

NEXT STEPS

**A guide for families with children with
autism spectrum disorders**



**This booklet outlines helpful information and statewide
resources for Vermont families with children with
autism spectrum disorders.**

August, 2008

Purpose of the guide

After the initial shock and sadness of receiving a diagnosis of an Autism Spectrum Disorder (ASD), the first questions that often arise are “Where do we go from here?” “What do we do next?”

The purpose of this Next Steps guide is to provide parents and others involved with families of children with ASD some basic information and resources for assistance. This will include a roadmap for locating assistance and a description of available services and resources. It should be helpful for parents, other family members, doctors, caregivers, therapists and educators.

Feel free to reprint and distribute this document. The latest version will be available on-line at <http://www.ddas.vermont.gov/ddas-programs/programs-autism-default-page#publications>.

This document has been produced by the Vermont Autism Task Force. It is adapted, with permission from the Autism Society of Wisconsin, from the Wisconsin *Next Steps: a guide for families new to autism spectrum disorders*. Printing has been made available with funding from the Vermont Departments of Health, Education and/or Disabilities, Aging and Independent Living. For updates, additions or corrections, contact Clare McFadden at 241-2863 or clare.mcfadden@ahs.state.vt.us .

What is an Autism Spectrum Disorder?

Autism is one of a group of diagnoses identified in the Diagnostic and Statistical Manual (DSM-IV, TR, American Psychiatric Manual of Mental Disorders, 2000) as pervasive developmental disorders (PDD). Included in this group are autistic disorder, Rett's disorder (also known as Rett's syndrome), childhood disintegrative disorder, Asperger's disorder (also known as Asperger's syndrome), and pervasive developmental disorder, not otherwise specified (PDD.NOS). Because there are some overlapping symptoms across these disorders, autism, Asperger's and PDD.NOS are often referred to in the professional literature as autism spectrum disorders (ASD).

Autism is a developmental disorder of neurobiological origin that can have life-long effects in the areas of social interaction and communication. Autism spectrum disorders vary in severity of symptoms, age of onset, and association with other disorders, such as mental retardation, language disability, and epilepsy. The manifestation of autism varies across children and an individual child's lifetime. No two individuals with autism are alike, even if they have the same diagnosis. Autism affects approximately four times more boys than girls. Autism Spectrum Disorders (ASD) have been estimated to occur in 1 in 150 individuals (Center for Disease Control, 2007). The characteristic behaviors of ASD may or may not be apparent in infancy, but usually become obvious during early childhood (ages 2-6).

More information about pervasive developmental disorders is available in the American Academy of Pediatrics *Understanding Autism Spectrum Disorders* which is included in the Vermont Child Development Clinic's Next Step packet or online from the Autism Society of America at www.autism-society.org .

What Causes ASD?

Autism is a neurological disorder whose cause remains unknown. It is likely that there is no single cause. Today, researchers believe that several genes, possibly in combination with environmental factors, may contribute to autism. Some studies of individuals with autism have identified differences in several regions of the brain. The amount of research being done has increased significantly in recent years in hopes of discovering the causes of ASD.

How Can ASD be Treated?

While no cure for ASD have been identified, continued research has led to better treatment and therapies. The primary interventions are educational. Research shows that up to half of children receiving intensive early intervention have made significant gains. Many children continue to show some symptoms in varying degrees throughout their lives and many require lifelong support and supervision. At this point research can not tell us which children will benefit from which type of intervention. No one intervention works for all children or even the same child across his/her lifespan.

Sorting through information regarding appropriate intervention can be daunting. Information is available on the internet, in books, from other parents and professionals. There is a lack of consensus in the field of autism regarding the most effective interventions. Some of the treatment approaches have research studies that support their effectiveness, while others do not. Parents should inform themselves regarding the range of available interventions. The Autism Society of America provides an overview of a range of interventions on their website at www.autism-society.org. They review [Learning Approaches](#), [Biomedical & Dietary Approaches](#) and [Complementary Approaches](#). The Vermont Autism Task Force has developed an online “toolkit” which describes various types of interventions and evaluates the current research available to support those interventions. This is available at www.AutismTaskForce.com. A discussion of interventions for young children with ASD is also available in the *Vermont Interagency White Paper on Autism Spectrum Disorders* which is available online at <http://www.ddas.vermont.gov/ddas-publications/publications-autism/publications-autism-documents/dds-autism-white-paper-march-2006>. Additional information is available on some of the autism websites listed in the appendix.

Where do I find help in Vermont?

Parent and Family Support

Raising a child with an autism spectrum disorder can be a challenge. Many families cope very well on their own. Others benefit from a variety of formal and informal support systems. Some informal supports include relying on the family’s social support network, such as friends, family, church, etc. Many families benefit from participation in parent support groups. These groups vary, but may provide emotional support, information regarding resources and interventions, empowerment, and a sense of community. Some groups are involved in advocacy. A list of support groups in Vermont is located in the appendix. New groups are forming, so if you do not see a group in your area, check the Vermont

Family Network website at www.vermontfamilynetwork.org or call 1-800-800-4005.

Formal systems include family support organizations that can provide information about the diagnosis and treatment options; referrals to resources such as support groups, programs and funding sources; referrals to medical services, respite care, summer camps and recreation activities; assistance and information regarding transition planning (from FITP to EEE to school to adult services); and parent training. Some family support organizations in Vermont include the following:

Vermont Family Network

600 Blair Park Road, Suite 240
Williston, VT 05495
1-800-800-4005/ 1-800-639-7170/ 1-802-764-5290
www.vermontfamilynetwork.org

Children with Special Health Needs

John Zampieri State Office Building
108 Cherry Street
P.O. Box 70
Burlington, VT 05402
1-800-660-4427/ local #: 1-802-863-7338/ TDD: 1-802-863-7200
www.healthvermont.gov/family/cshn/clinic.aspx

Vermont Federation of Families for Children’s Mental Health

95 S. Main St.
P.O. Box 507
Waterbury, VT 05676-0507
802-244-1955
1-800-639-6071 for families only
www.vffcmh.org

Additional supports and services are available from a variety of sources in Vermont. The majority of these are publicly funded through the state and federal government. These are described on the following pages.

Private Insurance and Medicaid

Some services can be paid for through private insurance or Medicaid insurance. Services such as speech, physical, and occupational therapy may be covered by the family’s private insurance or through Medicaid. There are generally limits to the type and amount of these services that can be covered by these sources, so check with the insurance provider in advance.

Medicaid

Medicaid insurance pays for medical services including some services that are unavailable through your private insurance. Children with ASD might use Medicaid to cover evaluations, speech, physical or occupational therapies, Children's Personal Care Services (described later), psychological services, assistive devices or mental health services.

Medicaid is a jointly funded state and federal program for the payment of medical services for those who qualify. While some people are eligible for Medicaid based upon income, some children are eligible based on having a disability, regardless of family income. This eligibility option is known as Katie Beckett. Your social worker from the Child Development Clinic can help you apply. You can also apply directly through the local Department for Children and Families, Economic Services Division District Office. You can locate your local office and additional information by calling 1-800-287-0589 or at http://www.dcf.vermont.gov/esd/contact_us/district_offices. Applications are also available online at this website under health insurance. Vermont Family Network (listed on the previous page) also has a helpful guide entitled *6 Ways to Access Medicaid/EPSTDT*, which explains who is eligible, what services are available and how to apply for Medicaid.

SSI

SSI stands for Supplemental Security Income. It is a monthly payment from the Social Security Administration to people with limited income and resources who are over 65 years old, blind or disabled. While there are income limits, there is a good chance that a child with a disability would qualify. You can apply for SSI at your local Social Security Administration office. Appointments for any office may be made by calling the national toll free number 1-800-772-1213/ TDD 1-800-328-0778 or calling the local SSA office. In Vermont, offices are located in Burlington, 802-951-6753, Montpelier, 802-223-3476 and Rutland 802-775-0893. Additional information on SSI is available online at www.ssa.gov or by calling 1-800-772-1213.

SSI payments can be spent for the benefit of the child for items such as food, clothing, shelter, medical care and personal comfort items. Once these needs are met, funds can be spent on things like life insurance, home accessibility modifications or medical equipment.

Personal Care Services: ages 0-21

Children, under age 21, with a significant disability or health condition that affects care giving needs and/or the development of self-care skills can receive personal care services. A child must have Medicaid insurance to receive this service. Personal Care Services provide individual assistance with activities of daily living such as bathing, dressing, eating, etc. in a person's home or community. Families can use these services flexibly when they are needed. Families can have services provided by an agency, in some areas of the state, or they can hire their own workers to provide this service.

Personal Care Services is piloting an option which increases the flexibility in allowable uses of funding through the service. Under the Children's Creative Connection (C3) option, Personal Care Services recipients can access an array of services and goods related to the child's indicated special care needs.

The C3 option is being piloted primarily in Addison, Bennington, Essex/Orleans and Franklin/Grand Isle during the summer of 2008. The pilot includes 150 recipients and is expected to run for approximately 12 to 18-months. Following the pilot stage, this option may be expanded statewide.

To apply for Personal Care Services, contact the local home health agency, Professional Nurses Services, the local developmental services agency, the local Family, Infant and Toddler program or your social worker at Children with Special Health Needs to arrange for an initial assessment. See list in appendix.

Additional information is available online at <http://www.ddas.vermont.gov/ddas-programs/programs-cpcs-default-page>. For general information, contact the Children's Personal Care Program at 888-268-4860. TTY: 866-410-5781, option 1, then enter 36255.

Family, Infant and Toddler Program: Birth to age 3

The Family, Infant and Toddler Program (FITP) provides for early intervention services for infants and toddlers, birth to three, who are experiencing or at risk of developmental delays. The purpose of the service is to prepare children to be ready to learn from school, learn from life, and to promote their development. The service is available throughout Vermont at no cost to families.

Services are based upon assessed needs of the child and family and are identified in an Individualized Family Service Plan. Early intervention

strategies and services are designed with the family to meet the identified needs. They may include audiology, assistive technology, family training, counseling and home visits, medical evaluations for diagnostic purposes, nursing, nutrition, transportation, service coordination, OT, PT, counseling or psychological services, social work, speech/language therapy, special instruction or vision.

You can call (800) 870-6758 for information on the program statewide and for referrals to regional host agencies that carry out the Family, Infant and Toddler Program. You may also contact: Helen Keith, Program Director, or Kathy Boulanger, Family, Infant and Toddler Program at (802) 241-3602.

To apply, you can either call the 800 number above or your regional host agency and speak with the FITP supervisor or a service coordinator/family resource coordinator. The numbers of the early intervention host agencies are listed in the appendix and online at:

http://dcf.vermont.gov/sites/dcf/files/pdf/cdd/dev/CIS_contacts.pdf

Additional information is available at:

http://dcf.vermont.gov/cdd/early_intervention/IDEA_Part_C

Special Education: 6-21 year olds

Special Education Regulations require that all children with disabilities have available to them a free appropriate public education (FAPE)...designed to meet their unique needs and prepare them for employment and independent living. Children, age 6-21 who have a diagnosed disability or an assessed developmental delay that negatively impacts their ability to learn from the general education program, are eligible for special education and related services. The disability must result in an adverse effect on the child's educational performance in one or more of the basic skill areas and the child must be in need of special education services to benefit from his or her educational program. Services may be provided in a regular classroom, special classroom in regular school or in special schools depending upon the needs of the student.

Special education services include specially designed instruction to meet the unique needs of a child with a disability. Related services mean transportation and such developmental, corrective and other supportive services as are required to assist a child to benefit from special education. Related services include audiology services, interpreting services, physical and occupational therapy, recreation, including therapeutic recreation, counseling services, including rehabilitation counseling, orientation services and medical services for diagnostic or evaluation purposes. Related services also include school health services, school

nurse services, social work services in school and parent counseling and training. Based upon the needs of a child, an Individualized Education Plan (IEP) is developed.

Parents and guardians can request an assessment to determine if their child is eligible for special education and related services through their local school. A school district, the Vermont Department of Education or other state agency may also initiate a request for an initial evaluation to determine eligibility.

Parents should learn about special education regulations and their rights. These are available from your local school or on-line at the Department of Education. See Department of Education website at http://education.vermont.gov/new/html/pgm_sped.html for special education regulations. The Department of Education can also answer questions about special education on their technical assistance line at 828-5114.

Assistance with understanding special education and with advocating for your child's education is available through Vermont Family Network listed above under Parent and Family Support.

Essential Early Education: 3 through 5.11 years old

Essential Early Education (EEE) is Vermont's early childhood special education for children ages 3 through 5 years old. Federal special education law, the Individual with Disabilities Education Improvement Act 2004, indicates that a child, ages three through five years of age who demonstrates a significant developmental delay in one or more of the following areas: receptive and/or expressive communication; adaptive development; social or emotional development; physical development including gross or fine motor skills; cognitive skills or the child has a medical condition which may result in significant delays by the child's sixth birthday and the child is in need of special education, is entitled to these services. Once a child is determined eligible for special education, an Individualized Education Plan (IEP) is developed by the IEP team according to the child's unique needs. Early childhood special education and related services may be provided across a variety of settings i.e., public preschool classroom, Head Start or community-based childcare setting, and/or in the child's home. The goal for young children with disabilities is to ensure a free and appropriate public education within high quality inclusive early childhood settings/environments.

For more information about EEE services within your community, contact the EEE coordinator at your local school.

For additional information, see the Department of Education website at http://education.vermont.gov/new/html/pgm_earlyed/essential_early.html . Or contact Kate Rogers, EEE Consultant at 828-5115.

Section 504 Plans

Some children with disabilities do not meet the eligibility criteria for special education, because their disability is not negatively impacting their ability to learn from the general education program. These children may be eligible for a 504 plan.

504 plans refer to Section 504 of the Rehabilitation Act of 1973 which protects people with disabilities from discrimination in any program or activity receiving federal funding. Students with disabilities that substantially limit a major life activity such as learning, working, hearing, speaking, etc. may require an individual accommodation plan or specific services to ensure access to education and school sponsored activities. The Section 504 Guide is available on-line at the Department of Education at http://education.vermont.gov/new/pdfdoc/pgm_spned/laws/504_guide.pdf or upon request at Department of Education, 120 State Street, Montpelier, VT 05620-2501.

Transition from school to adulthood, age 16-adulthood

For the student with ASD, transition from high school to adult life happens best with early planning and the active participation of the student, family, and all involved providers. With an Individualized Education Plan (IEP) in school, services are required or mandated. After graduation or departure from high school, there are no guaranteed adult support services in Vermont. There are eligibility requirements and some services are prioritized for those with the most significant needs. As a result, the high school years are a critical time for developing talents, skills, tools and services necessary for “having a life”.

The transition plan within the IEP provides this roadmap, addressing four key areas: postsecondary education and training, community employment, independent living and community participation. There are many transition resources and sample IEP transition plans located on Vermont’s Secondary Transition Online Resource Center at <http://www.uvm.edu/~cdci/tripscy/?Page=TransHome.html&SM=goalssubmenu.html> . There are transition planning tools to assist with the plan design, such as MAPS (Making Action Plans), that are used as a resource by many high schools in Vermont. The Autism Society of America website (http://www.autism-society.org/site/PageServer?pagename=life_lifespan) offers helpful guidance, resources, and links for transition planning issues that are somewhat unique to ASD. For high schools in Vermont, the

student's first transition plan is to be done at age 16. Schools must provide reasonable and appropriate access to transition planning prior to graduation for special education students. Specific transition goals can then be addressed in the student's IEP as well as by the student, family or other providers. In some cases, the student and their team may consider continuing the high school experience up to age 22. The transition plan identifies the other agencies involved and the responsibilities they have in the transition planning process.

Young adulthood is a time of big changes in many areas of life. Change can be difficult for many individuals with ASD. One young adult described it as "the best of times and the worst of times." Some adults with ASD can navigate adult living with natural support from friends and family. Each individual's situation is unique. There are a range of possible adult services for adults with ASD available from a variety of agencies such as Vocational Rehabilitation, Developmental Services or Community Mental Health Agencies. These are described on the following pages.

An important guideline: Involve the young adult in the planning and decision making about his/her life. This may require a tailored approach, for example, allowing extra time and assistance to process and prepare responses. There are also peer self-advocacy groups growing throughout Vermont that give students and families support and connection with others who are thinking about similar issues. A list of self-advocacy groups is listed in the appendix.

Developmental Services, (some limited services for children under 18, more comprehensive services for adults)

Purpose of Service: To provide support to individuals with developmental disabilities to live, work and participate as citizens in their local communities.

Who is eligible: Person with a developmental disability defined as having 1) a diagnosis of mental retardation OR a pervasive developmental disorder including Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder and Pervasive Developmental Disorder, NOS AND 2) significant deficits in daily functioning AND 3) onset of the disability prior to age 18.

Types of services available: Under the Home and Community-based waiver funding mechanism, services include service coordination, employment support, home support, respite, clinical intervention and crisis support. Funding for these services is prioritized to those most in need based upon the Developmental Disability Services State System of Care Plan. These services are primarily available to adults. New waiver

funding for children under 18 is currently available to children in state custody or children at risk of admission to a psychiatric hospital or nursing home. Services are individually tailored depending on assessed needs. These services are provided by private developmental service agencies or can be self or family managed.

For children under 18 and adults, Developmental Services may provide crisis services, Flexible Family Funding, respite and referral. Crisis services are available 24 hours a day for anyone experiencing a crisis. Flexible Family Funding is money available to eligible families with a family member with a developmental disability living at home. An amount up to \$1,300 per year may be used at the discretion of the family towards goods or services that are in the person's/family's best interest. Respite is also available for up to 14 days a year at four respite homes around the state at no charge to the family. Developmental Services agencies can also direct people to other resources or supports available in their community.

Public guardianship is available for adults over 18 with developmental disabilities. Public guardians assist and empower people under guardianship in making decisions and taking actions in critical life areas. For information regarding obtaining a public guardian, go to <http://www.ddas.vermont.gov/ddas-units/units-opg/units-opg-default-page> or call 241-2663.

For more detailed information about Developmental Services, go to <http://www.ddas.vermont.gov/ddas-programs/programs-dds/programs-dds-default-page> .

How to apply for services: Contact the Designated Developmental Service Agency for the area where the person lives. For a list of Designated Agencies, go to <http://www.ddas.vermont.gov/ddas-programs/programs-dds/programs-dds-default-page> or see the attached list in the appendix.

Child, Adolescent and Family Mental Health Services, age 0-22

Purpose of the service: The mission of this system is to assure timely delivery of effective prevention, early intervention, and behavioral health treatment and supports through a family-centered system of care for all children and families in Vermont.

Who is eligible: a child or youth, ages birth to 22, who has diagnosed mental health disorder.

Types of services available: immediate crisis response, family support, prevention, screening, referral. Also, available on a statewide basis for those children with acute mental health needs are emergency placements, intensive residential services and inpatient hospital services. Some of the specific services available within these categories include assessment; group, individual or family therapy; intensive in-home or out-of-home community support; medication services; service coordination; skills training and social support; respite; family education; training; and consultation. These resources are limited and those children with the highest level of need are prioritized.

For more detailed information regarding Child, Adolescent and Family Mental Health Services, go to <http://www.healthvermont.gov/mh/programs/cafu/child-services.aspx> or call the Department of Mental Health at 1-800-464-4343, 1-802-652-2000 or TTY 1-800-253-0191.

How to apply for services: People apply for services at the Designated Community Mental Health Center in their area. See the attached list in the appendix or find the list online at <http://www.healthvermont.gov/mh/programs/how-to-apply.aspx> .

Adult Mental Health Services, age 18 and above

Purpose of service: To provide access to effective prevention, early intervention and mental health treatment and supports as needed for people to live, work, learn and participate fully in their communities.

Who is eligible: people with a wide range of emotional, behavioral and other mental health problems. Not all programs have the same eligibility criteria or services available. The intake coordinator works with people to agree on what their needs and strengths are, what services are available to them, and what they need to do to apply for services.

Types of services available: Depending upon the program they are eligible for, people may receive evaluation, individual, family or group therapy, medication prescription and monitoring, community supports, help in finding and keeping a job, help in finding and keeping a place to live, getting an education, education to help individuals understand their mental illness, help in getting life goals met, crisis services, social and recovery skills, consumer and family support programs, substance abuse services and hospitalization when needed.

How to apply for services: People apply for services at the Designated Community Mental Health Center in their area. See the attached list in the

appendix or find the list online at <http://www.healthvermont.gov/mh/programs/how-to-apply.aspx> .

For more information: go to <http://www.healthvermont.gov/mh/programs/adult/aboutadult.aspx> or call the Department of Mental Health at 1-800-464-4343, 1-802-652-2000 or TTY 1-800-253-0191.

Vocational Rehabilitation, transition age youth to adulthood

Purpose of service: “ VocRehabVermont” is a section of state government. Its job is to help people with disabilities to prepare themselves for work, find a job, or maintain current employment.

Eligibility: Any person in Vermont may be eligible who:

- Has a disability that is a barrier to working.
- Requires the services of VR to become or remain employed.

* For high school students with disabilities, VR is available to help with transition planning.

Types of services available: The basic vocational services are vocational counseling and guidance and help with job placement. A counselor assists with determining the specific services needed to reach each person’s employment goals. VR may provide financial assistance or help find additional resources.

Some of the services may include:

1. Transportation assistance such as bus/taxi fare or mileage reimbursement for job interviews, employment, training and school and, under specific circumstances, vehicle accommodations, repair, and/or vehicle purchase.
2. Occupational tools, licenses and equipment.
3. Vocational and post-secondary training costs such as tuition, fees, books, tools, equipment, etc.
4. Personal and family services such as interpreters, personal attendants, job coaches, childcare and assistive technology evaluations.
5. Health restoration including physical and mental health evaluations and prosthetic devices.
6. Rehabilitation technology such as home modifications, ramps, flashing clocks and doorbells.
7. Self-employment assistance such as feasibility studies, market research, business plans and start-up costs.

How to apply: Contact your local Vocational Rehabilitation office. Listings for local offices are available by phone or on the VR website.

Contact information: Call VR at 866-879-6757/ 802-241-2186 or TTY: 802-241-1455 or www.VocRehabVermont.org

The website also includes information about other special programs such as: benefits counseling, traumatic brain injury, deaf and hard of hearing, SSA Ticket to Work, and others.

Agency of Human Services

The Vermont Agency of Human Services provides other services in addition to those listed above. The range of services for individuals and families include accessing child care, child support, protection from child abuse, employment services, economic support for families in need and others. Information regarding what is available is located on the agency's website at <http://humanservices.vermont.gov/> or by calling 802-241-2244. This website includes a web-based tool called the Screen Door to help Vermonters find out what services might be available to meet their specific needs. Information and referral to specific services in Vermont can also be obtained by calling Vermont 211. Just dial 2-1-1 to speak to an information specialist. Information is also available at their website at www.vermont211.org

The Future

Much has been learned about autism spectrum disorders in the last fifteen years and research continues to advance our knowledge. Now, with appropriate treatment, many children with ASD grow to become active, participating members of their communities. People with ASD can learn to compensate for and cope with their differences, often quite well. While each individual is unique and it is hard to predict the future for an individual child, it may help to know that:

- Children with ASD are learning in regular education classrooms with and from their peers.
- Students with ASD continue their education beyond high school and some graduate from college.
- Adults with ASD, even those with significant challenges, are capable of holding jobs in the community.
- In Vermont, the vast majority of people with ASD live in home and community settings, not institutions.
- People with ASD receive assistance and support in the natural settings of daily life (at school, on the job and in their homes.)
- People with ASD are becoming self-advocates. Self-advocacy is well supported in Vermont, promoting opportunities for peer

support and having self-advocates voices heard in their personal lives and in the public arena.

- Increasingly, people with ASD are attending and/or speaking at conferences and workshops on autism.
- People with ASD are providing valuable insight in the challenges of this disability by publishing articles and books and by appearing on television specials about their lives and their disabilities.

In conclusion, as difficult as the diagnosis of autism can be for your family, remember that with proper resources, support and education, people with ASD can cope and prosper.

Where Can I Get More Information?

Vermont Resources

Division of Disability and Aging Services

103 S. Main Street
Waterbury, VT 05671
Clare McFadden, Autism Specialist
802-241-2863
clare.mcfadden@ahs.state.vt.us

Department of Education

120 State Street
Montpelier, VT 05620
Claire Bruno, Autism Consultant
802-828-5116
claire.bruno@state.vt.us

Children with Special Health Needs

John Zampieri State Office Building
108 Cherry Street
P.O. Box 70
Burlington, VT 05402
1-800-660-4427/ local #: 1-802-863-7338/ TDD: 1-802-863-7200
www.healthvermont.gov/family/cshn/clinic.aspx

Vermont Family Network

600 Blair Park Road, Suite 240
Williston, VT 05495
1-800-800-4005/ 1-800-639-7170/ 1-802-764-5290
www.vermontfamilynetwork.org

Vermont Federation of Families for Children’s Mental Health

95 S. Main St.

P.O. Box 507

Waterbury, VT 05676-0507

802-244-1955

1-800-639-6071 for families only

www.vffcmh.org

Vermont Autism Task Force Website

www.AutismTaskForce.com

National Resources

Autism Society of America

7910 Woodmont Ave., Suite 300

Bethesda, MD 20814-3067

1-800-328-8476/1-310-657-0881

www.autism-society.org

See list of additional websites in appendix.

Appendix

Support Groups for Parents of Children with ASD

Name	Area	Contact	Phone
AAWARE of Central VT	Washington County	Claudia I. Pringles, Esq. www.aaware.org	229-4665 info@aaware.org
Autism Support Daily	All counties of Vermont – online support. Meetings in Chittenden County. Recreational activities, grants, trainings & PCA database available.	Laurie Mumley	985-8773 Sign up at: www.autismsupportdaily.com
Parents Supporting Our Children	Bennington	Wendy Ballou	802-447-5716 asdbenningtonvt@gmail.com www.asdvt.org
Shadows of the Moon	Franklin	Cheryl Underwood Laura Weber	868-3658 849-2817 mlaweber@surfglobal.net
AAWARE of the Northeast Kingdom	Northeast Kingdom	Lauren Ware	533-2472 laware@gmail.com www.aaware.org/wst_page2.html
AAWARE in Lamoille Valley	Lamoille	Tina Karl Terry Holden	498-7464 Hourseinvt@vtlink.net 644-2759
Asperger's Association of New England-Southern VT chapter	Serving all of VT	Phelippa Marriner	775-5422 aanesouthernvt@yahoo.com www.aanesouthernvermont.org
Exceptional Parents Exceptional Children	Rutland County, but all are welcome	Heidi Corcoran Wener	345-5006 greeneyes71ish@yahoo.com
ARCH of the Upper Valley, Inc.	Upper Valley in VT & NH	Kirsten Murphy	649-2720 ARCH@valley.net Kirsten.murphy@valley.net

Personal Care Services Evaluators/Providers

Addison County

Community Associates (802) 388-4021
Addison County Home Health & Hospice (802) 388-7259

Bennington County

United Counseling Services (802) 442-5491
VNA & Hospice of Southwestern VT Health Care (802) 442-5502

Caledonia County

Northeast Kingdom Human Services (802) 748-3181
Caledonia Home Health Care & Hospice (802) 748-8116

Chittenden County

HowardCenter, Developmental Services (802) 488-6500
VNA of Chittenden & Grand Isle Counties (802) 658- 1900

Franklin County

Northwest Counseling & Support Services (802) 524-6561
Franklin County Home Health Agency (802) 527-7531

Lamoille County

Lamoille County Mental Health (802) 888-6627
Lamoille County Home Health Agency (802) 888-4651
Sterling Area Services (802) 888-7602

Orange County

Upper Valley Services (802) 728-4476
VNA/VNH (800) 575-5162

Orleans County

Northeast Kingdom Human Services (802) 748-3181
Orleans, Essex VNA & Hospice (802) 334-5213

Rutland County

Community Access Program (802) 775-0828
Rutland Area Visiting Nurse Association (802) 775-0568

Washington County

Washington County Mental Health (802) 479-2502
Central Vermont Home Health & Hospice (802) 223-1878

Windham and Windsor Counties

Health Care & Rehabilitation Services (802) 254-7500 ext. 1247
VNA/VNH (800) 575-5162

Please note,
local agencies
vary in their
availability to
provide PCS
assessments
and/or services

Statewide Professional Nurses Services

(800) 446-8773

Family, Infant and
Toddler Programs
(see next list in
appendix)

Autism Support
Daily- Maintains a
database of
potential Personal
Care Attendants
throughout Vermont,
accessible to
parents only. Join
the group at
www.AutismSupportDaily.com

Family, Infant and Toddler Host Agencies

ADDISON REGION

Sue Harding
Addison County Parent Child Center
Family, Infant & Toddler Program
Box 646
Middlebury, VT 05753
802-388-1437 or 1-800-639-1577
Fax: (802) 388-1590

BENNINGTON REGION

Kathy Riley
Southwest Vermont Medical Center
Family, Infant & Toddler Program
100 Hospital Drive East
Bennington, VT 05201
802-447-2768 or 1-800-750-6975
Fax: (802) 442-8331 - Attention box 29

CALEDONIA REGION

Bill Crenshaw
Northeast Kingdom Learning Services, Inc
3762 VT RT 5
Derby, VT 05829

Family, Infant & Toddler Program
NEKLS
364 Railroad St, Suite 2
St. Johnsbury, VT 05819
748-6609, 748-0213
1-800-299-6609, Fax: (802) 751-8071
General #748-5624
802-334-3030 - Bill

CHITTENDEN REGION

Julie Arel
Vermont Family Network
Family, Infant and Toddler Program
600 Blair Park Road, Suite 240
Williston, Vermont 05495
802-764-5294 FITP or 1-800-870-6758
Fax: (802) 876-6290

FRANKLIN/GRAND ISLE REGION

Elizabeth West
Family Center of Northwestern Vermont
Family, Infant and Toddler Program
27 Lower Newton Street
St. Albans, VT 05478
802-524-6574 or 1-800-427-6574
Fax: 802-524-1126

LAMOILLE REGION

Dave Connor

Lamoille Family Center
Family, Infant and Toddler Program
480 Cady's Falls Road
Morrisville, VT 05661-9222

802-888-5229 or 1-800-639-1932
Fax: (802) 888-5392

ORANGE/WINDSOR REGION

Elaine Guenet/Anne Marie Darsney
The Family Place
Family, Infant and Toddler Program
319 U.S. Rte 5 South
Norwich, VT 05055

802-649-3268 or 1-800-639-0039
Fax: (802) 649-3270

ORLEANS/ESSEX REGION

Eric Erwin
Orleans Essex North Supervisory Union
Family, Infant and Toddler Program
338 Highland Ave., Suite 1
Newport, VT 05855

802-334-3324 or 1-800-253-6621
Fax: (802) 334-2047

RUTLAND REGION

Nan Josephson
Rutland County Parent Child Center
Family, Infant and Toddler Program
61 Pleasant St.
Rutland, VT 05701

802-747-5039 or 1-800-974-2034
Fax: (802) 775-5473

WASHINGTON REGION

Lee Lauber
The Family Center of Washington County
32 College Street, Suite 100
Montpelier, VT 05602

Family, Infant and Toddler Program
383 Sherwood Dr
Montpelier, VT 05602
802-262-3292 or 1-800-270-4231
Fax: (802) 262-6071

WINDHAM REGION

Chloe Learey
Winston Prouty Center
20 Winston Prouty Way
Brattleboro, VT 05301

802-258-2414 or 1-800-281-7852
Fax: (802) 258-2413

WINDSOR SOUTH REGION

Betty Kinsman/Sherry Hatt
Springfield Area Parent Child Center
2 Main Street
North Springfield, VT 05150

802-886-5242 or 1-800-808-4442
Fax: (802) 886-2007

Self Advocacy Groups (for adults with developmental disabilities)

Group	Contact Person(s)	Contact Information	Locale
Advocates for Action	Donna Bennett Kate Berge-Charter	(802) 295-3032	Bellows Falls
Bennington Peer Support	Lisa Rudiakov Melanie Brunina	(802) 442-5491	Bennington
Burlington Self-Advocacy Club	Scott Brunelle Tracy Drake	(802) 652-2152	Burlington
Capitol City Advocacy Association (CCAA)	Robert Purdue Karen Noone	(802) 262-1236	Montpelier
Champlain Voices	Paul Nichols Priscilla Thomas	(802) 655-0511	Colchester
Connections of Peer Support (COPS) of White River Junction	Helen George Karen Daley Regan	(802) 886-1833	White River Junction
Friends Helping Friends	Margaret Pearlstein Kaili Goslant	(802) 479-2502	Barre
HEAT	Amanda Daniels Gina Brown	(802) 472-6581	
Getting Acquainted	Patti Mack	(802) 888-6627	Morrisville
Next Step of St. Albans	Jonathan Fitzgerald Syd Boyd	(802) 524-6561	St. Albans
Our Drop In Center	Roland Maurais Gail Rowe Francine Heywood	(802) 334-8378	Newport
Randolph Area Peer Support (RAPS)	Edwin Place Sue Gorman	(802) 728-4476	Randolph
Rutland High School	Maggie Rafter	(802) 770-1012	Rutland
Self-Advocates Becoming Empowered of Rutland	Patty Czarnecki Lisa Lynch	(802) 775-1370	Rutland
Self-Advocates Meeting (SAMS) of Springfield	Kerry Banks	(802) 886-1833	Springfield
Strong Advocate Voices & You (SAVY)	Laura Benton Rafael Rice	(802) 888-7602	Morrisville
Speak Up Addison County	Delsie Farnsworth Lindsey Hescocock	(802) 388-3381	Middlebury
Vermont Choices	Ryan Whipple Robin Burnash	(802) 748-3181	St. Johnsbury

Vermont Developmental Services Providers

(CCS) CHAMPLAIN COMMUNITY SERVICES, INC.

512 Troy Ave., Suite 1
Colchester, VT 05446
Phone: 655-0511 FAX: 655-5207

Exec. Director: Kelley Homiller
County: Chittenden

(CAP) COMMUNITY ACCESS PROGRAM OF RUTLAND COUNTY

PO Box 222, 1 Scale Avenue
Rutland, VT 05701
Phone: 775-0828 FAX: 747-7692

Director: Gerald Bernard
County: Rutland

(CA) COMMUNITY ASSOCIATES

61 Court Street
Middlebury, VT 05753
Phone: 388-4021 FAX: 388-1868

Director: Greg Mairs
County: Addison

(CDS) COMMUNITY DEVELOPMENTAL SERVICES

50 Granview Drive
Barre, VT 05641
Phone: 479-2502 FAX: 479-4056

Director: Juliet Martin
County: Washington

(FF) FAMILIES FIRST

PO Box 939, Wilmington, VT 05363
Phone: 464-9633 FAX: 464-3173

Director: Julie Cunningham
Counties: Windham and Bennington

(HCRS) HEALTH CARE AND REHABILITATION SERVICES OF SOUTHEASTERN VT

49 School Street, Hartford, VT 05047
Phone: 295-3031 FAX: 295-0820

Director: Josh Compton
Counties: Windsor and Windham

Regional Offices:

51 Fairview Street, Brattleboro, VT 05301
Phone: 257-5537 FAX: 257-5769

390 River Street, Springfield, VT 05156
Phone: 886-4565 FAX: 886-4580

One Hospital Court, Suite 410,
Bellows Falls, VT 05101
Phone: 463-3947 FAX: 463-3961

14 River Street, Windsor, VT 05089
Phone: 674-2539 FAX: 674-5419

(HCS) HOWARDCENTER, INC.

102 South Winooski Ave.
Burlington, VT 05401-3832
Phone: 488-6500 FAX: 860-2360

Director: Marie Zura
County: Chittenden

(LCMH) LAMOILLE COUNTY MENTAL HEALTH SERVICES, INC.

275 Brooklyn Street
Morrisville, VT 05661
Phone: 888-6627 FAX: 888-6393

Director: Jackie Rogers
County: Lamoille

(LSI) LINCOLN STREET INCORPORATED

374 River Street
Springfield, VT 05156
Phone: 886-1833 FAX: 886-1835

Executive Director: Cheryl Thrall
County: Windsor

(NCSS) NORTHWESTERN COUNSELING AND SUPPORT SERVICES, INC.

107 Fisher Pond Road
St. Albans, VT 05478
Phone 524-6561 FAX: 527-8161
375 Lake Street, St. Albans, VT 05478
Phone: 524-0574 FAX: 524-0578

Director: Jean Danis
Counties: Franklin and Grand Isle

(NKHS) NORTHEAST KINGDOM HUMAN SERVICES, INC.

PO Box 724, 154 Duchess Street
Newport, VT 05855
Phone: 334-7310 FAX: 334-7455
Regional Office:
PO Box 368, 2225 Portland Street
St. Johnsbury, VT 05819
Phone: 748-3181 FAX: 748-0704

Director: Dixie McFarland
Counties: Caledonia, Orleans and Essex

(SCC) SPECIALIZED COMMUNITY CARE

PO Box 578, 3627 RT 7 South
East Middlebury, VT 05740
Phone: 388-6388 FAX: 388-6704

Executive Director: Ray Hathaway
Counties: Addison and Rutland

(SAS) STERLING AREA SERVICES, INC.

109 Professional Drive
Morrisville, VT 05661
Phone: 888-7602 FAX: 888-1182

Executive Director: Kevin O'Riordan
County: Lamoille and Washington

(T-II) TRANSITION II, INC.

346 Shelburne Road
Burlington, VT 05401
Phone: 846-7007 FAX: 846-7282

Executive Director: Kara Artus
County: Statewide

(UCS) UNITED COUNSELING SERVICES, INC.

PO Box 588, 100 Ledge Hill Drive
Bennington, VT 05201
Phone: 442-5491 FAX: 442-3363

Director: Kathy Hamilton
County: Bennington

(UVS) UPPER VALLEY SERVICES, INC.

267 Waits River Road
Bradford, VT 05033
Phone: 222-9235 FAX: 222-5864

Executive Director: William Ashe
Counties: Orange and Washington

Regional Offices:

12 Prince Street, Randolph, VT 05060
Phone: 728-4476 FAX: 728-6741

PO Box 719, Moretown, VT 05660
Phone: 496-7830 FAX: 496-7833

Children and Adult Mental Health Service Providers

If you need help right now, go to the [Crisis Numbers page](#).

Clara Martin Center

11 Main Street, Box G
Randolph, VT 05060
Phone: (802) 728-4466
FAX: (802) 728-4197

Route 5, Box 278
Bradford, Vermont 05033
Phone: (802) 222-4477 FAX: (802) 222-3242
24-Hour Emergency: 1-800-639-6360

Counseling Service of Addison County

<http://www.csac-vt.org/main.html>

89 Main Street
Middlebury, VT 05753
Phone: (802) 388-6751
FAX: (802) 388-3108

Health Care and Rehabilitation Services of Southeastern Vermont

<http://www.hcrs.org/>

390 River Street
Springfield, VT 05156
Phone: (802) 886-4500

HowardCenter for Human Services

<http://www.howardcenter.org/>

208 Flynn Ave., Ste 3J
Burlington, VT 05401
Phone: (802) 488-6000 /TTY: (802) 488-6001
FAX: (802) 488-6901

Lamoille County Mental Health

275 Brooklyn street
Morrisville, VT 05662
Phone: (802) 888-4635
FAX: (802) 888-5916

Northeastern Family Institute (children's only)

30 Airport Road
South Burlington, VT 05403
(802)658-3924

Northeast Kingdom Human Services

<http://www.nkhs.net/>

PO Box 724
154 Duchess Street
Newport, VT 05855-0724
Phone: (802) 334-6744
FAX: (802) 334-7455

P. O. Box 368
2225 Portland St.
St. Johnsbury, VT 05819
Phone: (802) 748-3181
FAX: (802) 748-0704

Northwestern Counseling and Support Services

<http://www.ncssinc.org/>

107 Fisher Pond Road
St. Albans, VT 05478
Phone: (802) 524-6554
FAX: (802) 527-7801 (General)
FAX: (802) 524-3894 (Confidential)

Rutland Mental Health Services, Inc.

<http://www.rmhsccn.org/>

PO Box 222
Rutland, VT 05701
Phone: (802) 775-2381
FAX: (802) 775-3307

United Counseling Service, Inc.

<http://www.ucsvt.org/>

1 Ledge Hill Drive
PO Box 588
Bennington, VT 05201
Phone: (802) 442-5491
FAX: (802) 442-3363

Washington County Mental Health Services, Inc.

<http://www.wcmhs.org/>

PO Box 647
Montpelier, VT 05601-0647
Phone: (802) 229-0591
FAX: (802) 223-8623

Autism Spectrum Disorders Websites

www.autism-society.org

Autism Society of America

Information regarding: overview of autism, diagnosis, treatment options, education, guidance about making intervention/treatment decisions, ASA advocacy efforts, newsletter, latest news on autism issues, local chapters of ASA, resources, state-by-state local resources.

www.aane.org

Asperger's Association of New England

General information regarding Asperger's Syndrome, resources, books, support and social groups, upcoming trainings and events, local chapters, articles, newsletter, legislative advocacy, adult services and programs.

www.AutismSupportDaily.com

Autism Support Daily

Vermont family support organization providing online message board for parents and professionals, live support group meetings, family oriented recreational activities, financial assistance and information.

www.asatonline.org

The Association for Science in Autism Treatment (ASAT)

General info about autism, description of treatment options and evidence base to support them, info about scientific approach to evaluating treatment, suggested readings.

www.researchautism.org

Organization for Autism Research (OAR)

Raises funds for applied research in autism. Describes studies funded, research grant opportunities, general info about autism, diagnosis, intervention, family support, *A Parent's Guide to Research*, advice for educators, Aspergers' info, forums, suggested readings, links to other websites, events, newsletter, conferences.

<http://info.med.yale.edu/chldstdy/autism/index.html>

Yale Developmental Disabilities Clinic

Info about the clinic, research studies, general info about autism and Asperger's, *Guidelines for Assessment, Diagnosis, Treatment & Intervention in Asperger's*, Resources, books.

www.larsperner.com/autism/colleges.htm

Lists colleges that have supports available for individual on the autism spectrum and a description of the available supports.

www.autcom.org

Autism National Committee

Autism advocacy group dedicated to social justice for all citizens with autism. Position statements, advocacy, newsletter, links to other websites, articles, commentary by people with autism, interventions, discussions of various supports, etc.

www.maapservices.org

More advanced individuals with Autism, Asperger's syndrome and Pervasive developmental disorder. Information and advice about autism, Asperger's and related developmental disorders, newsletter, articles, state resources, links to research.

www.autismweb.com

A parent's guide to the diagnosis, treatment and education of children with autism, Pervasive Developmental Disorder and related disorders. Includes information about definitions of diagnoses, warning signs, education, diet, recommended readings, news, conferences and how to find resources within local communities.

www.iidc.indiana.edu/irca/

Indiana Resource Center for Autism

Information about autism spectrum disorders, publications available for purchase, database of articles, book chapters, videos, etc, newsletter, research conducted by the center, Indiana resources. Good example of a state autism resource center.

www.cdc.gov/ncbddd/autism/index.htm

Autism Information Center at National Centers on Birth Defects and Developmental Disabilities.

Information about prevalence of autism spectrum disorders, symptoms, causes, treatment, vaccines and ASD, research efforts of Center for Disease control, resources for parents and researchers.

www.autismspeaks.org

Autism Speaks

Organization to fund autism research, increase awareness and legislative advocacy. Information about autism, legislative activities, public awareness campaign, autism in the news, resources, etc.

www.nectac.org/topics/autism/autism.asp

National Early Childhood Technical Assistance Center

Resources for young children with ASD, including state guidelines for early intervention for young children with ASD, projects for personnel training, research, links to other resources.

<http://nichcy.org>

National Dissemination Center for Children with Disabilities

General information about ASD, resources to assist with understanding research, links to many other useful websites, resources, research, helpful organizations, resources about education of students with ASD, books.

www.jkp.com

Jessica Kingsley Publishers

Offers of long list of books related to autism for families and teachers.

www.asperger.net/index.htm

Autism Asperger Publishing Company

A wide range of material on ASD. Lists of books available to purchase from their bookstore, events, links, resources and newsletter.

www.fhautism.com

Future Horizons

Publishers of many books on ASD. Books available to purchase, conferences, info on ASD, newsletter links to other websites.

www.nap.edu/catalog/10017.html

National Academy Press

Educating Children with Autism. This book is available to read for free online or can be ordered at this website. This book, put out by the National Research Council in 2001 examines the research underlying educational practices, programs and strategies for children with ASD birth to 8 years old. Identifies recommendations for early intervention for young children with ASD.

www.pecs.com

Picture Exchange Communication Systems, Pyramid Educational Consultants. Information about PECS, training workshops, products, etc.

www.teacch.com

Division TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children).

Information about autism, guide to services in North Carolina, review of TEACCH model, training resources, publications, research, TEACCH materials, etc.

www.thegraycenter.org

The Gray Center for Social Learning and Understanding

Information and resources about Carol Gray's Social Stories, information about ASD, books and resources, articles, workshops and conferences.

www.tonyattwood.com.au

Website of Tony Attwood, Asperger's Syndrome expert

Books and articles by Tony Attwood, presentation schedule.

www.rdiconnect.com

Relationship Development Intervention website.

Description of RDI program, training workshops, online store for RDI products, newsletter, research foundation, research summaries.

www.floortime.org

The Floortime Foundation.

Information and resources about Developmental, Individual Difference, Relationship-based Therapy (DIR/Floortime) intervention model developed by Stanley Greenspan and Serena Wieder. Information for parents and professionals, conferences, local DIR clinicians, etc.

www.scerts.com

SCERTS (Social-Communication, Emotional Regulation and Transactional Supports) intervention model.

Overview of SCERTS model developed by Barry Prizant and others. Resources, research articles.

www.education.ucsb.edu/autism

University of California Santa Barbara Koegel Autism Center

Information about Pivotal Response Training developed by Lynn and Robert Koegel. Training manuals, books, conferences, workshops, research, grants.

www.lovaas.com

Lovaas Institute

Information about the Lovaas model of intervention, services available, books, research articles, links, local clinics, training and consultation.

www.card.ufl.edu/visual.htm

Center for Autism and Related Disorders, University of Florida

Resources for developing visual supports, such as picture schedules, choice boards, etc.

<http://www.gwu.edu/~iri/pdf/32-nd-IRI-2007-Final-03-09-2007.pdf>

Institute on Rehabilitation Issues

Rehabilitation of Individuals with Autism Spectrum Disorders. A guide for assisting individuals through the transition process from school to adult living. Includes guidance on supporting people in college and in becoming employed.