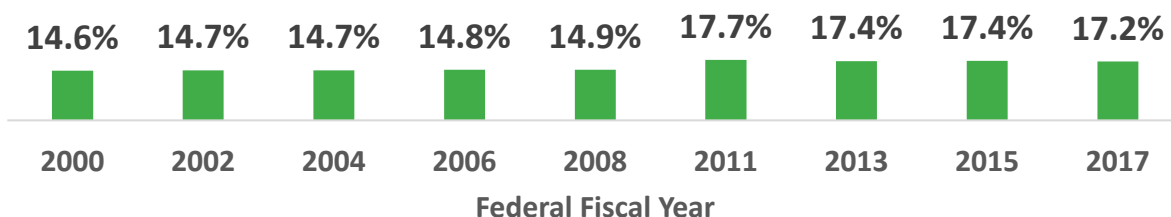
### HOW:

Researchers from the State of the States in Intellectual and Developmental Disabilities Project at the University of Colorado estimates the number of aging family caretakers based on DD prevalence and other factors. The DD prevalence rate used in calculations was 1.58% for years 2000 through 2015 and 2.28% in 2017.

### WHEN:

The data is typically published every other year and is reported by federal fiscal year.

### Virginians with DD with Caregivers Aged 60+



Source: Tanis, Emily S., Amie Lulinski, Jiang Wu, David L. Braddock, and Richard E. Hemp. *The State of the States in Intellectual and Developmental Disabilities*. Aurora: University of Colorado Anschutz Medical Campus, 2020.

### WHAT ARE THE TRENDS?

In more recent years, almost 20% of family caretakers for Virginians with DD are approaching retirement age. The percentage of caregivers aged 60 and older ranged from 14.6% in federal fiscal year 2000 to 17.7% in 2011. As Virginians with DD live longer, and their caretakers grow older, the Virginia disability and health services system must prepare for increased need for services. An increased number of Virginians with DD and their caretakers will soon require personal care, health, and other community-based services.

# **ACCESSIBILITY INDICATORS**

## **About Direct Support Professionals**

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The following accessibility indicators discuss the annual salaries of direct support professionals. The President's Committee for People with Intellectual Disabilities identified home health aides, personal care assistants, and nursing assistants as the three primary occupations that were direct support professionals among the U.S. Department of Labor occupational wage data.

These indicators show one facet impacting high direct support professional turnover, which in turn impacts service capacity and accessibility for people with disabilities:

- Average Home Health & Personal Care Aide Salary
- Average Nursing Assistant Salary

## Average Home Health & Personal Care Aide Salary

### WHAT:

Average annual salary for home health and personal care aides, compared to a livable salary for a single parent with one child, and a livable salary for a parent with a working partner and one child.

Home health and personal care aides provide in-home or institutional services to people with disabilities, senior citizens, and people in medical recovery. Services provided by home health aides include wound care, application of topical medications, bathing, and more. Services provided by personal care aides include assistance in meal preparation, nutritional advice, and personal grooming.

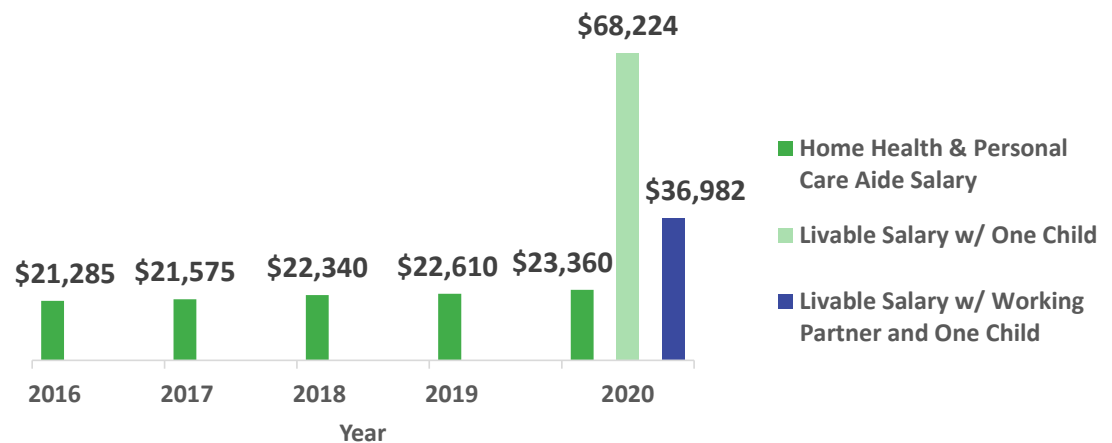
### HOW:

Annual and livable salary are based on full-time work (2,080 hours a year). Annual salary is calculated by the Bureau of Labor Statistics based on the Occupational Employment Statistics survey. Living wage data is calculated by the Massachusetts Institute of Technology in 2020 dollars, and it measures the minimum amount of income required to pay for basic family expenses and taxes without relying on public assistance or without experiencing food and housing insecurity.

### WHEN:

The Bureau of Labor Statistics publishes Occupational Employment Statistics data annually. The Massachusetts Institute of Technology publishes livable wage data on their online Living Wage Calculator annually.

### Home Health & Personal Care Aide Average Salary v. Livable Salary



Source: U.S. Bureau of Labor Statistics. State Occupational Employment and Wage Estimates. Washington, D.C., 2017-2021. Produced by U.S. Bureau of Labor Statistics.

Glasmeier, Amy K. Living Wage Calculation for Virginia. Cambridge: Massachusetts Institute of Technology, 2021.

### WHAT ARE THE TRENDS?

Although the average home health and personal care aide salary increased from 2016 to 2020, Virginians in this occupation still made less than a livable salary needed for basic living expenses such as rent, home meals, healthcare, and more, while supporting a single child in 2020. The average salary for home health and personal care aides in Virginia ranged from almost \$21,300 in 2016 to about \$23,400 in 2020. From 2019 to 2020, the average salary increased by \$750 (or +3.3%). In 2020, home health and personal care aides on average made about \$14,000 less than a livable wage if they had a working partner. Aides who were single parents made almost \$45,000 less than a livable wage.

## Average Nursing Assistant Salary

### WHAT:

Average annual salary for nursing assistants, compared to a livable salary for a single parent with one child, and a livable salary for a parent with a working partner and one child.

Nursing assistants provide basic care services under supervision of nurses. Services include feeding, bathing, dressing, personal grooming, helping the patient move, and other services. They can serve in people's homes or in a health facility.

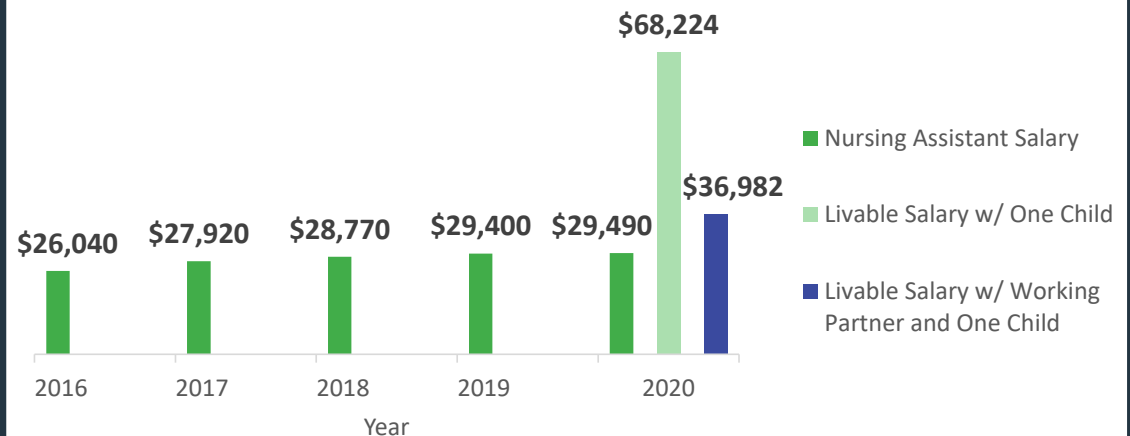
### HOW:

Annual and livable salary are based on full-time work (2,080 hours a year). Annual salary is calculated by the Bureau of Labor Statistics based on the Occupational Employment Statistics (OES) semiannual survey. Living wage data is calculated by the Massachusetts Institute of Technology in 2020 dollars, and it measures the minimum amount of income required to pay for basic family expenses and taxes without relying on public assistance or without experiencing food and housing insecurity.

### WHEN:

The Bureau of Labor Statistics publishes Occupational Employment Statistics data annually. The Massachusetts Institute of Technology publishes livable wage data on their online Living Wage Calculator annually.

### Nursing Assistant Average Annual Salary v. Livable Salary



Source: U.S. Bureau of Labor Statistics. State Occupational Employment and Wage Estimates. Washington, D.C., 2017-2021. Produced by U.S. Bureau of Labor Statistics.

Glasmeier, Amy K. Living Wage Calculation for Virginia. Cambridge: Massachusetts Institute of Technology, 2021.

### WHAT ARE THE TRENDS?

The average nursing assistant salary in Virginia has increased each year, but was still less than a livable salary for supporting a single child in 2020 if the nursing assistant had a partner who was also working full time. From 2016 to 2020, the average salary for nursing assistants ranged from about \$26,000 in 2016 to about \$29,500 in 2020. Despite the increase in salary over the past few years, a nursing assistant who was a single parent did not make enough money to pay for basic expenses such as home-cooked food, rent, healthcare and other expenses without needing public assistance, or without experiencing housing and food insecurity.

## **ACCESSIBILITY INDICATOR**

### **About Virginians with Disabilities Using Center for Independent Living Services**

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The following accessibility indicator is based on Virginians with significant disabilities who had consumer service records at Centers for Independent Living (CILs), and received CIL Independent Living Program services funded by the Department for Aging and Rehabilitative Services (DARS).

This indicator gives insight into CILs' reach and accessibility for people from a variety of cultures:

- People Who Use Center for Independent Living (CIL) Services Who Are a Racial/Ethnic Minority

## People Who Use Center of Independent Living (CIL) Services Who Are a Racial/Ethnic Minority

### WHAT:

The percentage of Centers of Independent Living (CILs) participants who are of a racial/ethnic minority compared to the estimated disability prevalence in Virginia.

CIL participants are people with significant disabilities. Significant disabilities are mental, physical, cognitive, or sensory impairments that hinder a person in employment or independent living. People included in this indicator identified as American Indian, Alaskan Native, Asian, Black, Hispanic or Latino, Native Hawaiian, or Pacific Islander.

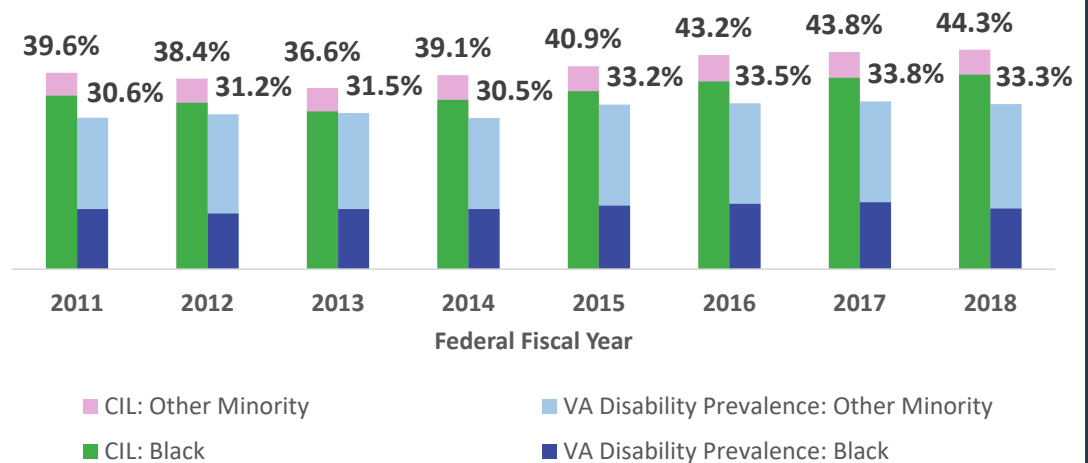
### HOW:

Only CIL participants (people with disabilities) with consumer service records are included in this indicator. Centers for Independent Living collect information on race and ethnicity for federal reporting. Virginia disability prevalence data was calculated based on American Community Survey statistics published in Cornell University's Disability Status Reports.

### WHEN:

CIL data is reported by federal fiscal year, while Virginia disability prevalence data is reported by calendar year.

### Minority Representation among CIL Independent Living Program Participants and Disability Prevalence in Virginia



Source: Department for Aging and Rehabilitative Services. Centers for Independent Living Data. Richmond, 2019. Produced by the Department for Aging and Rehabilitative Services Independent Living Services.

Erickson, William, Camille G. Lee, and Sarah von Schrader. Disability Status Report: Virginia. Ithaca: Cornell University Yang-Tan Institute on Employment and Disability, 2010-2020.

### WHAT ARE THE TRENDS?

From 2011 to 2018, ethnic/racial minority representation among Centers for Independent Living (CIL) Independent Living Program participants ranged from about 37% in 2013 to about 44% in 2018. This was about 5 to 11 percentage points greater than minority representation in Virginia disability prevalence rates. Most of the CIL participants who were of a ethnic/racial minority were Black. Comparatively, disability prevalence data says that only about one third of Virginians with disabilities of ethnic/racial minority are Black. This suggests that cultural or structural barriers may exist that dis-incentivize Virginians from other minority groups from accessing CIL services, or that Virginians from other minority groups tend to seek services from other organizations.

# **ACCESSIBILITY INDICATOR**

## **About Virginians with Developmental Disabilities**

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The following accessibility indicator describes Virginians with developmental disabilities (DD) who are not currently receiving DD waiver services. This indicator reflects state system capacity for the DD waiver program:

- Developmental Disability (DD) Medicaid Waiver Wait List



## Developmental Disability (DD) Medicaid Waiver Wait List

### WHAT:

The number of Virginians on the developmental disability (DD) Medicaid waiver wait list.

Prior to 2016, waivers included the Individual and Family Developmental Disabilities (DD) Support, Intellectual Disability (ID), and Day Support waivers for Individuals with Intellectual Disability. After 2016, waivers include the Family and Individual Supports, Community Living, and Building Independence waivers.

### HOW:

Prior to redesign, DBHDS oversaw one wait list for the DD waiver, and one for the ID waiver. Now, there is only one wait list. This indicator includes data from both pre-redesign wait lists, and the single wait list after redesign. DBHDS periodically updates the wait list as waiver slots are opened or assigned to individuals. In more recent years, the wait list is updated at least once a month.

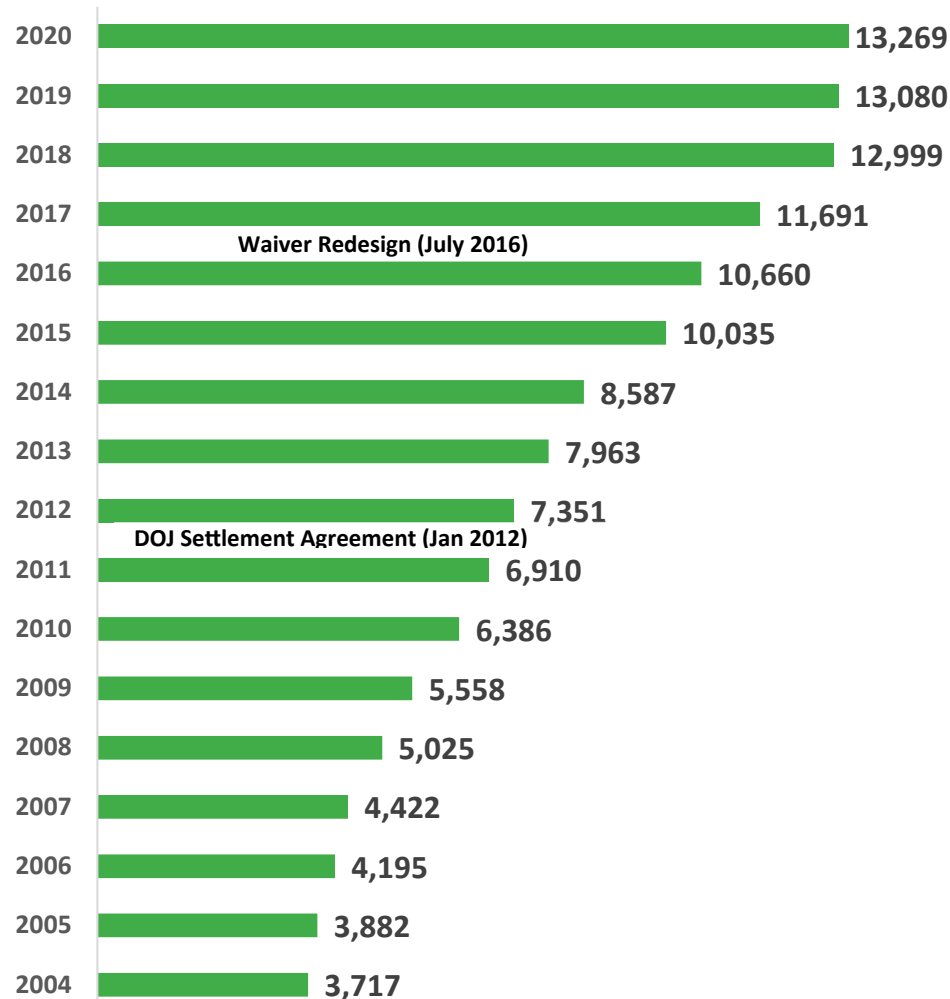
### WHEN:

Data is reported as point-in-time. All data points in the graph are from June of that calendar year, except for years 2005 (March), 2011 (July), and 2020 (May).

### WHAT ARE THE TRENDS?

The waiver wait list has steadily increased each year. The wait list has increased from about 3,700 in 2004 to almost 13,300 in 2020. Since 2004, the number of people on the waiver wait list has more than tripled (+257%). The increase in the waiver wait list was less dramatic from 2019 to 2020 (+1.4%).

### Number of Virginians on the DD Medicaid Waiver Wait List



Source: Department of Behavioral Health and Developmental Services. DBHDS DS Dashboard Data. Richmond, 2020. Produced by the Department of Behavioral Health and Developmental Services.

# METHODOLOGY

**1. Researched how other states and organizations measure service quality and quality of life:** VBPD identified nine states/regions that offered online public access to quality assurance data of services: Washington, D.C., Connecticut, Illinois, Louisiana, Massachusetts, Oregon, South Carolina, Tennessee, and Washington. VBPD also identified several national scorecards including the United Cerebral Palsy (UCP) Case for Inclusion, and the State Scorecard on Long-Term Services and Supports. VBPD reviewed the data points that were reported, and the method through which they were presented. Many scorecards included data that related to quality of life, such as Washington D.C.'s Provider Certification Reviews, which included measures of individual rights protection; Connecticut's Quality Service Review, which included measures of relationships and community inclusion; and UCP's Case for Inclusion, which included measures of health and safety.

**2. Reviewed academic literature on the measurement of quality of life for people with developmental disabilities:** Academic literature discusses quality of life in terms of rights, choice or self-determination, community inclusion and interpersonal relationships, safety, health and wellness (including emotional, physical, and mental well-being), and satisfaction. Researchers agree that measuring outcomes from these different categories is important in determining whether people with DD are living their best lives, in addition to measuring their subjective satisfaction levels.

**3. Reviewed agency state plans, policies, and procedures; federal benchmarks; and other national benchmarks:** This step helped

in the identification and selection of indicators most relevant to Virginia's disability services system, as well as the identification of targets against which to meaningfully compare the data. VBPD initially intended to make systematic comparisons between Virginia data and other states' data, national data, and data for people without disabilities. Although such comparative data is available for some indicators, VBPD decided not to make this systematic comparison due to data limitations. For example, for some indicators, other states chose differing methodologies for measurement, so direct comparisons would be misleading. Direct comparisons with national average data which are based on these states' data would also be misleading. Additionally, data on people without disabilities does not exist for many indicators. For example, data on independent living is gathered for individuals with disabilities, but not for people without disabilities.

**4. Identified data sources for reporting service and quality of life outcomes:** VBPD first reviewed and compared data that was already publicly available online, in order to minimize the extent to which state agencies would need to provide additional data and to better ensure sustainability of the trend report. Next, VBPD solicited feedback from and discussed possibilities of data sharing with other agencies that serve the DD population: the Centers for Independent Living (CIL), the Department for Aging and Rehabilitative Services (DARS), the Department for the Blind and Vision Impaired (DBVI), the Department of Behavioral Health and Developmental Services (DBHDS), the Department of Medical Assistance Services (DMAS), and the Virginia Department of Education (VDOE). Each agency expressed enthusiasm for the

project, and some have offered to share additional data.

**5. Selected indicators:** Indicators that best addressed the three following categories were included in the trend report:

i) Quality: VBPD defined quality based largely on VBPD's statement of values and factors which researchers and other states have found important to measuring positive life and service outcomes for people with DD. VBPD's stated values, which are published in each annual policy assessment, are inherent dignity, presumed capacity, self-determination, integration, diversity, freedom from abuse and neglect, and fiscal responsibility. The quality of life areas identified by researchers and other states are listed in #2 above.

ii) Satisfaction: Satisfaction was identified by researchers

as an important factor of measuring life and service outcomes, as identified in #2 above. VBPD separated satisfaction indicators from the "quality" category in order to highlight the importance of the experiences of the individuals being served and their families, recognize that satisfaction may be based on factors including but not limited to quality, and recognize that satisfaction may not necessarily mirror observable measures of quality due to its subjective nature.

iii) Accessibility: Accessibility is an important component of service delivery. If the service is inaccessible, then the quality of the service is moot. The accessibility of a service can be affected by factors such as funding levels and staffing levels, and can be observed via measures including but not limited to service wait times and cost to the beneficiary.

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***Special thanks to the agencies and organizations  
that provided feedback for this trend report:***



STATE OF THE STATES  
IN INTELLECTUAL AND  
DEVELOPMENTAL DISABILITIES

# DATA SOURCE & LIMITATIONS

**Trend arrows in the trend summary** are based on percentage change over time, using the formula  $((\#2 - \#1) / \#1) \times 100$ , in which #2 is the most recent data point, and #1 is the less recent data point. For one-year trends, #1 is drawn from the previous year. For four-year trends, #1 is drawn from the year three years prior to the most recent data point, so that the time frame of interest spans a total of four years. Similarly for eight year trends, #1 is drawn from the year seven years prior to the most recent data point, so the time frame of interest spans a total of eight years. A change equal to or greater than 1% percent is indicated with “↑,” while a change equal to or less than -1% is indicated with “↓.” Any changes that are less than 1% in either direction (in other words, a change that is between -0.9 and 0.9) are indicated with “↔” in the trend summary. This 1% threshold does not indicate statistical significance, so it is possible that fluctuations greater or less than 1% were due to random chance. VBPD was unable to determine statistical significance due to limitations in data availability and staff resources.

**Below are the data sources from which this report drew its indicators.**

## 1. Centers for Independent Living (CILs)

The Department for Aging and Rehabilitative Services (DARS) funds and oversees the Independent Living Program at Virginia. DARS regularly collects data on CIL Independent Living Program activities. Some of this data is publicly available through federal Section 704 Annual Performance Reports. Thus, DARS provided data from all CILs for this trend report, organized by federal fiscal year. This trend report used CIL data for the indicators called *Self-Advocacy Goals Set*, *Self-Care Goals Set*, *Mobility/Transportation Goals Set*, *Personal Resource Management Goals Set*, and *People Who Use Center of Independent Living (CIL) Services Who Are a Racial/Ethnic Minority*.

CIL services are accessed voluntarily by people of all ages. There is no data on people who did not seek out CIL services. While any person regardless of disability status may receive information and referral services from CILs, only people who meet significant disability eligibility criteria may have access to

other CIL services that receive state funding through the DARS Independent Living Program. A significant disability is a mental, physical, cognitive, or sensory impairment which substantially limits a person’s ability to live or work independently in their family or in the community. This definition is not a diagnostic definition, but is only used for eligibility purposes. Because each CIL acts as an independent non-profit organization, determination of Independent Living program eligibility is ultimately decided by each CIL. Thus, individuals accepted at one CIL’s Independent Living program may not be accepted at the same program at a different CIL.

CIL services funded through the DARS Independent Living Program include advocacy, independent living skills training, peer counseling, and transitional assistance. Use of these services requires documentation in consumer service records. The indicators in this report draw from CIL data that only reflect the activities of people with significant disabilities with consumer service records. The outcomes of people who only access information and referral services, and the outcomes of people who do meet significant disability eligibility criteria are unknown.

For the indicators *Self-Advocacy Goals Set*, *Self-Care Goals Set*, *Mobility/Transportation Goals Set*, and *Personal Resource Management Goals Set*, people with disabilities set goals with the support of CIL Independent Living Specialists. The participants determine their action steps, and goals are considered achieved when participants believe they have achieved them. Thus, consumer service records may be opened in a given federal fiscal year, but goals listed in the record are not always achieved during that federal fiscal year. This trend report used data on the number of goals set rather than percentage of goal achievement to reflect the need of people with disabilities, rather than the speed with which they complete them.

For the indicator *People Who Use Centers of Independent Living (CIL) Services Who Are a Racial/Ethnic Minority*, race is voluntarily reported.

This may mean that the data is an undercount. Additionally, participants may have reported being two or more races. These individuals were not included in the indicator.

## 2. Department of Behavioral Health and Developmental Services (DBHDS)

DBHDS provided data for this trend report by request for the indicators *Individual and Family Supports Program (IFSP) Spending on Direct Temporary Financial Relief* and *Developmental Disability (DD) Medicaid Waiver Wait List*.

The IFSP was established in 2013 to provide temporary financial relief to people and families on the Medicaid waiver wait list. IFSP funding is determined by the Virginia General Assembly and administered by DBHDS. Beginning in 2014, the General Assembly designated \$3 million for IFSP each year. Data for 2013 is not shown here due to differences in budget and therefore comparability. Funding is completely spent each year, though how the money is distributed among the many IFSP subprograms and partnerships may vary.

Virginia's Medicaid waiver wait list was established in the late 1990s and is managed by the Department of Behavioral Health and Developmental Services (DBHDS). DBHDS updates the waiver wait list to determine the number of people receiving services and the number of people who are still in need of services. In more recent years, DBHDS has updated the wait list more regularly, often at the end of each month. In order to keep the wait list up-to-date, DBHDS mails individuals on the wait list to determine whether they would like to remain on the wait list. Wait list data is used in the indicator *Developmental Disability (DD) Medicaid Waiver Wait List*.

Among those who are not considered as being on the wait list are: individuals whose services are on hold due to admission to an intermediate care facility for individuals with intellectual disabilities (ICF/IID), admission to a rehabilitation hospital, incarceration, no receipt of waiver services for 30 uninterrupted days, or loss of Medicaid eligibility; individuals

currently receiving waiver services; and individuals appealing to keep their waiver slot. Because of lag time between occurrence and wait list update, deceased individuals may be mistakenly counted on the wait list. Additionally, individuals who have been assigned a waiver slot but have yet to receive services may unintentionally be counted as being on the wait list, depending on how recently they have been assigned a waiver slot. DBHDS moves individuals who have been assigned a waiver slot off of the wait list as quickly as possible. Trend analyses using data prior to the 2016 must be done with caution. Prior to the 2016 waiver redesign, the mailing system was not yet in place, so individuals who were receiving services may have been counted as being on the wait list.

## 3. Department of Medical Assistive Services (DMAS)

DMAS oversees Medicaid waiver authorizations, enrollment, and expenditures. This data was accessed for this trend report through a Chapter 12 data request to DMAS. Data was provided by waiver type (Day Support or Building Independence, Developmental Disability or Family and Individual Supports, and Intellectual Disability or Community Living waivers). Thus, some calculations were done to obtain the statistics used for the indicators *Percentage of Eligible People Enrolled in Community Engagement or Coaching*.

All waiver recipients, regardless of waiver type, are eligible for community engagement and coaching services. The data for *Percentage of Eligible People Enrolled in Community Engagement or Coaching* were calculated by combining the number of recipients for the community engagement and community coaching services in each waiver, then dividing by the total number of unduplicated waiver recipients.

## 4. Living Wage Calculator

The Living Wage Calculator is published and maintained by researchers at the Massachusetts Institute of Technology. Living wage data is published each year, but only data for the most recent year of analysis is available because of the incomparability of data across years due to inflation. This trend report uses the Living Wage Calculator as comparative data points



in the indicators *Average Home Health & Personal Care Aide Salary* and *Average Nursing Assistant Salary*.

Living wage is based on basic needs expenses and relevant taxes. Basic needs expenses are costs of food, housing, transportation, childcare, healthcare, and other necessities. Living wage does not cover meals from restaurants or other establishments outside of the home, costs for leisure time such as unpaid vacations or holidays, or savings and investments.

Food costs are calculated based on the USDA's low-cost food plan national average, which assumes that the family is making adequately nutritious snacks and meals at home, using lower-cost groceries. Housing costs are determined using the Housing and Urban Department's Fair Market Rents estimates, weighted to take population into account. Population estimates are from the Census Bureau's American Community Survey. For families that have only one child, the child is assumed to be four years old and in need of childcare. Childcare costs are based on state market rate surveys, with the assumption that the family will select the least expensive childcare.

Transportation, healthcare, civic engagement, and other necessity costs are calculated using the Bureau of Labor Statistics Consumer Expenditure Survey. Transportation costs are costs of a used vehicle, fuel, routine maintenance, and public transportation. Healthcare costs based on this source are costs of medical services, drugs, and supplies. Healthcare costs also include employer-sponsored health insurance, drawing from the Agency for Healthcare Research and Quality's Health Insurance Component Analytical Tool. Civic engagement costs are expenses for basic activities that enrich a person's life, such as audio and visual equipment and services, hobbies and playground equipment, toys, pets, reading, education, fees and admissions, other entertainment supplies, and equipment and services. Other necessity costs based on the survey are costs of clothing, housekeeping supplies, reading, and other miscellaneous personal care items.

Other miscellaneous expenses not based on the Statistics Consumer Expenditure Survey are broadband and cell phone service, and taxes.

Broadband costs are calculated based on the BroadbandNow tool. Cell phone service costs are based on the assumption that a customer will select a prepaid unlimited call and text plan with 10 to 15 gigabytes of monthly data for a less expensive cell phone with minimal smart phone features, and that a new cell phone is purchased every three years. Tax costs are based on federal and state taxes, and property and sale taxes were accounted for in housing rent costs and other necessities. Federal taxes are from the Urban-Brookings Tax Policy Center Microsimulation Model, and state taxes are from the CCH State Tax Handbook.

Living wage is adjusted to account for inflation for the year of analysis (in other words, 2020 dollars), using the Bureau of Labor Statistics' Consumer Price Index inflation multiplier.

## 5. National Core Indicators (NCI) Adult In-Person Survey

NCI is a national project which collects and publishes data on individuals with developmental disabilities (DD). NCI depends on voluntary participation from states. Virginia has participated in the NCI Adult In-Person Survey since state fiscal year 2012. In the first year of data collection, however, Virginia's sample size was below the standard minimum sample size of 400 and is therefore excluded from this trend report. In the 2018-19 cycle, Virginia interviewed 807 people. Survey participants are randomly selected from all Virginians with developmental disabilities (DD) aged 18 or older who are receiving at least one publicly-funded service (excluding case management), in this case DD waiver services. The differences between those who received DD waiver service and those who received none are unknown. This trend report used NCI data for the satisfaction indicators *Staff Have Right Training to Meet Person's Needs*, *Community Group Participation*, and *DD Waiver Recipients Who Have Friends Who Are Not Staff or Family Members*.

The indicator *DD Waiver Recipients Who Have Friends Who Are Not Staff or Family Members* are from Section I of the Survey. Section I asks about personal opinions, so only the person with DD may answer questions from

this section. The indicators *Staff Have Right Training to Meet Person's Needs and Community Group Participation* are from Section II, which ask about observable behaviors and allow for proxy respondents. In the case of *Staff Have Right Training to Meet Person's Needs*, only friends or family members could be proxy respondents. For *Community Group Participation*, family, friends, or staff close to the respondent could answer the question. While questions regarding observable behavior tend to have higher levels of agreement between the person with DD and their proxy, compared to questions regarding subjective experiences, it is possible that the proxy's answer in Section II questions does not accurately reflect what the individual would answer.

## 6. Occupational Employment Statistics (OES)

The OES is a semiannual survey that is funded by the Bureau of Labor Statistics and administered by state workforce agencies. The survey is distributed in May and November, and the final published dataset is based on three years-worth of data (or six semiannual panels). For example, the dataset published for May 2020 was based on semiannual panel data from November 2017, May 2018, November 2018, May 2019, November 2019, and May 2020. Each panel consists of data from a sample of 200,000 establishments, so that each published dataset totals up to a sample of about 1.2 million establishments. Data is collected through mail, email, in-person, and other methods. Final statistics are weighted to account for all establishments in the reference period and adjusted by the ratio of employment totals from the two most recent semiannual panels. Wage data is straight-time, gross pay. Overtime pay and other types of supplemental pay are excluded. This trend report uses this data for the indicators called *Home Health & Personal Care Aide Salary and Nursing Assistant Salary*.

The Bureau of Labor Statistics provided definitions for each occupation. The definition for nursing assistant had minor changes beginning in 2019. In 2019, nursing assistant services included toileting, medication administration, and other health-related tasks. Prior to 2019, services included changing bedding. Because salary data for nursing assistants

included both those who worked in the home and those who worked in facilities, this trend report is unable to provide the salary only for nursing assistants who work in personal homes in Virginia.

Data for home health aides and for personal care aides was first combined in 2019. The separate data for home health aides and personal care aides for previous years was combined and presented as a simple average for this trend report. Consequently, the presented data for home health and care aides for years prior to 2019 in this report may not be the exact figures that the Bureau of Labor and Statistics would have presented if they had combined the data themselves.

## 7. State of the States in Intellectual and Developmental Disabilities Project

This is a longitudinal data Project of National Significance conducted by the University of Colorado. This project typically publishes a report every other year. The State of the States report tracks public spending for developmental disability (DD) services, as reported by DD agencies such as Virginia's Department of Behavioral Health and Developmental Services. Most of the State of the States data presented in this report were provided by project staff through a data sharing agreement. State of the States data was used for the indicators called *Aging Family Caregivers and Family Caregivers Aged 60 and Older*.

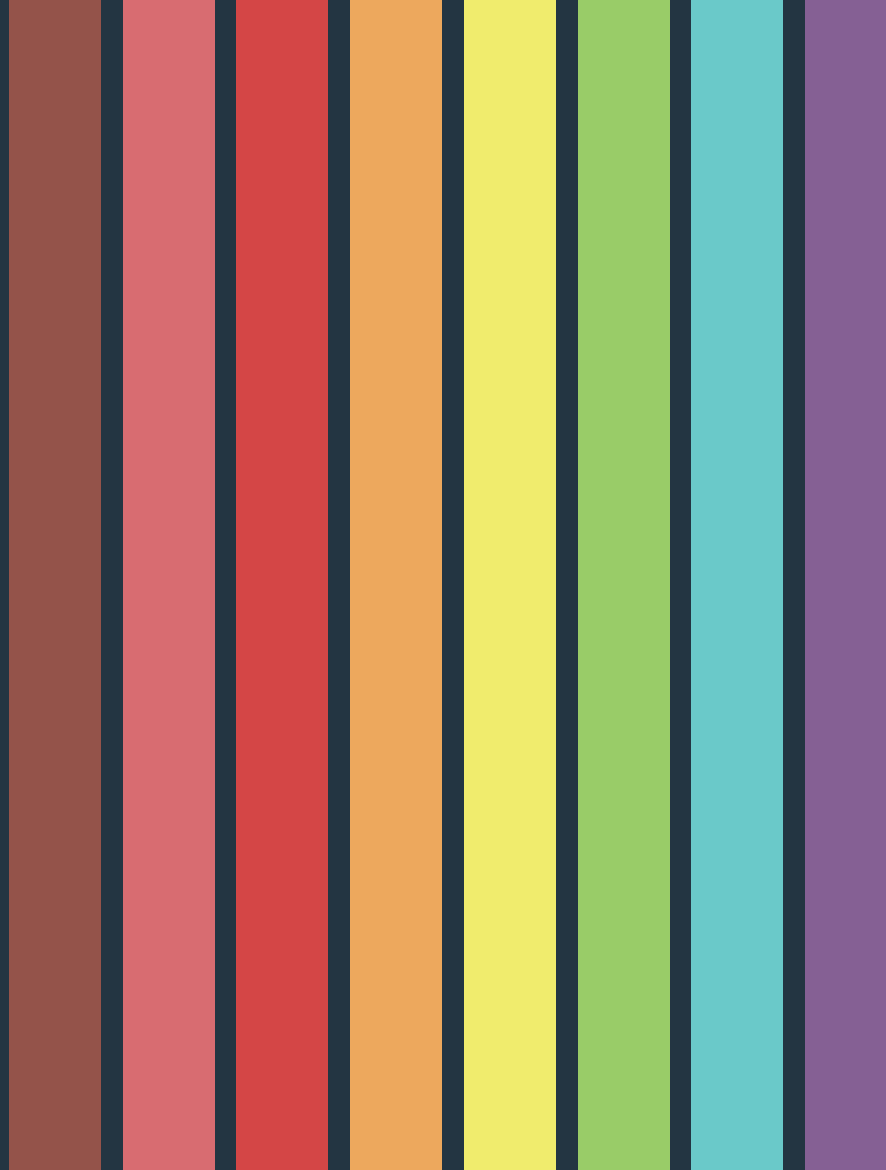
Data from as early as federal fiscal year 1989 was provided to VBPD, although only data from as early as 2000 was published in this trend report. Data from the years 2018 and 2019 are preliminary and have not completed verification for accuracy. Because data from State of the States only describes items related to people with DD, the family caregiving circumstances of other people with disabilities is unknown. Family caregiver data was calculated based on estimates of DD prevalence and the assumption that the caregiver is single and a non-spouse family member. It is possible that a person with DD has more than one caregiver or an unpaid, non-family caretaker.



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