Assessment of Virginia's Disability Services System:

# Early Intervention



# 2019 Assessment of Disability Services in Virginia Early Intervention

First edition

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The Virginians with Disabilities Act § 51.5-33 directs the Virginia Board for People with Disabilities (VBPD), beginning July 1, 2017, to submit an annual report to the Governor, through the Secretary of Health and Human Resources, that provides an in-depth assessment of at least two major service areas for people with disabilities in the Commonwealth. In June 2018, the Board selected Early Intervention and Community Living as the areas to be covered in the 2019 Assessments. The Board, as part of its authority and responsibility as a Developmental Disabilities (DD) Council under the federal Developmental Disabilities and Bill of Rights Act (42 U.S.C.§15021-15029), is also required to complete a similar analysis as it develops and amends its federal State Plan goals and objectives.

The Assessments on Early Intervention and Community Living, respectively, are not intended to be a comprehensive inventory of all of the services and supports available to individuals with disabilities in the Commonwealth and should not be relied upon as such. Rather, in this Assessment, the Board seeks to identify critical issues, data trends, and unmet needs of people with developmental disabilities, and offer recommendations for improving the delivery of services for people with developmental disabilities in the Commonwealth and the full integration of people with developmental disabilities into all aspects of community life. Although the focus of the analysis and recommendations is on individuals with developmental disabilities and other populations with similar needs.

The data for this Assessment was obtained from a variety of sources, including state and federal agency websites and reports, legislative studies, and various research publications. We appreciate the assistance of the state agencies that provided information and clarification on the services relevant to their agencies. The policy recommendations contained within this Assessment were developed by an ad hoc committee of the Board and approved by the full Board at its March 13, 2019 meeting.

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# i

# **Statement of Values**

Physical or mental disabilities in no way diminish a person's right to fully participate in all aspects of society, yet many people with physical or mental disabilities have been precluded from doing so because of discrimination ...; historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem ...

#### - 42 U.S. Code § 12101 – Americans with Disabilities Act – Findings and Purpose

The Virginia Board for People with Disabilities serves as Virginia's Developmental Disabilities Council. In this capacity, the Board advises the Governor, the Secretary of Health and Human Resources, federal and state legislators, and other constituent groups on issues important to people with disabilities in the Commonwealth. The following assessment of Early Intervention services and outcomes is intended to serve as a guide for policymakers who are interested in improving supports for infants and toddlers with or at risk of developmental delays in the Commonwealth of Virginia. The Board's work in this area is driven by its vision, values, and the following core beliefs and principles:

**Inherent Dignity:** All people possess inherent dignity, regardless of gender, race, religion, national origin, or disability status.

**Presumed Capacity:** All people should be presumed capable of obtaining a level of independence and making informed decisions about their lives.

**Self-determination:** People with disabilities and their families are experts in their own needs and desires and they must be included in the decision-making processes that affect their lives.

**Integration:** People with disabilities have a civil right to receive services and supports in the most integrated setting appropriate to their needs and desires, consistent with the Supreme Court's *Olmstead* decision.

**Diversity:** Diversity is a core value. All people, including people with disabilities, should be valued for contributing to the diversity of the Commonwealth.

**Freedom from Abuse and Neglect:** People with disabilities must be protected from abuse and neglect in all settings where services and supports are provided.

**Fiscal Responsibility:** Fiscally responsible policies are beneficial for the Commonwealth, and they are beneficial for people with disabilities.

97%

### **Executive Summary**

The Early Intervention program, administered by the Department of Behavioral Health and Developmental Services (DBHDS), provides services and supports to infants and toddlers with developmental delays and their families, in accordance with Part C of the Individuals with Disabilities Education Act (IDEA). These services may include, but are not limited to, speech therapy, physical therapy, occupational therapy, psychological services, and service coordination. The services are intended to minimize developmental delay, maximize potential for independent living, and reduce costs to society by minimizing future need for special education and related services. About two-thirds of children receiving Virginia's Early Intervention services in recent years have

Indicator	1-Year Trend	4-Year Trend	Most Recent Data			
Reach of Virginia's Early Intervention Program						
Number of children served by Virginia's Early Intervention program (2018)	1	1	20,202			
Annual funding for Virginia's Early Intervention program (2018)	1	1	\$73,505,965			
Annual funding per child served by Virginia's Early Intervention program (2018)	1	Ļ	\$3,639			
Functional Outcomes of Virginia's Early Intervention Program	<u> </u>	<u> </u>				
Children with Individual Family Service Plans who demonstrate substantially improved social-emotional skills (2017)	$\leftrightarrow$	1	66%			
Children with Individual Family Service Plans who demonstrate substantially improved ability to acquire and use knowledge and skills (2017)		t	70%			
Children with Individual Family Service Plans who demonstrate substantially improved use of appropriate behaviors to meet needs (2017)	$\leftrightarrow$	Ļ	70%			
Service Provision Setting for Early Intervention & Early Childhood Special Education Programs						
Children from birth to age three receiving Early Intervention services in home- or community-based settings (2017)	+	<b>+</b>	99.96%			
Children ages three through five with Individualized Education Plan who attend regular early childhood program and receive most services in regular program (2017)	1	t	32%			
Children ages three through five with Individualized Education Plan who attend separate special education class, separate school, or residential facility (2017)		t	27%			
Timeliness of Service Provision & Transition to Early Childhood Special Education Program						
Percent who begin receiving Early Intervention services within 30 days of parent consent (2017)	+	+	97%			
Initial Early Intervention evaluation and assessment, and initial Individual Family Service Plan meeting, conducted within 45 days of the referral (2017)	ţ	ţ	98%			
Transition steps and services in Individual Family Service Plan by 90 days prior to 3rd birthday (2017)	t	t	96%			

Transition conference at least 90 days prior to 3rd birthday if potentially eligible for Part B Preschool services (2017)

*Table 1: Key performance indicators of Virginia's Early Intervention program.* 



experienced substantial improvement in various skills (see Table 1, previous page).

Virginia's Early Intervention program has insufficient resources, despite some significant investment by the General Assembly in recent years. The number of infants and toddlers served by the Early Intervention program is growing faster than the program's funding (see Table 1, previous page), and all indication is that growth will continue. Consequently, Early Intervention funding per child served has decreased by 12 percent, from \$4,137 in 2014 to \$3,639 in 2018.

Virginia has opportunities to serve more children in integrated settings. While nearly all children from birth to age three receive Early Intervention services in a home- or community-based setting (see Table 1, previous page), services provided to older children in Virginia's Early Childhood Special Education program, established via Part B of IDEA, are less integrated. For example, 27 percent of children ages three through five with an Individualized Education Plan attended a separate special education class, separate school, or residential facility in 2017. As the Commonwealth focuses on increasing opportunities for young children to receive the supports they need to become productive members of their communities, it is more important than ever that these programs have a shared vision and philosophy of inclusion.

The vast majority of children begin receiving Early Intervention services in a timely manner, but the transition from the Early Intervention program to the Early Childhood Special Education program has not always been as timely. The percentage of children who had an Individual Family Service Plan with transition steps and services, and the percentage of children who had a transition conference, at least 90 days prior to their third birthday, decreased substantially between 2014 and 2016. There were substantial improvements the following year, but the Commonwealth should continue ensuring that transitions occur on a timely basis.

Most of the data for this report was provided by the Department of Behavioral Health and Developmental Services' (DBHDS) Infant & Toddler Connection of Virginia, either in published reports or in response to direct requests for information. The data suffers from well-known limitations, but the trends noted in this Assessment have been so consistent over time that the conclusions drawn from them are nonetheless well supported.

The vast majority of children begin receiving Early Intervention services in a timely manner, but the transition from the Early Intervention program to the Early Childhood Special Education program has not always been as timely.

# I. Recommendations Related to Reaching Those in Need

# The Infant and Toddler Connection of Virginia, in collaboration with its governmental and community partners, should:

**Recommendation 1:** Develop, through meaningful analysis of available data, an estimate of the number of infants and toddlers in Virginia who meet Virginia's Early Intervention eligibility criteria (i.e., the number of infants and toddlers who would be found eligible for Early Intervention services if every infant and toddler in Virginia were evaluated). This data should then be used for setting future Child Find goals and estimating future service and funding needs for Virginia's Early Intervention program.

**Recommendation 2:** Review efforts in other states focused on promoting the identification and screening of eligible infants and toddlers served through the state's Medicaid managed care system to determine the efficacy of adopting similar practices in Virginia.

**Recommendation 3:** Examine expanded eligibility options utilized by other states to determine their applicability to Virginia's Early Intervention program for infants and toddlers and their potential to improve early childhood outcomes for Virginia's infants and toddlers.

**Recommendation 4:** Improve identification of potentially eligible infants and toddlers by increasing training opportunities for early childhood providers. Training and outreach should be directed towards the following providers, at a minimum: pediatric and other healthcare providers, neonatal practitioners, nurse practitioners, physician assistants, child care providers, Child Protective Services, and other professionals who come into contact with infants, toddlers, and their families in their professional practice. Training should address both when a child should be referred to Early Intervention, as well as appropriate and best practice post-referral follow up activities.

**Recommendation 5:** Include autism screening with other developmental screening that is provided by the Early Intervention program; and provide training for early childhood providers to recognize early signs of developmental delay, including early signs of autism in accordance with the "Learn the Signs. Act Early." campaign of the Centers for Disease Control and Prevention.

**Recommendation 6:** Enhance outreach to linguistically, racially, and socioeconomically diverse communities to ensure that the Early Intervention program in Virginia is reaching these communities.

# **II. Recommendations Related to Accessing Services**

#### The Virginia General Assembly and localities should:

**Recommendation 1:** Increase funding for the Early Intervention program to accommodate the projected need for increased services based on historical data that indicates continued growth in infants and toddlers served.

**Recommendation 2:** Analyze the causes of the decrease in private insurance reimbursement for Early Intervention services and consider amending Virginia law to expand the services that must be covered by private insurance carriers in Virginia and regulate reimbursement rates by private insurance, as well as any other steps that can ensure that the spirit of Virginia's private insurance Early Intervention mandate is being met.



# The Infant and Toddler Connection of Virginia, in collaboration with its governmental and community partners, should:

**Recommendation 3:** Conduct a study to compare reimbursement rates for Early Intervention providers, including care coordination, to those of other states; determine the role that Early Intervention reimbursement rates play in creating or exacerbating provider shortages, excessive provider caseloads, and issues with the timely initiation of Early Intervention services; and increase Early Intervention reimbursement rates, including but not limited to reimbursement rates for care coordination, in order to attract and retain quality Early Intervention providers.

**Recommendation 4:** Work with local Early Intervention agencies to map existing Early Intervention providers and identify current and future Early Intervention workforce needs to meet growing demands and ensure timely access to Early Intervention services, and to identify critical shortages of specific workforce areas and develop a workforce development plan to address these shortages. This should include, but not be limited to, deaf mentors and other professionals who support infants and toddlers who are deaf or hard of hearing, blind or vision impaired, or deaf-blind.

**Recommendation 5:** Develop a workgroup, which should include Department of Behavioral Health and Developmental Services (DBHDS), the Department of Medical Assistance Services (DMAS), managed care organizations (MCOs), and representatives of respective occupational groups, to identify Early Intervention services that are suitable for telehealth delivery models and approve these services for Medicaid reimbursement when delivered via telehealth technologies.

**Recommendation 6:** Based on outcomes of the above referenced workgroup, consider development of a pilot Early Intervention telehealth program in an under-served area to expand access to quality Early Intervention services.

**Recommendation 7:** Determine an effective method of gathering data on the adequacy and sufficiency of Early Intervention services provided to infants and toddlers in Virginia.

# **III. Recommendations Related to Performance**

# The Infant and Toddler Connection of Virginia, in collaboration with its governmental and community partners, should:

**Recommendation 1:** Make the completion of a new and more reliable data system a priority for the Early Intervention program.

**Recommendation 2:** Work with the Governor's Children's Cabinet to ensure that, as the Commonwealth expands access to early childhood programs for all children, children with disabilities have access to the same inclusive early childhood services and programs as children without disabilities.

**Recommendation 3:** Develop a shared definition, philosophy, and vision of inclusion among early childhood programs, including Early Intervention.

**Recommendation 4:** Work with the Virginia Early Intervention Professional Development Center, the Virginia Cross-Sector Professional Development Team, and other stakeholders to expand opportunities for integrated early childhood professional development in the Commonwealth that supports the inclusion of young children with and without disabilities and their families.

**Recommendation 5:** Work with the Governor's Children's Cabinet to continue to explore opportunities to securely link Early Intervention data to other early childhood programs and existing Virginia Longitudinal Data System partners, as envisioned by the Children's Cabinet, and explore opportunities to use this data for value-based reimbursement to Medicaid managed care organizations.

**Recommendation 6:** Continue to monitor performance indicators related to the transition from the Part C Early Intervention program to the Part B Early Childhood Special Education program, in order to ensure that recent system improvements in these indicators persist.





### Background

Research indicates that Early Intervention services during the first few years of a child's life can significantly benefit the child in the long run.

The RAND Corporation reviewed existing research on 19 Early Intervention programs that represented various approaches to Early Intervention, although they typically involved educating the parents, educating the child, or educating both the parents and the child. The review, which was published in 2005, found that Early Intervention programs improved participant outcomes regarding cognition and academic achievement, behavioral and emotional competencies, educational progression and attainment, child maltreatment, health, delinquency and crime, social welfare program use, and labor market success. Many of these gains were long-lasting. The review also found that for each dollar invested in effective Early Intervention programs, the return to society ranged from \$1.80 to \$17.07.

The federal Individuals with Disabilities Education Act established two optional programs for states to serve young children with disabilities.

The Early Intervention program provides services and supports to infants and toddlers with developmental delays and their families, in accordance with Part C of the Individuals with Disabilities Education Act (IDEA). Certain children under three years old may be eligible to receive these Early Intervention services. Services may include speech therapy, physical therapy, occupational therapy, psychological services, service coordination and other services described in Part C of the IDEA and in accordance with the individualized needs of the infant or toddler and her family. The stated purposes of these services are to minimize developmental delay, maximize potential for independent living, and reduce educational costs to society by minimizing future need for special education and related services (IDEA Subchapter III (Part C) 1431 – Findings and Policy).

The regulation and implementation of the Early Intervention program is a shared responsibility of federal, state, and local entities. Part C of the IDEA and its implementing regulations define the basic framework within which state Early Intervention programs must operate. Pursuant to these regulations, states who receive Part C grant funding must:

1. Assure that Early Intervention is available for every eligible infant and toddler in the state

2. Designate a lead agency to administer the program

3. Appoint an Interagency Coordinating Council, which must include, among others, parents of young children with disabilities to advise the lead agency, and

4. Specify the minimum components of the comprehensive statewide Early Intervention program, including a program of public awareness and a referral system

IDEA also established an Early Childhood Special Education program, which provides instruction specifically designed to meet the educational and developmental needs of children with disabilities, in accordance with Part B, Section 619, of IDEA. Certain children ages three through five, and some children under three, may be eligible to receive these services. Some, but not all, of the children eligible for Early Childhood Special Education services may also have been eligible for the Early Intervention services when they were younger. While this Assessment focuses on the Early Intervention program, the Assessment also addresses certain aspects of the Early Childhood Special Education program.

### I. Reaching Those Children in Need: Eligibility Criteria and Identifying Eligible Children

#### Virginia's Early Intervention Eligibility Criteria

Eligibility criteria for Early Intervention programs are defined by each state individually, in accordance with a federally mandated framework under Part C of the IDEA. States must include children who are experiencing a developmental delay regarding cognitive, physical, communication, social or emotional, or adaptive development. States must also include children who have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay.

Each state must define the meaning of "developmental delay" for the purposes of determining eligibility, resulting in some significant differences in eligibility criteria across states. Virginia's definition is among the more comprehensive (Rosenberg, et al. 2013). In Virginia, an infant or toddler has a developmental delay if they are functioning 25 percent or more below their chronological or adjusted age in one or more areas of development (see Exhibit 1). Additionally, infants and toddlers who manifest atypical development or behavior are also considered to have a developmental delay in Virginia.

# States have additional flexibility to expand eligibility to other classes of individuals as well.

States may, for instance, include among eligible infants and toddlers those who are "at risk" for developmental delay because of biological or environmental factors, such as low birth weight, respiratory distress as a newborn, lack of oxygen, brain hemorrhage, infection, nutritional deprivation, a history of abuse or neglect, being directly affected by illegal substance abuse or withdrawal symptoms resulting from prenatal drug exposure, or other circumstances that are associated with an increased risk of experiencing developmental delay. Serving children with identified biological and environmental risk factors for developmental delay may help prevent developmental delay before it is apparent through assessment methods. However, Virginia does not serve "at risk" children through its Part C Early Intervention program, nor do most states. Only five states serve children who are at risk of developmental delay: Illinois, Massachusetts, New Hampshire, New Mexico, and West Virginia (Ullrich, et al. 2017).

States may also choose to exercise an option to extend the Early Intervention program to children ages three through five who had previously received services through the program and who are now eligible for the Early Childhood Special Education Program, until such children enter or are eligible to enter kindergarten.

A proportion of federal funds for Early Intervention are reserved to provide incentive grant funding to states that choose to exercise this option in any year in which the total appropriated funds for Early Intervention exceed \$440 million. Virginia has not exercised this option. Indeed, few states have taken advantage of this option to date. Maryland was one of the earliest states to do so when it received a \$14.4 million incentive grant in 2009 to develop an extended Part C program. Since exercising the option, 67 percent of eligible families have chosen to remain in Part C, rather than to transfer into Maryland's Part B system when their child turned three years of age (Zero to Three 2017).

There is little data available to assess the benefits and risks of extending eligibility for Early Intervention to children up to age five. Because children must be eligible for Early Childhood Special Education services in order to be eligible for extended Early Intervention, it is not clear what, if any, the overall financial impact of expanding eligibility in this way would be. Maryland does attribute increased rates of children age three through five who are served in integrated, community-based settings to the extension (Zero to Three 2017).

, 	
	Functioning 25% or more below chronological or adjusted age, in 1+ of the following areas:
	<ul> <li>Cognitive development;</li> <li>Physical development, including vision and hearing;</li> <li>Communication development;</li> <li>Social or emotional development; or</li> <li>Adaptive development.</li> </ul>
Children up to Age 3 Who Have	OR Demonstrates atypical development or behavior in one or more of the following areas:
Developmental Delay	<ul> <li>Atypical or questionable sensory-motor responses such as abnormal muscle tone, limitations in joint range of motion, abnormal reflex or postural reactions, poor quality of movement patterns or skill performance, and oral-motor skills dysfunction including feeding difficulties;</li> <li>Atypical or questionable social-emotional development, such as delay or abnormality in achieving expected emotional milestones, persistent failure to initiate or respond to most social interactions, and fearfulness or other distress that does not respond to comforting by caregivers;</li> <li>Atypical or questionable behaviors that interfere with acquisition of developmental skills; or</li> <li>Impairment in social interaction &amp; communication skills, along with restricted &amp; repetitive behaviors.</li> </ul>
OR Children up to Age 3	Diagnosed physical or mental condition that has a high probability of resulting in a developmental delay, including but not limited to the following conditions:
Who Have High Probability of Developmental Delay	<ul> <li>Autism spectrum disorder;</li> <li>Born at gestational age of 28 weeks or younger;</li> <li>Congenital or acquired hearing loss;</li> <li>Down syndrome;</li> <li>28 days or more spent in Neonatal Intensive Care Unit;</li> <li>Spina bifida; or</li> <li>Visual disabilities.</li> </ul>
OR Children up to Age 3 Who Are At Risk for Delay (optional category)	Individuals "at risk" for a developmental delay due to biological or environmental factors are not eligible in Virginia.
OR Ages 3-5 & Eligible for Early Childhood Special Education (optional category)	Virginia has not extended the Early Intervention program to 3-5 year olds who previously received Early Intervention services and are now eligible for the Early Childhood Special Education program.

*Exhibit 1: Eligibility Criteria for Virginia's Early Intervention Program.* 

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# Because of differing eligibility requirements, as well as differing levels of success in reaching all eligible children, the percentage of infants and toddlers served by each state's Early Intervention program varies significantly.

The percentage of individuals served across the states and the District of Columbia is quite variable, ranging from 1.7 percent in Arkansas and Mississippi to nine percent in Massachusetts in 2015 (see Table 2).

The variation across states indicates Virginia may have opportunities to serve more infants and toddlers through its Early Intervention program. In 2008, Virginia served 2.1 percent of infants and toddlers, ages birth to three, well below the national average of 2.8 percent. By 2015, the percentage of infants and toddlers served in Virginia had grown by almost 45 percent to three percent. This placed Virginia on par with the national average in 2015, but still significantly below states that served the highest percentages of children.

#### **Identifying Eligible Children**

States are required to develop a comprehensive system for identifying, assessing, and evaluating infants and toddlers who may be eligible for Early Intervention services. This is called Child Find. In accordance with this system, states must identify and evaluate all infants and toddlers who are eligible for Early Intervention

State	2008	2015	Percentage Change	State	2008	2015	Percentage Change
United States	2.8	3	7.5	District of Columbia	1.5	2.9	96
Arkansas	2.4	1.7	-28	Idaho	2.6	2.9	8.4
Mississippi	1.6	1.7	5.3	Iowa	2.9	2.9	-1.1
Alabama	1.6	1.8	14.7	Nevada	1.8	3	70
Oklahoma	1.9	1.8	-6	Virginia	2.1	3	44.6
Montana	2	1.9	-2.3	Colorado	2.3	3.1	37.3
Florida	2	2	-1.5	Hawaii	6.9	3.1	-54.7
Texas	2.3	2	-12.3	Delaware	2.5	3.2	29.2
Arizona	2	2.1	4.1	Puerto Rico	3.5	3.2	-8.6
Nebraska	1.8	2.1	13.9	South Daktoa	3.2	3.2	-2.4
Tennessee	1.8	2.1	17.8	Illinois	3.7	3.3	-10.4
Maine	2.3	2.3	1.1	Maryland	3.3	3.6	6.9
South Carolina	2.4	2.3	-3.8	North Dakota	3.6	3.7	3.2
Georgia	1.3	2.4	75.1	Indiana	3.7	3.9	4.6
Ohio	3.4	2.4	-28	Kansas	2.8	4	43.8
Louisiana	2.1	2.5	21.3	New Jersey	3	4	31.1
Alaska	1.9	2.6	38.9	New York	4.4	4.2	-4.7
Michigan	2.7	2.6	-5.2	Connecticut	3.8	4.3	12.6
Minnesota	2.1	2.6	22.9	Pennsylvania	3.8	4.4	14.2
Missouri	1.6	2.6	64.9	Vermont	4	5	24
Oregon	1.8	2.6	45.6	New Hampshire	3.3	5.2	59.4
California	2.6	2.7	1.2	West Virginia	4.2	5.2	24.5
Kentucky	2.9	2.7	-8.3	Wyoming	4.6	5.5	18.1
Utah	2	2.7	39	Rhode Island	5	6.1	22.9
Washington	1.9	2.7	43.8	New Mexico	5	6.8	34
North Carolina	2.4	2.8	15.9	Massachusetts	6.7	9	34.1
Wisconsin	2.8	2.8	2.3				

*Table 2: Percentage of infants and toddlers served by state Early Intervention programs in 2008 and 2015 according to the U.S. Department of Education 39th Annual Report to Congress.* 



services (IDEA, Part C, Subpart D, Section 303.302(b) (1)). This requirement is echoed in state regulations as well:

The department shall implement a comprehensive child find system that is consistent with Part B of the Individuals with Disabilities Education Act, 20 USC § 1411 et seq., and ensures that all children with disabilities who are eligible for early intervention services in Virginia are identified, located, and evaluated for eligibility determination.... 12VAC35-225-40

The responsibility for carrying out Child Find activities is shared between the state and local lead agencies. Activities include the development and dissemination of information to educate both families and professionals about the purposes of the Early Intervention program, eligibility criteria, available services, and the process for making a referral. It is difficult to assess these activities directly because much of the Child Find process occurs at the local level. Available data suggests that Virginia's Child Find activities have been effective at expanding the identification of eligible infants and toddlers, but that there may be much further to go before the Commonwealth fulfills its obligation to identify and assess all eligible children in the state.

The total number, as well as the percentage of infants and toddlers served by Virginia's Early Intervention program, have been increasing steadily for years.

### Annualized Count of Infants and Toddlers, Birth to Age 3 Served in Virginia's Early Intervention Program by Year

Year	Number Served	Percentage Served	Target	Percentage Change
2007	10,330	1.92%	2.20%	n/a
2008	11,351	1.99%	2.10%	10%
2009	11,766	1.95%	2.30%	4%
2010	12,234	2.43%	2.60%	4%
2011	14,069	2.77%	2.60%	15%
2012	15,676	2.72%	2.88%	11%
2013	15,523	2.76%	2.88%	(1%)
2014	16,272	2.87%	2.76%	5%
2015	17,022	2.97%%	2.76%	5%
2016	17,839	3.18%	2.76%	5%
2017	19,085	3.29%	2.76%	7%
2018	20,202		2.89%	6%

*Table 3: Number and percentage of infants and toddlers served in Virginia by year, as reported in annual reports on Virginia's Early Intervention program to the General Assembly.* 

Between 2007 and 2018, the number of infants and toddlers served by Virginia's Early Intervention program reportedly increased by 96 percent, from 10,330 to 20,202 (see Table 3, previous page). The average annual rate of increase between 2014 and 2018 was nearly 6 percent. The percentage of children served also increased, from 1.92 percent in 2007 to 3.29 percent in 2017, exceeding annual targets in recent years set by the Infant & Toddler Connection of Virginia.

There are a number of factors that contribute to increasing numbers of children identified for Early Intervention. In its annual reports to the General Assembly, DBHDS identified increasing prevalence rates of autism, increasing rates of infants born to mothers affected by the opioid epidemic, and increased efforts to identify eligible children through, for instance, a Virginia Board for People with Disabilities' grant project to increase Early Intervention referrals from Neonatal Intensive Care Units. While every indication is that the percentage of infants and toddlers served by Virginia's Early Intervention program will continue to increase, it is not clear how much further there is to go, because there is no current estimate of the percentage of children who could be served but are not currently.

#### It is not entirely clear how many infants and toddlers in Virginia meet the state's eligibility criteria for Early Intervention services.

Virginia has not conducted any recent analyses of the total number of infants and toddlers who would likely meet the eligibility criteria for El services if every infant and toddler was assessed. It is impossible, therefore, to estimate what the overall impact on the Early Intervention program would be of increased efforts to identify, refer, and screen potentially eligible children for Early Intervention. It is likely, however, that there are significantly more children eligible for Part C services in the Commonwealth than are currently served by the system.

A study conducted in 2013 by researchers from the University of Colorado School Of Medicine found that eligibility criteria in most states, including Virginia, was estimated to make vastly more infants and toddlers eligible than the system can possibly serve with existing resources. The authors of the study expected that nearly 40 percent of children in Virginia would be eligible at nine months of age, and by twenty-four months, the number would approach 60 percent, nearly twenty times the percentage of infants and toddlers served by Virginia's Part C system (Rosenberg 2013).

#### If Rosenberg's estimates were accurate, then there are a large number of eligible infants and toddlers who are not served by Virginia's Early Intervention program.

There are likely multiple reasons that eligible children are not served by Virginia's Part C system. Some children are simply never referred for assessment. Half of all referrals to the Early Intervention program come from pediatricians and other primary care physicians. Recognizing that more referrals could come from Neonatal Intensive Care Units (NICUs), the Virginia Board for People with Disabilities recently completed a grant project to improve Early Intervention referral processes at Virginia's NICUs. Outcomes from this project included an increased rate of referrals for Early Intervention assessment from hospitals and an increase in the number of hospitals that have implemented new policies and practices related to Early Intervention referral and data collection. Few hospitals tracked referrals to Early Intervention prior to participation in grant activities.

Many infants and toddlers who are referred for Early Intervention services never receive services. According to data from the Infant & Toddler Connection of Virginia, of 15,287 children referred for Early Intervention between July 1, 2017, and June 30, 2018, only approximately 70 percent went on to receive services. Some of these children did not receive services because they were found ineligible upon evaluation (11 percent). A larger number, however, were never evaluated due to an inability to contact the family either after a referral was made (16 percent), or after the assessment was completed (two percent). Other reasons that eligible children did not receive services include: the family declined services (two percent), the family moved (one percent), and the family chose to receive services from other sources (less than one percent).

#### **Recommendations Related to Reaching Those in Need** *The Infant and Toddler Connection of Virginia, in collaboration with its governmental and community partners, should:*

#### **Recommendation 1:**

Develop through meaningful analysis of available data, an estimate of the number of infants and toddlers in Virginia who meet Virginia's Early Intervention eligibility criteria (i.e., the number of infants and toddlers who would be found eligible for Early Intervention services if every infant and toddler in Virginia were evaluated). This data should then be used for setting future Child Find goals and estimating future service and funding needs for Virginia's Early Intervention program.

#### Rationale:

It is not presently known how many infants and toddlers in Virginia meet Virginia's Early Intervention criteria. Without this information, it cannot be known whether Virginia is fulfilling its obligation to identify and assess all eligible infants and toddlers, nor can it be known what the impact of continued efforts to improve the identification, referral and assessment of potentially eligible infants and toddlers will be on the resources and financial viability of the Early Intervention program. Current targets for the number of infants and toddlers to be based on historical trends, rather than on present need. A reliable estimate of the number of eligible infants and toddlers in the Commonwealth is essential to setting meaningful future targets and estimating future revenue and program capacity needs.

#### **Recommendation 2:**

Review efforts in other states focused on promoting the identification and screening of eligible infants and toddlers served through the state's Medicaid managed care system to determine the efficacy of adopting similar practices in Virginia.

#### **Rationale:**

States have enacted a variety of incentives to encourage managed care organizations (MCOs) to increase developmental screening rates. Some states, including Georgia and Minnesota, require MCOs to report their developmental screening rates. Georgia further incentivizes MCOs to increase developmental screening rates by rewarding the MCOs who achieve the best screening rates with automatic assignment preference for Medicaid beneficiaries who do not self-select a plan at enrollment (Mention and Heide 2016). As Virginia continues to expand its MCO-enrolled population and explores performance based reimbursement methodologies, there may be opportunities for the Commonwealth to incentivize the identification, screening and referral of infants and toddlers who are eligible for Early Intervention services.

#### **Recommendation 3:**

Examine expanded eligibility options utilized by other states to determine their applicability to Virginia's Early Intervention program for infants and toddlers and their potential to improve early childhood outcomes for Virginia's infants and toddlers.

#### Rationale

Several states have taken advantage of Early Intervention expanded eligibility opportunities that Virginia has not, including expanding eligibility to children who are at risk of developmental delay due to biological or environmental factors, and expanding eligibility to include children from ages three through five who received Early Intervention services prior to age three, and who are eligible for Early Childhood Special Education services after age three. Virginia should explore the impact of these options in the states that have chosen to exercise them.

#### **Recommendation 4:**

Improve identification of potentially eligible infants and toddlers by increasing training opportunities for early childhood providers. Training and outreach should be directed towards the following providers, at a minimum: pediatric and other healthcare providers, neonatal practitioners, nurse practitioners, physician assistants, child care providers, Child Protective Services, and other professionals who come into contact with infants, toddlers, and their families in their professional practice. Training should address both when a child should be referred to Early Intervention, as well as appropriate and best practices post-referral.

#### **Rationale:**

Referral by medical providers or other professionals who interact with children and families is the most common means by which an individual is identified for Early Intervention services. Indeed, half of all referrals for Early Intervention in 2018 were received from pediatricians and other primary care physicians alone. Some of the findings from a recent project funded by the Board included that many Neonatal Intensive Care Units (NICUs) lacked formal policies and procedures for referring children for Early Intervention services, and few had systems in place to track referrals that were made. By working with hospitals and NICU staff, the Virginia Hospital Research & Education Foundation was able to help hospitals put such policies and procedures in place and increase the number of children identified for referral from NICU units in Virginia. Additional training of providers is necessary to ensure that all children who are eligible for Early Intervention in Virginia are identified and referred.

#### **Recommendation 5:**

Include autism screening with other developmental screening that is provided by the Early Intervention program; and provide training for early childhood providers to recognize early signs of developmental delay, including early signs of autism in accordance with the "Learn the Signs. Act Early." campaign of the Centers for Disease Control and Prevention.

#### Rationale:

Research has consistently demonstrated that early diagnosis and early interventions can significantly improve long term outcomes for individuals with autism. Autism can be diagnosed prior to age two in many children. The CDC's Act Early Initiative promotes efforts by state early childhood programs to identify children with autism through early screening and provision of effective supports to children and families through early intervention. Because of the importance of early identification and early intervention, the American Academy of Pediatrics recommends a preliminary screening for autism for all children between eighteen and twenty-four months of age (American Academy of Pediatrics, 2012).

#### **Recommendation 6:**

Enhance outreach to linguistically, racially, and socioeconomically diverse communities to ensure that the Early Intervention program in Virginia is reaching these communities.

#### Rationale:

While there is limited research on the topic, some research has suggested that racial and cultural minority populations may be underrepresented in Early Intervention and other early childhood programs (see, e.g., Morgan, et al, 2012). The reasons for this underrepresentation are not entirely clear, but may be indicative of a lack of sufficient and effective outreach to these communities.

### **Accessing Services: Funding and Provider Capacity**

If Virginia was successful in identifying and screening all eligible infants and toddlers in the Commonwealth, it is not clear that the program currently has the capacity to provide quality Early Intervention services to them. Like Early Intervention programs across the country, Virginia's program suffers from inadequate funding, insufficient provider rates, and resulting provider shortages in some areas of the Commonwealth. These problems are not new. In its 2014 Assessment of Disability Services in Virginia, the Board noted that provider shortages and a weakening economy had resulted in waiting lists for Early Intervention services in some localities. Waiting lists are not permitted under Part C of the IDEA. The revenue and provider shortages noted in 2014 continue to plague the Early Intervention program, despite recent investment by the General Assembly in Virginia's Early Intervention program.

#### **Early Intervention Revenue**

Funding for Virginia's Early Intervention program is woven together from a variety of funding streams. The largest single stream of funding according to these reports is Medicaid, which accounts for approximately one-third of total funding entering the Early Intervention program (see Table 4). Other sources of funding include federal and state funds specific to the Early Intervention program, local funds, private insurance and Tricare reimbursements, family fees, other state general funds, in-kind contributions, grants/gifts/donations, and other unspecified sources.

Until very recently, Early Intervention services were carved out of Medicaid managed care organizations and reimbursed on a fee-for-service basis. This changed in 2018. It is too early to know whether this transition will have any impact on Medicaid funding for Early Intervention. Some older research suggested that earlier shifts from fee-for-service payment models to managed care resulted in decreased Medicaid funding for Early Intervention services in other states (see, e.g., Fox, et. al, 1998). DMAS has, however, taken steps to preserve funding for Early Intervention programs through Virginia's Medicaid managed care organizations. Medallion 4.0 contracts, for instance, require managed care organizations to cover Early Intervention services, and to compensate Early Intervention providers at rates that are at least as high as those previously provided through Medicaid fee-for-service.

#### Revenue for Virginia's Early Intervention program has not kept pace with increases in the number of infants and toddlers served.

Between 2014 and 2018, the number of infants and toddlers served by Virginia's Early Intervention program increased by 24 percent, from 16,272 to 20,202. Over that same period, however, total funding for Virginia's Early Intervention program only increased by approximately nine percent. Early Intervention expenditures as reported by Virginia's Part C local lead agencies have exceeded reported funding in four of the past five years.

Increasingly, the state and localities are paying a larger share of funding for the Early Intervention program than other sources. While direct federal funding increased by only eight percent between 2014 and 2018, for instance, both state and local funding specifically for the Early Intervention program have increased by approximately 30 percent. Funds received from Tricare and private insurance decreased by a total of 43 percent, from \$10,526,639 in 2014 to \$6,011,479 in 2018. It is not entirely clear what accounts for this decrease. Some, but not all, private insurance plans are required by Virginia law to cover some medically necessary Early Intervention services, but families must consent to the use of their private insurance for Early Intervention. Additionally, some Early Intervention services, including service coordination and developmental services, are not required to be covered by private insurance companies.

And finally, while some private insurance companies are required to cover some Early Intervention services, restrictive reimbursement criteria, reimbursement rates that are substantially lower than the costs of providing services, and restrictions on in-network providers all limit the revenue received by the Early Intervention program from private insurance plans.

Despite an increase in total funding, reported Early Intervention funding per individual served by the Early Intervention program has actually decreased by 12 percent since 2014, even without adjusting for inflation, from \$4,137 to \$3,639 (see Table 4). The Commonwealth will need to find additional funding just to maintain the current level of services, much less to accommodate the expected continued growth in Early Intervention recipients. In the absence of meaningful federal investment, options for increasing funding are limited to increasing state and local investments, identifying additional opportunities to leverage Medicaid and private insurance dollars, or placing additional financial burdens on families.

#### **Provider Capacity**

Early Intervention provider shortages and retention issues present challenges to the timely delivery of high-quality Early Intervention services. There is limited data presently available to assess the extent to which localities in Virginia face provider shortages, or how such shortages have changed over time. According to anecdotal reports, however, at least some localities have faced challenges in this area, particularly in rural regions of the Commonwealth. In its 2018 Report on Virginia's Part C Early Intervention program, the Department of Behavioral Health and Developmental Services noted that insufficient Early Intervention reimbursement rates were driving provider shortages in the Commonwealth:

Increasing costs over time have resulted in widespread reports from service providers in FY 2018 that the Early Intervention rates set in 2009 no longer cover the cost of providing early intervention services. In addition to impacting the

Funding Source	2014	2015	2016	2017	2018	Change	% Change
Federal Part C Funds	\$8,487,876	\$9,215,082	\$8,881,188	\$8,982,463	\$9,205,934	\$718,058	8%
State Part C Funds	\$14,282,542	\$15,045,226	\$16,546,427	\$17,306,373	\$18,642,543	\$4,360,001	31%
Other State General Funds	\$673,815	\$437,267	\$434,914	\$422,335	\$414,113	(\$259,702)	(39%)
Local Funds	\$8,077,743	\$9,536,372	\$9,382,978	\$10,128,910	\$10,533,071	\$2,455,328	30%
Family Fees	\$869,429	\$1,257,692	\$888,534	\$948,136	\$989,423	\$119,994	14%
Medicaid (Incl. Targeted Case Mgt.)	\$19,514,108	\$20,232,803	\$22,469,297	\$23,787,115	\$25,469,698	\$5,955,590	31%
Private Insurance and TRICARE	\$10,526,639	\$6,871,031	\$5,235,119	\$4,600,570	\$6,011,479	(\$4,515,160)	(43%)
Grants/Gifts/Donations	\$4,196	\$13,069	\$14,531	\$11,352	\$26,574	\$22,378	533%
In-Kind	\$438,406	\$505,489	\$665,777	\$763,422	\$877,142	\$438,736	100%
Other	\$4,446,144	\$5,019,063	\$969,534	\$1,087,886	\$1,335,988	(\$3,110,156	) (70%)
Total Funding	\$67,320,898	\$68,133,094	\$65,488,299	\$68,038,562	\$73,505,562	\$6,185,067	9%
Funding per individual served	\$4,137	\$4,003	\$3,671	\$3,565	\$3,639	(\$498)	(12%)
Total Reported Expenditures	\$70,632,468	\$71,900,043	\$65,695,471	\$65,828,711	\$79,390,560	\$8,758,092	12%

*Table 4: Early Intervention funding by source and year, as reported by the Virginia Department of Behavioral Health and Developmental Services in annual Early Intervention reports.* 



need for additional funds, this discrepancy in cost versus reimbursement is contributing to emerging provider shortages and, therefore, high caseloads.

Provider shortages and their impact on the timely delivery of Early Intervention services, particularly in rural areas, have also been noted nationally. Provider shortages have been identified as a prevalent cause of delays in the initiation of Early Intervention services nationwide. Chronic underfunding and insufficient provider reimbursement rates have resulted in delayed initiation of services and have caused some counties in some states to consider initiating waiting lists for Early Intervention services.

A number of states have sought to address provider accessibility through expanding the use of telehealth by Early Intervention practitioners. Studies looking at the efficacy of telehealth as a delivery model for Early Intervention services have found it to be an effective method of delivery (See e.g. Blaiser, Behl, Callow-Heusser, & White, 2013; Behl, Blaiser, Dawson & Brooks, 2015). However, telehealth is not widely used to deliver Early Intervention services in Virginia.

The Infant & Toddler Connection of Virginia is exploring the potential of telehealth services to help meet the increasing demand for Early Intervention services in Virginia and to help close the Early Intervention services access gap in rural localities. One of the biggest hurdles to the use of telehealth in Virginia is Medicaid reimbursement policies. Medicaid rules in Virginia limit the use of Medicaid funds to reimburse providers who deliver services via telehealth. Because Medicaid is the single largest source of revenue for the Early Intervention program, accounting for approximately a third of all program revenue, this creates a substantial obstacle to the adoption and expansion of telehealth options for Early Intervention services.

Without meaningful data about provider accessibility, it is difficult to pinpoint where efforts to build provider capacity are most needed. Currently, absent self-reporting by localities themselves, the Infant & Toddler Connection of Virginia is able to identify localities with provider accessibility issues only when provider shortages affect the timely initiation of Early Intervention services. Once identified, staff are able to work with local lead agencies to formulate strategies for addressing provider shortages and other barriers to the timely initiation of services. The Department of Behavioral Health and Developmental Services recently launched a provider development initiative that involved mapping out available providers of developmental disability services to target provider development efforts towards areas of the Commonwealth where they are most needed. Early Intervention service providers, however, are not part of this effort.

Provider shortages have been identified as a prevalent cause of delays in the initiation of Early Intervention services nationwide.



# **Recommendations Related to Accessing Services**

The General Assembly and localities should:

#### **Recommendation 1:**

Increase funding for the Early Intervention program to accommodate the projected need for increased services based on historical data that indicates continued growth in infants and toddlers served.

#### Rationale:

The number of infants and toddlers who are identified as eligible for Early Intervention services in the Commonwealth has been growing faster than the funding that supports the Early Intervention program. There is reason to believe that the population of children identified as eligible for these services will continue to grow. At the same time, direct federal funding for Early Intervention services remains nearly flat after accounting for inflation. It is essential for the future viability of the program and for the ability of the Commonwealth to fulfill its obligation to identify all eligible children to ensure that funding for the program is sufficient to support its current and future needs.

#### **Recommendation 2:**

Analyze the causes of the decrease in private insurance reimbursement for Early Intervention services and consider amending Virginia law to expand the services that must be covered by private insurance carriers in Virginia, and regulate reimbursement rates by private insurance, as well as other steps that can ensure that the spirit of Virginia's private insurance Early Intervention mandate is being met.

#### Rationale:

Funding for Early Intervention services from private insurance companies has decreased in recent years. This funding is reported along with Tricare reimbursement in aggregate form. Between 2014 and 2017, the combined revenue from private insurance and Tricare decreased by more than half, before rising slightly again in 2018 for a total decrease of 43 percent over the five-year period. Virginia law requires some private insurance plans to cover some Early Intervention services. Excluded from this requirement are developmental services, as well as self-insured insurance plans. DBHDS's reports on Early Intervention identify other issues that providers report related to private insurance reimbursement, including reimbursement rates that are inadequate to cover the costs of services provided. As one of multiple streams of revenue that support Virginia's Early Intervention program, the significant decrease in private insurance reimbursements for Early Intervention services in the Commonwealth should be explored.



# The Infant and Toddler Connection of Virginia, in collaboration with its governmental and community partners should:

#### **Recommendation 3:**

Conduct a study to compare reimbursement rates for Early Intervention providers, including care coordination, to those of other states; determine the role that Early Intervention reimbursement rates play in creating or exacerbating provider shortages, excessive provider caseloads, and issues with the timely initiation of Early Intervention services; and increase Early Intervention reimbursement rates, including but not limited to reimbursement rates for care coordination, in order to attract and retain quality Early Intervention providers.

#### **Rationale:**

Insufficient reimbursement rates for Early Intervention services are a frequently cited concern in Virginia and around the country. In its 2018 report to the General Assembly, DBHDS explained that:

Increasing costs over time have resulted in widespread reports from service providers in FY 2018 that the early intervention rates set in 2009 no longer cover the cost of providing early intervention services. In addition to impacting the need for additional funds, this discrepancy in cost versus reimbursement is contributing to emerging provider shortages and, therefore, high caseloads.

If Virginia is to meet current and emerging needs for Early Intervention, it will need to take steps to ensure that there is an adequate supply of competent early intervention providers in its communities. There are likely many contributing factors to provider shortages, but inadequate reimbursement rates are frequently identified as a contributing factor both in Virginia and nationally.

#### **Recommendation 4:**

Work with local Early Intervention agencies to map existing Early Intervention providers and identify current and future Early Intervention workforce needs to meet growing demands and ensure timely access to Early Intervention services, and to identify critical shortages of specific workforce areas and develop a workforce development plan to address these shortages. This should include, but not be limited to, deaf mentors and other professionals who support infants and toddlers who are deaf or hard of hearing, blind or vision impaired, or deaf-blind.

#### **Rationale:**

While the existence of provider shortages in Virginia and across the nation is a known barrier to the provision of competent Early Intervention services, there are limited mechanisms in use to proactively identify workforce issues before they begin to affect system performance outcomes. Proactive identification measures will allow the Commonwealth to identify and address workforce needs before shortages have a negative impact on children and families.



#### **Recommendation 5:**

Develop a workgroup, which should include DBHDS, DMAS, MCOs, and representatives of respective occupational groups, to identify Early Intervention services that are suitable for telehealth delivery models and approve these services for Medicaid reimbursement when delivered via telehealth technologies.

#### **Rationale:**

Telehealth is an emerging solution to geographically limited workforce shortages. Studies suggest that many Early Intervention services can be effectively provided via telehealth technologies. Currently, Medicaid billing policies in Virginia do not support the delivery of Early Intervention services via telehealth. Identifying Early Intervention services that are suitable for this delivery model and allowing for such use can help alleviate provider shortages in underserved areas.

#### **Recommendation 6:**

Based on outcomes of the above referenced workgroup, consider development of a pilot Early Intervention telehealth program in an under-served area to expand access to quality Early Intervention services.

#### **Rationale:**

Absent widespread adoption of policies and practices that support telehealth for Early Intervention across the Commonwealth, a pilot program would allow telehealth to be targeted towards areas with critical Early Intervention provider shortages.

#### **Recommendation 7:**

Determine an effective method of gathering data on the adequacy and sufficiency of Early Intervention services provided to infants and toddlers in Virginia.

#### **Rationale:**

While there is data available on the type, quantity, and cost of Early Intervention services received by infants and toddlers in Virginia through the Commonwealth's Early Intervention program, there is little data available to determine the adequacy or appropriateness of these services. An effective method for analyzing this issue would greatly improve the ability of the Board and other entities to assess the Early Intervention program.

### Performance: Program Metrics & Cross-System Collaboration

#### **State Performance Metrics**

DBHDS is the lead state agency responsible for monitoring the Commonwealth's Early Intervention program. Core performance data in the State Performance Plan/Annual Performance Reports suggests that Virginia had been slipping between 2014 and 2016 on key indicators related to timely transition from Early Intervention services to Early Childhood Special Education services (see Table 5). These indicators included 1) the timely inclusion of transition steps and services in a toddler's Individualized Family Services Plan; and 2) the scheduling of a transition conference at least 90 days prior to the toddler's third birthday if the toddler is potentially eligible for the Early Childhood Special Education program.

The Infant & Toddler Connection of Virginia targeted these areas for improvement through various means, including:

- Online tutorials and webinars
- Transition guidance documents
- Training
- Regional meetings on transition issues
- Targeted local record reviews and training

Subsequent to these interventions, the declines in performance were reversed in 2017. It is too early to determine whether this reversal will continue, but the significant improvement in these performance indicators is promising.

An initial review of performance metrics also suggests slower, but steady decline in infant and toddler outcome indicators, including indicators that reflect social and emotional skills, acquisition and use of knowledge and skills, and the use of appropriate behaviors to meet one's needs. There is reason to believe that these indicators may be deceptive, however, because the Commonwealth has focused in recent years on improving the training of providers in using assessments to accurately measure these indicators. What appears to be a decline in performance, therefore, may instead reflect more accurate assessment measures. These indicators will need to be monitored for additional years to determine whether they reflect actual decline of outcomes or more accurate measurement.

#### **Data Quality and Data Connectivity**

In its 2014 Assessment of Disability Services in Virginia, VBPD noted ongoing Early Intervention data quality issues. At that time, there were ongoing initiatives to improve data systems for Early Intervention services, as well as across Virginia's Health and Human Resources agencies. Many of the data limitations noted in that 2014 Assessment are still present today, and work to establish a new, more reliable data system is still ongoing.

At the same time, there are parallel data improvement efforts happening within and across agencies throughout the Commonwealth, with a strong focus on crossagency and cross-system data connectivity. For example, the Virginia Department of Education, State Council of Higher Education for Virginia, Virginia Community College System, and Virginia Employment Commission are collaborating on the Virginia Longitudinal Data System (VLDS) to improve access to data on Virginia's education and workforce systems for researchers and policymakers. One of the key areas of interest within the Governor's Children's Cabinet is the integration of early childhood data into the VLDS, including Early Intervention data.

The focus on improved data collection and data interconnectivity is not unique to Virginia. A number of states have worked in recent years to improve data collection and cross-agency data connections. In September 2018, the Early Childhood Data Collaborative outlined ongoing efforts to link early childhood data across agencies and programs (King, 2018). According to their report, 22 states currently link childhood data across systems and agencies to get a more complete picture of the experiences and outcomes of children served through state early childhood programs. Ultimately, the report made the following recommendations to increase and improve comprehensive early childhood data systems:

Percent who primarily receive services				2017	Trend	4-Year Trend
in home or community-based settings	99.80%	98.71%	99.92%	99.96%	$\leftrightarrow$	\$
INFANT AND TODDLER OUTCOME INDICATORS						
Substantially improved functioning: social-emotional skills	65.14%	64.07%	66.05%	66.28%	$\Leftrightarrow$	t
Exited within age expectations: social-emotional skills	64.47%	63.28%	60.71%	60.05%	$\Leftrightarrow$	Ŧ
Substantially improved functioning: Acquisition/Use of knowledge/skills	71.29%	68.29%	70.10%	69.96%	$\leftrightarrow$	Ļ
Exited within age expectations: Acquisition/Use of knowledge/skills	53.00%	51.53%	49.62%	48.69%	$\leftrightarrow$	Ļ
Substantially improved functioning: Use of appropriate behaviors to meet needs	73.37%	70.69%	70.38%	70.16%	$\leftrightarrow$	Ļ
Exited within age expectations: Use of appropriate behaviors to meet needs	55.46%	55.23%	53.84%	54.10%	$\Leftrightarrow$	Ŧ
FAMILY INVOLVEMENT INDICATORS - BASED ON	FAMILY REP	ORT				
El services helped family know their rights	75.59%	77.47%	79.55%	76.01%	ţ	+
El services helped family effectively communicate child's needs	72.10%	74.57%	75.65%	74.34%	ŧ	t
El services helped family help their children develop and learn	85.44%	85.70%	88.66%	85.74%	ŧ	+
TIMELINESS INDICATORS						
Initial evaluation and assessment and Individual Family Service Plans (IFSP) meeting conducted within 45 days of referral	98.99%	99.56%	99.91%	97.51%	ŧ	Ļ
Percentage who begin receiving early intervention services within 30 days of parent consent	96.35%	98.60%	97.24%	96.94%	$\leftrightarrow$	\$
Transition steps and services in IFSP by 90 days prior to 3rd birthday	98.23%	84.90%	82.85%	96.19%	1	Ļ
Notification to state and local educational agencies at least 90 days prior to 3rd birthday	91.34%	92.48%	93.16%	96.39%	t	t
Transition conference at least 90 days prior to 3rd birthday if potentially eligible for Part B Early Childhood Special Education program	97.90%	88.62%	79.01%	97.43%	t	+

Table 5: Early Intervention Program Performance Metrics by Year, 2014-17. Note: Some variation is expected from year to year, so changes less than one percent are deemed "about the same" and indicated with " $\iff$ ."



1. Establish and strengthen state data governance bodies regarding early childhood education to guide the coordination, security, and appropriate use of data.

2. Strengthen states' capacity to securely link data on young children across all state and federal early childhood education programs, including Head Start and home visiting.

3. Expand efforts to collect and link data about the early childhood workforce.

4. Communicate with parents about data privacy policies and uses of early childhood data.

5. Use existing data systems, planning tools, and technical assistance to support early childhood data system integration.

As the Commonwealth develops greater capacity for sharing and aggregating data between early childhood and other systems, opportunities will emerge to use this data to drive larger systems change initiatives. States are beginning to look at creative ways to use early childhood data to hold Medicaid managed care organizations accountable and to inform value-based reimbursement initiatives. Both Oregon and New York, for example, are actively exploring Medicaid quality metrics related to school readiness (Howard, et al. 2018). Given the Commonwealth's current emphasis on school readiness and evolving Medicaid managed care system, there are opportunities to explore how improved data systems can assist in the development of meaningful, performancebased Medicaid reimbursement metrics related to early childhood outcomes and school readiness indicators.

#### System Collaboration and Shared Vision

Early Intervention is only one of a number of programs that serve children with developmental delays and risk factors associated with developmental delays in the Commonwealth. A recent review of early childhood programs in Virginia conducted by the Joint Legislative Audit and Review Commission identified 34 distinct early childhood programs, 13 of which it determined were "core programs" (JLARC 2017). The 13 core programs include Early Intervention (Part C), Early Childhood Special Education (Part B), a childcare subsidy program, three pre-K programs, and seven home visiting programs.

Although this Assessment has focused primarily on Early Intervention, the role of the Commonwealth's Early Intervention program must be understood in relation to the overall goals of the Commonwealth to prepare children in early childhood for success in school and in their other endeavors as members of their communities. The Commonwealth continues to work towards expanding opportunities that ensure all families and children receive the services they need in order to be school-ready and to ultimately become productive members of their communities. As these efforts progress, it is even more important that these diverse programs share a common vision and a common philosophy.

Inclusion should be at the heart of a shared early childhood philosophy. Research has long supported the benefits of early childhood inclusion. The Council for Exceptional Children's Division for Early Childhood (DEC) and the National Association for the Education of Young Children (NAEYC) explained the importance of developing a shared definition and philosophy of inclusion in a joint position statement published in April 2009. According to the statement, the defining features of inclusion include:

1. *Access*: students with disabilities have access to a wide range of learning opportunities, activities, settings, and environments;

2. **Participation**: some children require additional individualized accommodations and supports to participate fully; and

3. **Supports**: system-level supports must be in place to support individuals and organizations providing inclusive services to children and families.

While it is difficult to measure inclusion directly, available data suggests that Virginia's young children with developmental delays almost always receive Early Intervention services in home- or community-based settings, but are often served in separate facilities or programs from children without disabilities when they enter the Early Childhood Special Education program.



According to the Virginia Department of Education's 2016-17 statewide performance report, less than onethird (32.14 percent) of all students between age three and age five who had an Individualized Education Plan attended a regular early childhood program and received the majority of special education related services in the regular early childhood program; while over a quarter (26.93 percent) attended a separate special education class, separate school, or residential facility.

The are multiple likely reasons for this lack of inclusion. Some communities in Virginia have few inclusive early education options available for students with disabilities to attend. Low expectations about the ability of students with disabilities to benefit from integrated settings and other stereotypes are a continuing barrier for professionals and families alike. As the Commonwealth focuses on increasing early childhood options, it is important to ensure that those options are inclusive of all students, including students with disabilities. The DEC/NAEYC further recommends an integrated professional development system that focuses on supporting the inclusion of young children with and without disabilities and their families. Virginia has an existing framework for integrated early childhood professional development. The Virginia Cross-Sector Professional Development Team works to:

- Encourage cross-sector collaboration in early childhood professional development,
- Enhance the knowledge, skills, and abilities of early childhood professional development providers, and
- Promote high quality professional development.

However, there are opportunities for Virginia to expand these professional development opportunities given that Virginia is still providing services to many children in segregated settings.

Low expectations about the ability of students with disabilities to benefit from integrated settings and other stereotypes are a continuing barrier for professionals and families alike.



### **Recommendations Related to Performance**

The Infant and Toddler Connection of Virginia, in collaboration with its governmental and community partners should:

#### **Recommendation 1:**

Make the completion of a new and more reliable data system a priority for the Early Intervention program.

#### Rationale:

The Board has recommended in prior Assessments that an updated data system be developed for Virginia's Early Intervention program that can more accurately and efficiently collect real time data about Early Intervention services, costs, and outcomes. Work towards the development of such a system has been ongoing for a number of years. The completion of this system must be a priority for the Department of Behavioral Health and Developmental Services (DBHDS) in order to facilitate more complete, accurate, and robust analysis of the system's performance and needs.

#### **Recommendation 2:**

Work with the Governor's Children's Cabinet to ensure that, as the Commonwealth expands access to early childhood programs for all children, children with disabilities have access to the same inclusive early childhood services and programs as children without disabilities.

#### Rationale:

Despite decades of research supporting high quality inclusion, Virginia's Early Childhood Special Education program often serves children with disabilities in separate classrooms or facilities. There are many reasons for this, including a lack of quality inclusive early childhood programs in the Commonwealth. As the Commonwealth expands the number and quality of early childhood programs, it is important that these programs share an understanding and commitment towards inclusion.

#### **Recommendation 3:**

Develop a shared definition, philosophy, and vision of inclusion among early childhood programs, including Early Intervention.

#### Rationale:

This recommendation is consistent with the Joint Position Statement of the Council for Exceptional Children's Division for Early Childhood and the National Association for the Education of Young Children on early childhood inclusion. If the Commonwealth is to increase early childhood inclusion for children with disabilities, early childhood programs must be guided by a shared understanding of, and commitment towards, inclusion.



#### **Recommendation 4:**

Work with the Virginia Early Intervention Professional Development Center, the Virginia Cross-Sector Professional Development Team, and other stakeholders to expand opportunities for integrated early childhood professional development in the Commonwealth that supports the inclusion of young children with and without disabilities and their families.

#### Rationale:

This recommendation is consistent with the Joint Position Statement of the Division for Early Childhood and the National Association for the Education of Young Children on Early Childhood Inclusion.

#### **Recommendation 5:**

Work with the Governor's Children's Cabinet to continue to explore opportunities to securely link Early Intervention data to other early childhood programs and existing Virginia Longitudinal Data System partners, as envisioned by the Children's Cabinet, and explore opportunities to use this data for valuebased reimbursement to Medicaid managed care organizations.

#### Rationale:

Integrated early childhood data opens up new opportunities for system evaluation and accountability. Several states are exploring opportunities to use early childhood data as a component of their value-based reimbursement system for their Medicaid managed care organizations. As Virginia seeks opportunities to link early childhood data across secretariats and across systems, it should explore opportunities to use that data to incentivize desirable outcomes.

#### **Recommendation 6:**

Continue to monitor performance indicators related to the transition from the Part C Early Intervention program to the Part B Early Childhood Special Education program, in order to ensure that recent system improvements in these indicators persist.

#### **Rationale:**

Virginia's performance on several indicators related to transition from Part C Early Intervention services to Part B Special Education services had been slipping between 2014 and 2016. The Infant & Toddler Connection of Virginia focused on improving these indicators through training and outreach to local Early Intervention programs. As a result of these efforts, Virginia's performance on these indicators improved markedly in 2017. It will be important to continue monitoring these indicators to ensure that these improvements persist.



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