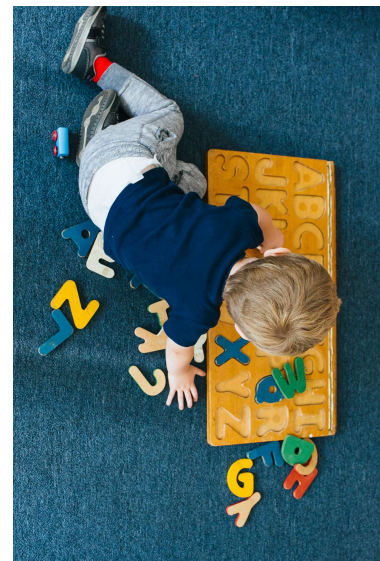


IDENTIFYING COMMUNITY NEEDS

As an innovative nonprofit, the mission of CA Human Services is to impact capacity development in human services systems through strategic public-private partnerships, leadership and collaboration. The organization started with the ideas and experiences of a visionary group of parents, and its future continues to be shaped by the voice of the community.

In 2021, CA Human Services initiated a study to better understand challenges and preferences in navigating autism information, supports, services and resources. The findings are summarized in this document to provide valuable insights about family and individual experiences, enabling stakeholders across the Commonwealth to work together to remove barriers and improve experiences for impacted citizens.



ENGAGING COMMUNITY VOICES

Knowledge Advisory Group (KAG) was selected to oversee and execute this project. Preliminary information for this study was collected by KAG through phone interviews and focus groups with 11 autism experts and service providers, as well as focus groups with 7 families of individuals diagnosed with autism and 5 adults diagnosed with autism. This background information was used to identify issues to explore further on a statewide survey, which was completed by 62 families of individuals diagnosed with autism.

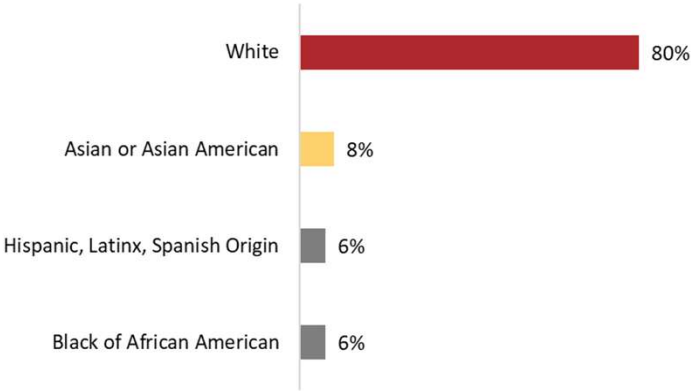


UNDERSTANDING SURVEY RESPONDENTS

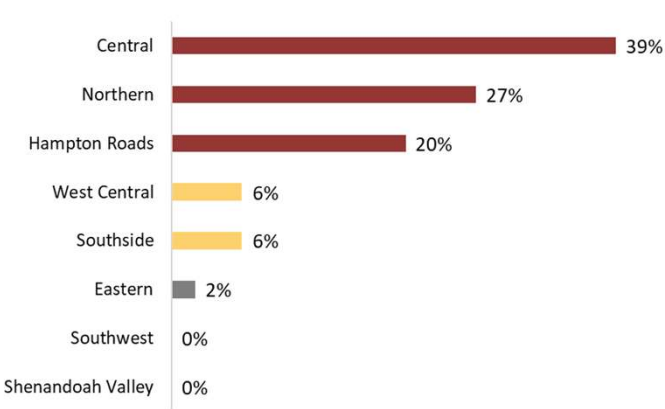
The survey effort entailed outreach to a wide variety of respondents across Virginia, including diverse racial/cultural backgrounds, income levels, and geographic regions. Most survey respondents were White with an income of \$75,000 or more. While KAG solicited participation in all regions of the Commonwealth, most respondents lived in Central Virginia, followed by the Northern and Hampton Roads areas. No responses were received from the Southwestern or Shenandoah Valley regions. Most respondents reported that the current age of the family member diagnosed with autism was less than 18, and the diagnosis had occurred within the past 10 years. About 83% of the survey respondents were women.



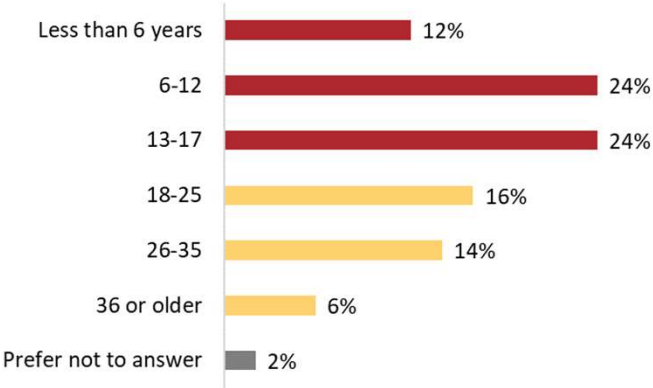
Race/Ethnicity



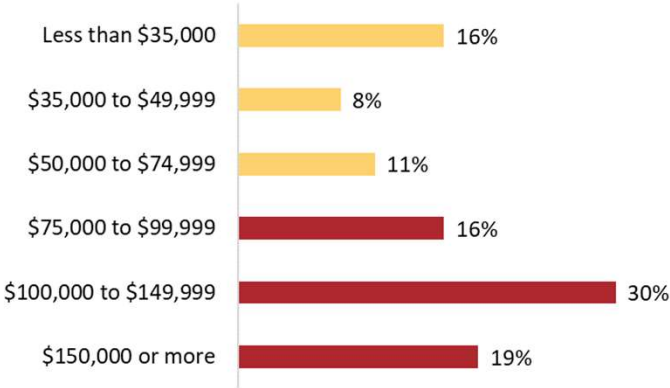
Region



Current Age of Family Member with Autism



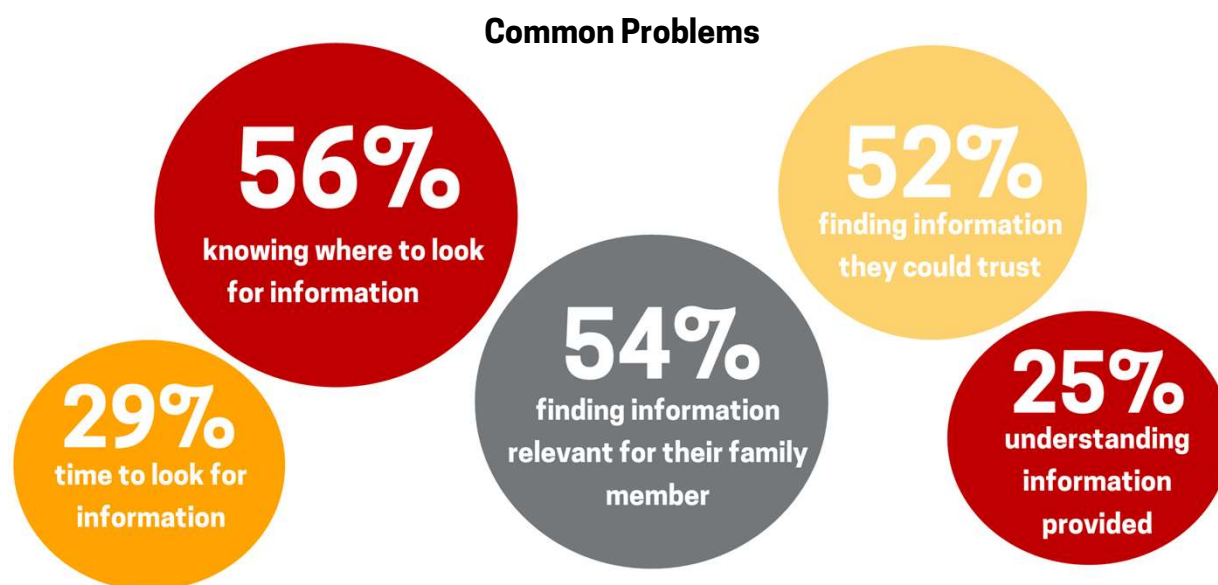
Income



Note: Results should be interpreted with caution due to the small sample size, as it may not be representative of all families who interact with autism services in Virginia.

KEY FINDING #1: INFORMATION ABOUT AUTISM PROGRAMS AND BENEFITS IS COMPLEX, DISJOINTED, AND OVERWHELMING FOR FAMILIES TO NAVIGATE.

Autism experts and service providers noted that information about autism programs and benefits may be obtained from a variety of organizations, but the lack of a centralized source of information can make it difficult for families to find the specific information they need. On the statewide survey, families indicated the most common problems they had experienced when obtaining information to help family members diagnosed with autism included *Difficulty knowing where to look for information*, *Difficulty finding information relevant for my family member*, and *Difficulty finding information I can trust*.



When asked about the helpfulness of specific organizations that provide information on autism services, most families could not respond because they were not familiar with them. For example, most families were unfamiliar with the behavioral health information services provided by Virginia referral resources, such as the No Wrong Door Network and the 211 Phone System. Similarly, most families were unfamiliar with most statewide nonprofits that provide autism information and assistance. However, regional nonprofits, such as the Autism Society chapters in Tidewater, Central Virginia, and Northern Virginia, were relatively well-known among survey respondents in those service areas.

The lack of awareness about autism resources may prevent families from discovering and applying for some of the state services and benefits for which they may qualify. For example, less than half of the survey respondents had applied for state programs such as FAPT/IEP, CCC Plus Medicaid Waiver, or Child Find. In addition, most families had not applied for services at any of the five Child Development Services Programs throughout the state. Although it is unclear how many of the family members in this study would have qualified for these programs, improved awareness about the organizations that connect families to these programs could increase the number of individuals with autism who receive appropriate services.

COMMUNITY FEEDBACK:

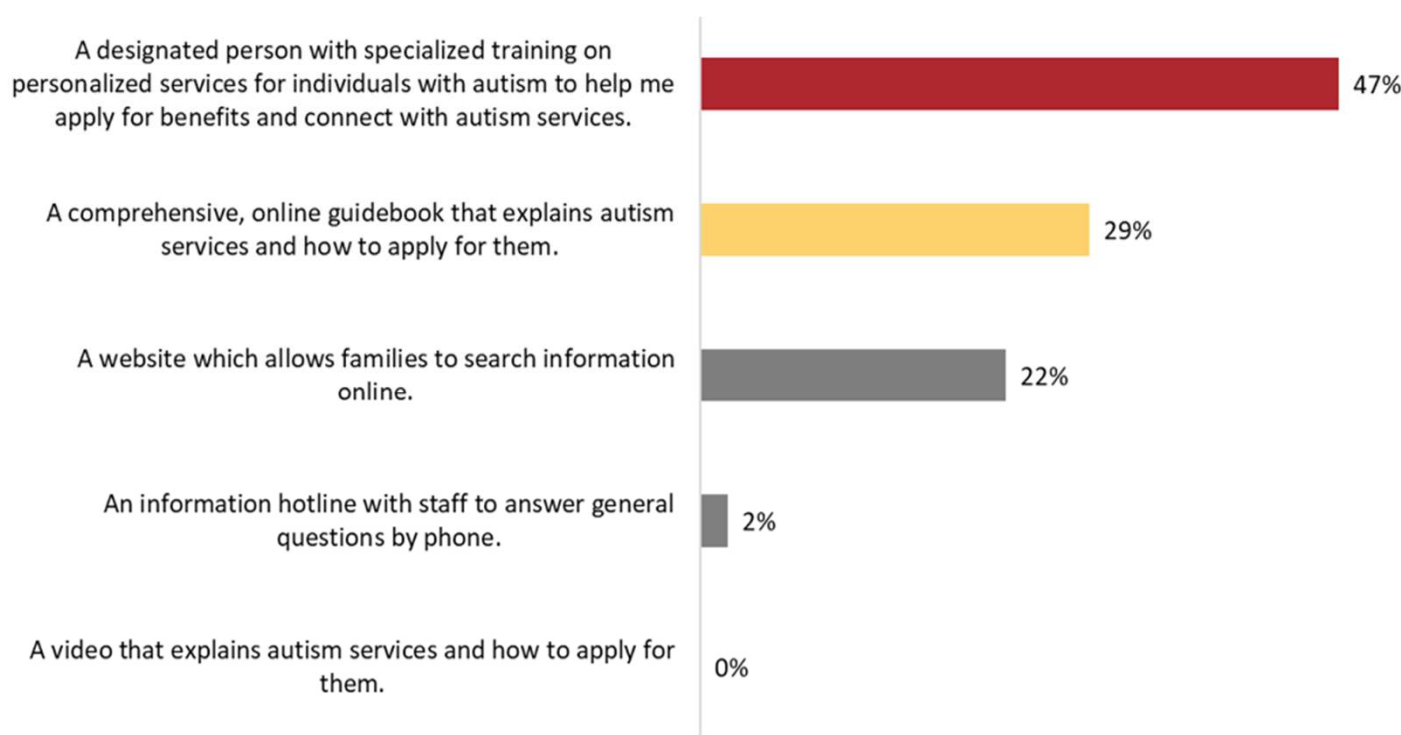
"It is an extremely complicated system of interlocking agencies, screenings and paperwork for all services."

"There is a lot of information out there. There is a lot of sorting and shifting to figure out what [my family member] specifically needs."

KEY FINDING #2: THERE IS NO CENTRAL POINT OF CONTACT TO ASSIST FAMILIES WHO NEED HELP UNDERSTANDING AUTISM PROGRAMS AND BENEFITS FOR WHICH A FAMILY MEMBER MAY BE ELIGIBLE.

During focus groups and interviews, autism experts, service providers, and families mentioned the lack of a central point of contact as a primary barrier to obtaining autism information and services. When asked on the statewide survey how they would prefer to get information about autism in the future, nearly half of all families indicated their first choice would be *A designated person with specialized training on personalized services for individuals with autism to help me apply for benefits and connect with autism services*. This finding applied to all families, regardless of race, but Nonwhite families were particularly likely to select this option.

Family Preferences on Obtaining Information about Autism (N=51)



COMMUNITY FEEDBACK:

"The parent is the only point person. I had to figure it out through my own tenacity. Even my support coordinator couldn't help."

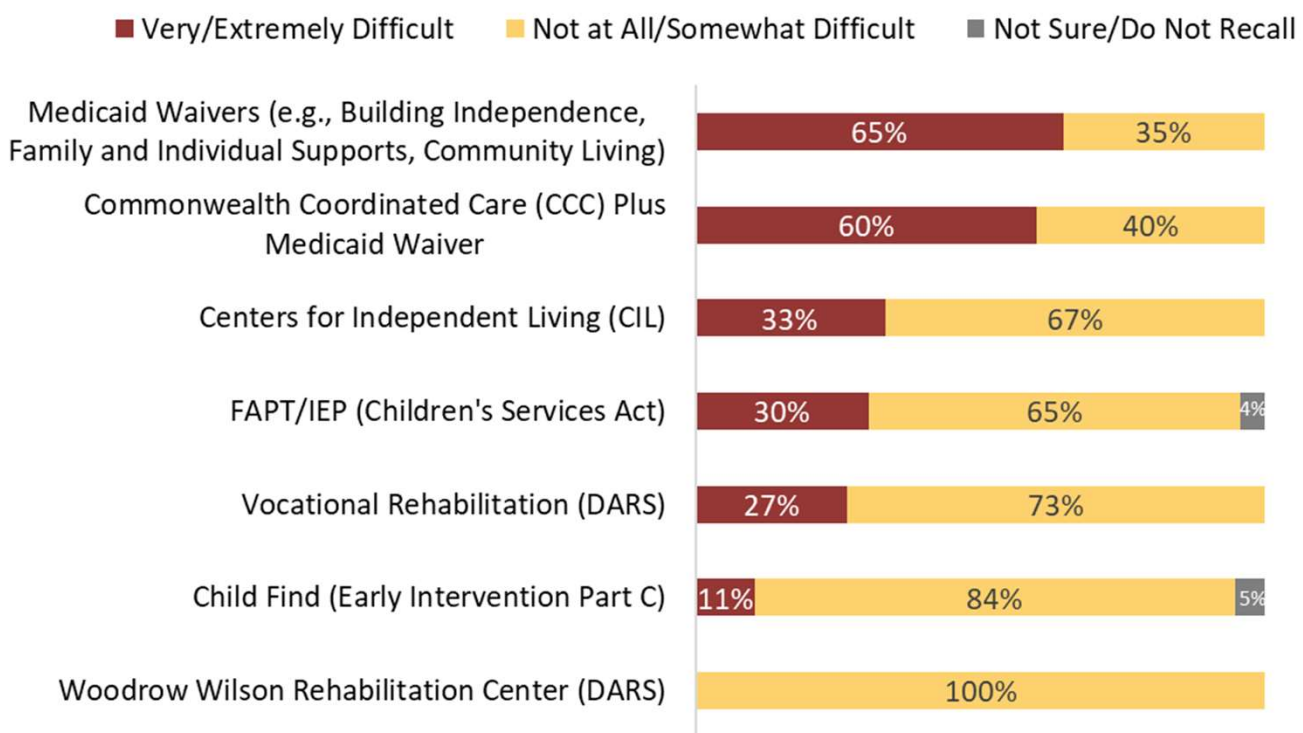
"We are required to do the same assessment multiple times through the school, CSB, service facilitator, and insurance because they don't share information."

"There are too many ways for families to get lost. Too many independent and governmental organizations that will not communicate with each other. This makes it so hard to find services and get help. There needs to be one place where families can go to get the information- a hub of autism related services- to show families what is available and what would be appropriate for their loved ones."

KEY FINDING #3: THE APPLICATION PROCESS FOR BENEFITS AVAILABLE THROUGH STATE PROGRAMS IS DIFFICULT FOR MANY FAMILIES.

During focus groups and interviews, autism experts, service providers, and families noted that the application process for state benefits was a significant barrier to obtaining autism services. On the statewide survey, most families who had applied for a Medicaid Waiver or a CCC Plus Medicaid Waiver indicated the application process was *Very* or *Extremely Difficult*, but most families who had applied for other state programs indicated the application process was *Not at All* or *Somewhat Difficult*. Long wait lists for Medicaid waivers due to a lack of state funding for those programs was a common complaint among autism experts, service providers, and families who provided feedback during focus groups and interviews.

Experiences Applying for State Services and Benefits (N=45)



COMMUNITY FEEDBACK:

"Finding information from the state is difficult. I feel like I'm getting a Ph.D. in navigating resources. Teasing out the information is a full-time job."

"It's difficult to understand what is available. Wait times are unrealistic and it's overwhelming trying to navigate without a strong support system."

KEY FINDING #4: FAMILIES FACE BARRIERS WHEN TRYING TO ACCESS INFORMATION FROM PROVIDERS IN SCHOOL AND HEALTH CARE SETTINGS.

During interviews and focus groups with autism experts and service providers, a lack of professional knowledge among school staff, CSBs, doctors, and other service providers was cited as a barrier to acquiring autism information for families. This finding was echoed during focus groups with families and individuals diagnosed with autism. In particular, they noted that CSB staff, school staff, and service providers need more specific expertise to improve the availability of information that addresses the different and distinct needs of individuals diagnosed with autism. When asked to share personal experiences about autism services on the statewide survey, families cited more examples of difficulties in obtaining adequate information, suggesting the staff with whom they interact in school and health care settings seem overwhelmed and lack resources to provide the assistance families need.



COMMUNITY FEEDBACK:

"More knowledgeable people are needed in this field. Each kid is different, and the needs are different as well."

"Educational services have been horrible in middle school this year. [There is] no adequate support. [There is] neglect."

KEY FINDING #5: ALTHOUGH THE SYSTEM OF AUTISM SERVICES IS CHALLENGING FOR MOST FAMILIES TO NAVIGATE, CERTAIN POPULATIONS FACE ADDITIONAL BARRIERS.

According to autism experts and service providers, additional barriers to autism information and services include *language*, *cultural beliefs*, *geography*, and *age*. There are many non-English speaking families residing in Virginia who may not understand information related to autism services because most of it is only available in English. In addition, autism diagnoses may not be recognized by certain cultures, which means that some families are not aware to look for signs or symptoms of autism in their children. There are also barriers to services among English-speaking and American-born families. For example, a recent study of access to autism services in the rural Appalachian region of Virginia indicated that availability and affordability of autism services, as well as cultural attitudes related to autonomy and trust towards outside professionals, are all barriers that may prevent families from participating in treatment.¹ A lack of services for adults diagnosed with autism was also mentioned frequently as a gap in services across the state.



COMMUNITY FEEDBACK:

“Language and cultural barriers are common in Northern Virginia. There are over 150 languages spoken by families in the Fairfax County school system.”

“When my adult daughter was diagnosed at the age of 19 in 2003, I had to quit my full-time job as an RN and spent all my free time searching for help. After several years, we made connections with DARS, CSB, SSA, CIL, and various providers with some knowledge regarding [autism]. Twenty years later, we lost most of these benefits because of the lack of consistent care management. Our family literally emptied all savings and equity in our home to find help for our daughter. I could never return to consistent full-time work because of the lack of knowledge that was placed into our hands. I know that most children are diagnosed earlier with better access to services, but what about the families whose son or daughter has aged out?”

[1] Scarpa A, Jensen LS, Gracanin D, et al. Access to autism spectrum disorder services for rural Appalachian citizens. *Journal of Appalachian Health* 2020; 2(1):25-40. DOI: <https://doi.org/10.13023/jah.0201.04>.



RECOMMENDATION 1:

Create a workgroup to determine the most feasible solution to address the need for a central point of contact to assist families with service navigation.

This research confirms that autism information and services are provided through many different points of contact for families, including hospitals and physician's offices, local schools and school systems, and Community Services Boards. Further, this study revealed that a "central point of contact" model is highly desired by users of the autism information and services system. At this point, it is unclear which organization may be best suited to provide "central point of contact" services for families; however, there are several possibilities to consider:

1) Public Schools. Public schools have regular contact with families during school age years, but this does not cover preschool years or the post-graduation time period.

2) Community Services Boards. Support Coordinators at CSBs could take on this centralized role with additional training and capacity, but they are reportedly understaffed at this time.

3) Nonprofits. The families in this study reportedly seek information from nonprofits more often than local CSBs, and therefore nonprofits may be well-positioned to take on this type of role. It is unlikely that any one nonprofit entity has the capacity or desire to provide this service, however.

A statewide workgroup of autism professionals could be convened to discuss this issue, select a coordinating entity, and create plans for future implementation.





RECOMMENDATION 2:

Create a comprehensive, online guidebook that explains autism services and how to apply for them.

Opinions about the most desirable way to access autism information varies. When asked on the statewide survey how they would prefer to obtain information about autism in the future, nearly one-third of the families selected a comprehensive, online guidebook as their first choice. Lower income families were more likely to select this option than any others, which suggests this strategy may be particularly beneficial for families who are most in need of benefits and services available through state programs.

A guidebook could be used to provide families with a cost-effective, streamlined source of information until funding becomes available for providing families with “central point of contact” services, as noted in Recommendation 1. Ideally, it should provide information on the eligibility criteria and application process for all state programs and benefits. Further, to support families that may be unaware of critical services, this guidebook should be managed by an oversight entity to ensure that accurate and complete information is maintained on a reasonable schedule.



RECOMMENDATION 3:

Enhance collaboration across organizations to improve and centralize autism information, clarify roles and responsibilities, and establish a centralized database as a long-term goal.

Study participants repeatedly shared that Virginia has a wide variety of sources for autism information. Because the system is vast and individual needs vary greatly, this presents challenges for both users and providers when finding information and resources. Multiple resources, including CA Human Services, regional Autism Societies, and others, may contain disparate information or cover different autism issues. Enhanced collaboration across information and service providers is recommended to create a more comprehensive resource for families and individuals diagnosed with autism. Ultimately, information resources may be merged, or a comprehensive database could be created as a long-term initiative. To improve the quality of information available, KAG further recommends expanding general and specialized training opportunities for relevant professionals. These efforts will improve navigation of autism information and create less confusion, saving valuable time in accessing services.



RECOMMENDATION 4:

Enhance collaboration across organizations to address the needs of special populations of families and individuals diagnosed with autism.

Interview, focus group, and survey findings suggest that opportunities exist to improve programming to serve selected subpopulations of families and individuals diagnosed with autism. Variations in language, cultural beliefs, geography, and age of the individual diagnosed with autism may increase barriers to access for some families, as well as the continuum of services available. While some customized services may be available in specific areas, the autism service delivery system partners may benefit from enhanced collaboration to purposefully expand service offerings, thereby benefiting high-barrier families.



RECOMMENDATION 5:

Partners within the autism information and service delivery system should continue advocating for additional funds to better support families and individuals diagnosed with autism.

The feedback gathered through this effort continued to emphasize one underlying reality: structures to disseminate information and deliver services for autism are substantially under-resourced. Funding deficits will impact the ability to address each recommendation above: training, service navigation, specialized services, online resources, and centralized information. Partners within the system should collaborate to create effective messaging, focused on demonstrating the connection between funding limitations and the difficulties expressed by families in need within Virginia. These compelling stories may be useful for continued advocacy to improve information and services.

This research was supported by a grant from the
Virginia Department of Behavioral Health and Developmental Services.

