

My Child is Waiting for an Autism Evaluation Frequently Asked Questions

October 2022

Families often have questions about what they can do while their child is on a waiting list for an autism evaluation or a developmental assessment. We acknowledge that waiting for an evaluation may feel difficult and uncertain. This resource was developed based on questions raised by actual families and their care teams. We hope this information is helpful to you.

Does my child need an autism diagnosis to access Medicaid?

No. Children may access Medicaid coverage before having an autism diagnosis. Your family or child will need to meet the eligibility criteria, which includes:

- Children under the age of 19 may be eligible for <u>Dr Dynasaur</u> if your household income is below <u>312% federal poverty level.</u>
- <u>Disabled Children's Home Care</u> (DCHC) is a Green Mountain Care Program that allows certain children under the age of 19 who have long term disabilities, or complex medical needs that require a high level of care, to become eligible for Medicaid even though their family's income is above the eligibility level for Dr. Dynasaur.
 - What is Disabled Children's Home Care Fact Sheet
 - Disabled Children's Home Care Katie Beckett Completing the Application Fact Sheet
 - What is Disabled Children's Home Care (VT's Katie Beckett Medicaid) Eligibility & New Application (10/29/20)

Are there therapies available that could help my child?

There are therapies that can help with your child's development, skills or overcoming challenges that your child is experiencing. Talk with your child's health care provider or medical home about your child's needs and how to make referrals for therapeutic services and supports. Assessments conducted by therapists/clinicians are a first step to determine the level of services your child needs. Some examples of therapies are below:

- <u>Speech & Language Pathologists/SLP</u> Help children communicate effectively by assisting with the improvement of their verbal and non-verbal language skills. They also help with things like feeding and swallowing abilities.
- <u>Physical Therapy (PT)</u> Help children improve or maintain their range of motion, strength, flexibility, and movement patterns.

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- <u>Occupational Therapy (OT)</u> Help children gain independence while also strengthening the development of fine motor skills, sensory motor skills, and visual motor skills that they need to function and socialize.
- <u>Behavioral Therapy</u> teaches children and their families how to strengthen positive child behaviors and eliminate or reduce unwanted or problem behaviors.
- <u>Mental Health Therapy</u> Psychological therapy is meant to treat a mental health condition or help a child manage their symptoms so that they can function well at home, in school, and in their community.
- <u>Nutrition Consultation</u> Registered Dieticians (RDs) provide individualized nutrition service/consultations for children who have specific growth, feeding and dietary needs.
- The Centers for Disease Control and Prevention (CDC) has a resource page on <u>Treatment</u> and Intervention
- <u>Healthychildren.org</u> which is powered by the American Academy of Pediatrics has an informational page on <u>If Autism is Suspected. What's Next?</u>

Where can I get assistance and supports if my child is under 5 years of age?

- Talk with your child's health care provider/medical home if you have questions and concerns about your child's health and development.
- Connect with Children's Integrated Services (CIS). CIS offers early intervention, family support, and prevention services. CIS services are family-centered, child-focused, and delivered through a network of providers throughout Vermont. CIS helps you decide what services you need, and helps you access those services.
 - Contact information for local CIS coordinators
 - Information on Early Intervention Services for Infants and Toddlers IDEA Part C
 - Information on Early Childhood and Family Mental Health
- If your child is between three and six years of age, you can reach out to <u>Early Childhood Special</u> <u>Education Services</u> (ECSES) to ask about their programs and request a comprehensive evaluation. ECSES is administered through local school districts to ensure access and participation in early childhood programs for every child who is determined eligible for services.
 - Map of School Districts by Town
 - <u>Vermont Agency of Education School Directories</u>

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Does my child need an autism diagnosis to get special education services?

Your child does not need an ASD diagnosis to qualify for special education services. Services should be based on a child's needs, that are found by testing and evaluations.

While it is true that a child does not need an ASD diagnosis, the they still need a diagnosis to be found <u>eligible and there needs to be an adverse effect</u> – in addition to the needs <u>gate</u>.

- Request a comprehensive evaluation for your child from your school district to find out if your child qualifies for:
 - A Section <u>504 Plan;</u> or
 - Individualized Education Plan (IEP)
- Work with the school team to develop appropriate and individualized services for your child.
- <u>Vermont Family Network</u> has helpful resources on their website. They have family support consultants that can answer your questions and help you prepare for school meetings.
- <u>Vermont Law Help (Vermont Legal Aid)</u> has a page of information and resources around special education and other supports for children who are struggling in school

Does my child need an autism diagnosis to get services through my local Designated Agency?

It depends; there are some services and programs that do require an autism diagnosis in addition to other qualifications. Below are some examples, but you should check with your local <u>Designated</u> <u>Agency</u> to see what they have to offer and if there are any wait lists.

- <u>Early Childhood and Family Mental Health</u> does not require an autism diagnosis. They work with children who are experiencing social, emotional, or behavioral struggles and their families. The child needs to have Medicaid to access.
- <u>Bridge Program</u> requires a developmental disability diagnosis and Medicaid to access.
- <u>Family Managed Respite</u> funding is to provide a child's caregiver a break. The child must have Medicaid and an identified mental health condition and/or developmental disability.
- <u>Flexible Family Funding</u> is provided to eligible families of individuals with developmental disabilities to help pay for any allowable child needs, such as respite, assistive technology, home modification, individual and household needs or recreational activities.

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To access this benefit, a child must quality for developmental services which would require an autism diagnosis, or other developmental disability and/or function impairments.

• <u>Children's Personal Care Services</u> (CPCS) Assessments – CPCS may be able to help families and caregivers to pay for one-on-one assistance with dressing, bathing, grooming, toileting, eating and/or mobility.

Does my child need an autism diagnosis to get Children's Personal Care Services?

Your child does not need an autism diagnosis for <u>Children's Personal Care Services</u>, but there are other qualifications:

- Must be under the age of 21
- Actively enrolled in Medicaid
- Have a documented health condition; developmental or physical disability/chronic mental or behavioral health diagnosis/cognitive impairment.
- Have significant delays in activities of daily living (bathing, toileting, grooming, eating, mobility, and transfers)

Call your <u>designated agency</u> and ask about a Children's Personal Care Services assessment.

My child is experiencing difficultly at childcare. Do I need a diagnosis to access support?

No. There are resources through the <u>Child Development Division</u> available for all families. There are also specific resources for families that have children with special health needs. Some examples of support include:

- <u>Bright Futures Child Care Information System</u>: An on-line search engine to find available childcare.
- <u>Child Care Financial Assistance</u>: A program for families in Vermont; that is based on income and, can help pay for childcare.
- <u>Special Accommodation Grant</u>: If your child is in a childcare program and at risk of being asked to leave due to needing additional support, childcare facilities can apply for a grant that will pay for a one-on-one staff person for your child at the childcare.
- <u>Specialized Childcare</u>: If you have a child on an IEP or One Plan, you may be able to access these programs:

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- Child with Special Health Needs Child Care is for children with special physical, medical, behavioral, or development needs.
- Family Support Childcare is for families experiencing significant stress.
- \circ $\;$ The school district may help with getting transportation to this care.

Where can I talk with other parents who have a child waiting for an autism evaluation?

- Ask your child's healthcare provider/medical home if they know of parents/caregivers who can connect with you.
- Vermont Family Network has a:
 - <u>Parent Match Program</u> They will match you with a mentor parent(s)who has walked a similar path and understands the challenges of raising a child with a disability.
 - <u>Facebook group</u> where families of children with special health care needs, educational needs, and disabilities can engage in discussions, post for support, and meet members of the community.
 - List of <u>Support Groups</u> in the state facilitated by parents with additional listed non-parent led groups.

How do I access Applied Behavior Analysis (ABA) therapy for my child while we wait?

CSHN is not promoting the use of ABA over other therapies, but rather posting the question we are hearing often from families.

- Your child may be able to access ABA with a recommendation & referral from your child's healthcare provider/team prior to an ASD diagnosis.
 - Set up a time to talk with your child's healthcare provider/medical home/team about ABA.
 - Write down your questions for the meeting ahead of time so you are prepared.
 - Make sure the conversation is productive and you come away with next steps (like a referral) and name someone who is responsible for completing each step.
- Call your insurance to ask about their policy for coverage both with and without a diagnosis. You can inquire about their appeals and exception policies.
- Medicaid covers ABA with the appropriate <u>medically necessary</u> documentation.
- For the <u>Vermont Medicaid ABA Benefit</u>, a referral for services can come from anyone but a prescription is needed from one of the following providers:

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- Board certified or board eligible psychiatrist
- Doctorate-level licensed psychologist
- Board certified or board eligible pediatrician
- Board certified or board eligible neurologist
- Developmental-behavioral or neurodevelopmental disabilities pediatrician
- If your child is in school and already on an Individualized Education Plan (IEP) or Section 504 plan, then you will need to speak with the school team.
 - Request an IEP or Section 504 Plan team meeting.
 - Write down your questions ahead of time so you come prepared.
 - Connect with a <u>Vermont Family Network</u> family support consultant to talk about ways to have productive school meetings. They can help you frame questions to ask about services like ABA, <u>evaluation</u>, and inclusion.
- If your child is under six years of age connect with <u>Children's Integrated Services</u> or <u>Early</u> <u>Childhood Special Education Services</u> to see if your child might qualify for their services. If your child qualifies for these services, ABA could be part of the services plan.
- There are <u>community-based ABA providers.</u>

Are there community supports I can look for and connect with?

Visit these websites and connect with these organizations for more information about services, supports, and more information about autism:

- <u>Vermont Family Network</u>'s mission is to empower and support all Vermont children, youth, and familes, expecially those with disablities or special health needs. They do this by giving a strong start, lifting family voices, and advancing inclusive communities.
- <u>Children with Special Health Needs</u> (CSHN) supports Vermont children and youth with special health needs by ensuring comprehensive, culturally sensitive, community-based, and family-centered services. This is a free public health program for families.
- The <u>Vermont Autism Task Force</u> (VATF) seeks to improve relevant policy and service delivery to promote best practices and the inclusion of people on the autism spectrum in communities across Vermont. The VATF advocates for people on the spectrum and their families by sharing information to facilitate connections to existing resources.
- <u>Help Me Grow Vermont</u> is dedicated to the success and wellbeing of Vermont's families and the communities they live in. Help Me Grow helps early childhood partners work together to build strong, connected communities and healthy, resilient families.

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You can also access information on your rights and your child's rights by connecting with these organizations:

- <u>Vermont Legal Aid</u> is a non-profit 501(c)(3) law firm established in 1968. They provide free civil legal services for Vermonters, including those living in poverty, with a disability, or over age 60. They advance fairness and justice in the civil legal system, address the social and economic interests of their clients, and confront the underlying causes of poverty, discrimination, and inequality.
- <u>Disability Rights Vermont</u> (DRVT's) mission is to promote the equality, dignity, and selfdetermination of people with disabilities.
- <u>Autism Self Advocacy Network</u> (ASAN) seeks to advance the principles of the disability rights movement regarding autism. ASAN believes that the goal of autism advocacy should be a world in which autistic people enjoy equal access, rights, and opportunities. They work to empower autistic people across the world to take control of their own lives and the future of this common community and seek to organize the autistic community to ensure their voices are heard in the national conversation about them.

Other Links and Resources:

- What You Can Do While Your Child is Waiting for an Autism Evaluation infographic
- COMING SOON: Link to Autism Resources in Vermont produced by the Autism Workgroup
- <u>UVM Center on Disability and Community Inclusion Autism Resources</u>
- Disabilities, Aging and Independent Living/Youth
- Link Where You Can Look Up Medicaid Providers
- <u>Early and Periodic Screening, Diagnostic, and Treatment</u> (EPSDT) The EPSDT benefit provides comprehensive and preventive health care services for children under age 21 who are enrolled in Medicaid.
- <u>Vermont Family Network Grant/Funding Resource List</u>
- <u>Vermont Family Network's Funding for Families</u>: Includes conference funding and the family support funds where income-eligible families of children, ages birth to 21 years with special health needs may apply for funding for self-identified respite needs or for assistance with unmet medical needs.

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