



## A Holistic Transition Guide for Families of Children with Disabilities

# Introduction

Most families begin to think of their children's transition to adulthood when they are in their teens. For families with children with disabilities, making plans for the future is an ongoing process from the moment of diagnosis. This guide was created by parents, for parents, family members, and caregivers of children with disabilities of any pre-transition age. In the following pages, we hope you will find useful information and advice to ease your mind and help you set your child on the path to a smooth transition to adulthood. Remember that you are not alone in this process. Vermont Family Network is here to help!

Vermont Family Network (VFN) promotes better health, education, and well-being for all children and families, with a focus on children and young adults with special needs.

Our office is located at 600 Blair Park Road, Suite 240 in Williston, Vermont and we are open Monday through Friday from 9:00 am until 4:30 pm. For more information about our programs and services, please contact us at (802) 876-5315 or 1-800-800-4005.

This Guide was funded in part by grants from the Vermont Department of Health – Children with Special Health Needs and the Vermont Developmental Disabilities Council.

## ABOUT THE AUTHORS

**Jan Hancock** is the parent of four grown sons, the youngest of whom was adopted at age 2 and has had some mental health challenges. She taught in adult education programs in several states and in a public elementary school in the years prior to moving to Vermont. Hired by Parent to Parent of Vermont in 2002 (and later VFN), Jan enjoys connecting parents with each other and with future professionals in education and healthcare.

**Claudia Inés Pringles** is a parent of two children, including a daughter on the autism spectrum. Claudia is also an attorney in private practice with a focus area of special needs planning. She enjoys systems advocacy in her spare time.

**Ellen Vaut** is a Family Consultant at VFN, specializing in transition and mental health issues. She connects families with resources and occasionally supports them at meetings. Ellen sits on several teams concerning children's mental health and family welfare in Chittenden County. She is the parent of two adult children, one of whom has a developmental disability and a mental illness. She wishes she had had all this information when her child was younger.



# Contents

1	<b>Home &amp; Community Life</b> .....	3
2	<b>Education</b> .....	7
3	<b>Health</b> .....	11
4	<b>Employment &amp; Income</b> .....	15
5	<b>Adult Services for People with a Developmental Disability</b> .....	18
6	<b>Planning for the Future</b> .....	21
7	<b>Final Thoughts</b> .....	24
8	<b>Resources</b> .....	25





## Home & Community Life

In Vermont, we value full inclusion for all people, regardless of disability. Whether your young person lives at home or in another residential setting, he/she most likely wants to have friends and participate in community life.

As parents, we want these things for our children but we probably worry more than most about issues of safety and vulnerability. Like all parents, we want our children to make safe and responsible choices. They will be the most successful doing so if they are given the appropriate information, training and tools.

In this section, you will find information on ways your young adult can access and participate in his/her community. We include tips on how to prepare your child for more responsibility and independence in the home and community, from taking the bus to making friends. It is our belief that, no matter the challenges they may have, all people should have opportunities to be active members of their community.

### Recreation

Staying active, as much as possible, is not only healthy but also provides a good way to foster social interactions. Check with your local recreation department or YMCA to see what programs they offer that might be appropriate and enjoyable for your young person. Vermont is home to a number of organizations that specialize in recreational and social opportunities for people with disabilities, including horseback riding, skiing, and camps that offer sessions for adults. For a comprehensive list of recreation options in Vermont, visit the recreation pages of the Vermont Family Network website ([www.vermontfamilynetwork.org](http://www.vermontfamilynetwork.org).) Activities are frequently posted on our listserv. You can join on the website by clicking *Stay connected – Become Involved under Family Network*.



## Friendship

Once your child leaves school, the peer group he/she has become accustomed to will likely disperse. Finding, making and keeping new friends can be a challenge, but having opportunities for a satisfying social life is very important. Some organizations for people with disabilities offer ways to socialize – for example, Special Olympics, Partners in Adventure, Green Mountain Self-Advocates, and other local self-advocacy groups. Adult service agencies may also include activities, classes and resources that provide ways for people with disabilities to come together. As much as possible, encourage participation in the general community. Taking a class in a community education, arts or recreation program or having a job might also open some doors to creating new friendships.

Of major concern to us, as parents, is the vulnerability of certain of our young adults. We worry that our children could fall prey to opportunists who may take advantage of them financially, sexually or in other ways. This is particularly important if your young adult is more independent. The drive to be accepted and have friends can compromise a young person's better judgment. You can help by steering your young adult toward appropriate venues for potential friends, with the understanding that your child will want to make his/her own decisions about whom to accept as a friend, just as we all do. Again, the best strategy is to help your child understand the potential pitfalls of hanging out with others who may be involved in unsafe or illegal activities such as drugs, graffiti, shoplifting, vandalism, etc. Keeping busy with positive activities (e.g., sports and recreation, classes, self-advocacy groups) is one way for your young adult to meet peers and make new friends.



## Self-advocacy

Many of the accommodations for people with disabilities that we take for granted resulted from hard work and advocacy not so long ago. As they leave our homes and schools and go out into the world, our young adults' ability to advocate for their wants and needs becomes especially critical. Learning to become a good self-advocate is a life-long process, so it is never too early to start helping your child develop the skills he/she will need to get necessary services and accommodations. Consider including self-advocacy skills as a goal in your child's Individualized Education Plan (IEP). When your child reaches transition age (16), try to connect him/her to a local self-advocacy group. Contact the Green Mountain Self-Advocates (GMSA) for more information and a list of self-advocacy groups.

## Safety

Our young adults will have differing abilities to access the community. Some may always be in the company of another adult while others may be able to move about independently. Whatever your child's level of independence, you can help him/her learn to make safe choices by practicing strategies through role-play, social stories, and watching and discussing TV shows or movies. Be open and honest with your child about your concerns, ask questions and be willing to listen to his/her point of view. One way to allay fears and concerns about safety is to create a safety plan.

### TIPS FOR SAFETY:

- Keep up with your child's interests, what he/she likes to do and preferred places to go
- Develop a set of clear expectations for your young person so he/she knows when to come home. Remember to check the bus schedules for last bus times
- Consider having a contingency fund for a taxi
- Discuss places that are appropriate to go and places to avoid
- Help your young person create a "going out" checklist: remember key, make sure cell phone is charged, take wallet, leave names and phone numbers of people you will be with, etc
- Go over what to do in an emergency
- Agree on a phone check-in time
- Have a backup person to call should you be unavailable
- Review the importance of making good choices and staying safe

## Independent living skills

Many of us worry about how our adult children will live if we are no longer able to provide a home for them. Some of our young people will have independent living goals in their transition plans. Regardless of their level of independence in the future, our children should learn to care for themselves to the best of their ability. Whether that means working on toileting skills or learning to do the laundry, kids with disabilities should be given the opportunity to take responsibility for self-care.

If your child receives some life skills instruction at school, make sure that the instruction conforms to your way of doing things. In other words, if teaching use of a washing machine, let the school know what kind of machine is used in the home. Consult with the life skills instructors about toileting and other hygiene issues so that the instructional approach can be consistent across settings. We all do best when we know what is expected.

## Housing options

Housing for our young adults is a major concern for us. As we age, we are less able to care for them in our homes. That issue aside, young adults with disabilities should have the same opportunities to experience other living options as their siblings and friends. The reality is that our young folks will probably need accommodations and supports, which can limit choice.

Some housing models found around the state include:

**Shared Living:** Living with a family or sharing an apartment with a paid roommate along with varying degrees of support and supervision depending on need.

**Supported Living:** Independent living with minimal supervision for adults for whom few supports are needed.

**Group Homes:** In Vermont, when more than two individuals with disabilities live together and receive care, it is called a group home and must be licensed. There are very few around the state and they are often specialized for particular needs.

### Some new initiatives include:

**Neighborhood Model:** Adults live in their own apartments but in proximity to other adults with disabilities in order to share support and resources;

**Transitional Model:** Adults transitioning from their homes can learn independent living skills in preparation for a more independent housing situation.

For comprehensive information about housing options for your child in your area, please contact your local Designated Agency.



## Transportation

Does your child know how to take the bus? Is there a possibility that he/she might become a driver? What are the transportation options for people who can do neither of the above?

**Local Bus:** Your child may be eligible for a Medicaid bus pass. This pass is intended for getting to and from a medical appointment or when picking up a prescription. You can also purchase a general pass for your child through your local transportation agency.

Depending on where you live, there may be para/transit services available to people who cannot use the regular bus system because of a disability. For example, in Chittenden County, the SSTA provides pre-arranged transportation on an accessible bus at a cost per ride. Call 2-1-1 to locate services near you.

Busses can be very user-friendly for people with mobility issues. All transit busses in Vermont are accessible, with special space to accommodate wheelchairs. Drivers are trained to help with getting on and off the bus.

**Driver's Ed:** The New and Potential Driver Program (Fletcher Allen and UVM) can evaluate your young person and design a training program specific to his/ her needs. They can also suggest adaptive equipment and automobile modifications.

## TIPS FOR TRANSPORTATION:

- Learning to use transportation or to drive can be an important goal in your son or daughter's transition plan.
- If it is unlikely your child will be able to drive, it is a good idea to help him/her come to terms with this eventuality before his/her friends are signing up for driver's ed.
- **Long Distance Travel:** If your child will be traveling on a long-distance bus, train or airplane, make plans well in advance for a safe and trouble-free journey. Call the bus, train or airline company to find out about accommodations they offer to travelers with disabilities. Even if you are accompanying your child, accessibility may be a concern for a person in a wheelchair or using a walker. Always have your child carry identification and contact information and make a contingency plan in case you are separated.
- **Bus:** Greyhound has accommodations for people with disabilities if given proper notice (at least 48 hours). Accessible seating and assistance getting on and off the bus are available. Transportation personnel are not allowed to provide personal care assistance, but Greyhound offers a discount for a personal care assistant traveling with a minor if the minor pays full fare. Check with Greyhound or the bus company you plan to use about other services for customers with special needs.
- **Train:** Amtrak offers several services for people with disabilities but you must book your trip early by phone or in person. Your child may qualify for a discount if you can provide documentation of the disability. Anyone traveling with the child as a personal care attendant may also qualify for a discount. Accessible space can be booked ahead of time, even on open seating trains. You can also request assistance boarding and disembarking. Please allow plenty of time before departure to negotiate the station. As always, let the train personnel know your child's needs well in advance in order to have a safe and comfortable trip.
- **Air Travel:** Travel by air may present challenges for people with some disabilities, in particular mobility issues. If your child uses a walker or wheelchair, you will need to consider accessibility of the airplane. Boarding and de-planing may require special equipment if the plane is parked on the tarmac away from jet ways. While larger planes are equipped with accessible lavatories, smaller or older planes may not be. Check your airline's website for more information about accessibility.

## TIPS FOR TRAVEL FROM EXPERIENCED PARENTS:

- Prepare your child in advance for the hustle and bustle of the airport. If your child has a problem with noise, consider earphones.
- Check ahead with your airline to learn about accommodations for travelers with disabilities. You may be able to bypass lines.
- Alert Transportation Security Administration (TSA) and flight personnel to any problems, such as communication problems, your young person may have during screening. Check their website for more tips.
- Take extra meds and snacks in case your flight is delayed or canceled. Pack meds, insurance information and extra clothing in your carry on.
- Create an ID and medical information sheet for your child in case you become separated. Put ID information on any equipment that your child uses, such as a walker or wheelchair.
- Take advantage of the invitation for early boarding.
- If traveling for medical reasons, reimbursement for meals, lodging and mileage is possible. This must be arranged ahead of time.

If your child is traveling alone, you may be able to hire an airline escort for gate transfers. Each airline has its own policies, restrictions and fees for escorts so be sure to check around. Paying a bit more for peace of mind is worth it. In any case, be sure your child has all the identification and contact information he/she will need as well as a plan for what to do if flights are delayed or cancelled.





# Education

Aside from home, school is probably the most important environment in a child's life. Most children spend part of their day in some sort of educational setting. As the parent of a child with a disability, you will no doubt become very familiar with your child's educational team and may find yourself in the position of advocating for services. This chapter will offer information, recommendations, and tips on how to help ensure a successful school experience for your child.

## Educational support team

Extra supports are available to any student who is struggling academically. The Educational Support Team (EST) is comprised of teachers who work with a child. The team may recommend an evaluation in areas of weakness that could lead to a higher level of support.

## Section 504

Students with disabilities who are eligible for accommodations under Section 504 must have equal access to all academic and non-academic activities and programs available to other students at a school.

To qualify for a 504 plan, a student must have a physical or mental disability that substantially limits one or more major life activities. Major life activities include self-care, walking, seeing, hearing, speaking, breathing, learning, working or performing a manual activity.

### Support services include:

- Specialized software
- Modified attendance policies
- Behavior supports
- One-on-one assistance
- Counseling services
- Occupational therapy or physical therapy services

## Special education

Special education is specially designed instruction, provided at no cost to parents to meet a child's individual needs for children ages 3 through 21. Children ages 3 to 5 may participate in Essential Early Education (EEE). Children under three may qualify for supports and services through Children's Integrated Services/Early Intervention (CIS/EI). This is not part of special education.

### The special education process includes:

**Referral and evaluation:** You may request a comprehensive special education evaluation if you have concerns about your child's learning. If the school agrees, you will be invited to an Evaluation Planning Team (EPT) meeting. This is the time and place to pose any questions you have about your child's abilities. The questions the team generates will guide the kinds of evaluations that are conducted.

If you are dissatisfied with the school's evaluation, you may also request an independent special education evaluation at no cost to you.

**Eligibility:** The EPT (which includes you) meets to review the findings of the evaluation and to determine eligibility. Your child must meet three criteria, or "gates," to qualify for an Individualized Education Program:

- Your child has a disability;
- The disability results in an adverse effect on learning;
- Your child requires specialized instruction.

**Individualized Education Program (IEP):** The IEP contains annual goals, short-term measurable benchmarks, delivery of services, related services and accommodations. It also indicates where your child will receive the services and the frequency.

## Who writes the IEP?

If your child is found eligible for special education, the information gathered from the evaluation will guide the development of the IEP. One person on the team, usually the special educator, will develop an IEP that contains information about the child, goals, accommodations, service levels, related services, transition goals when appropriate, and whether he/she will participate in state-level assessments. Your child may also have a medical, behavior or crisis plan as part of his/her IEP. The final step in developing an IEP is placement. Each of these areas is explained below.

**Narrative:** An IEP will begin with a narrative about the child, including a description of both academic and functional

performance levels. Information is taken from evaluations, school reports and parent observations. You should feel free to contribute information about home life if it would be helpful to the team to better understand your child (i.e., a family life event that may affect a child). Alternatively, you can ask to have removed any information you feel to be incorrect or irrelevant.

**Goals:** Annual goals are broken down into objectives with benchmarks to measure progress over the year. Goals should be written in a concrete and measurable manner. Be sure you understand how the goals are relevant to your child, how the team will measure progress towards the goals (i.e., testing, observation, work sampling, and how often you will receive a progress report. Because a child's needs may change over time, an IEP should be considered a fluid document that can be changed at any time, within the IEP process.

**Services Page:** The IEP contains a page that lists the services provided to your child, for example, specialized instruction such as one-on-one instruction in an academic area. Related services include social skills instruction, physical therapy, etc. The frequency, duration and location of the service as well as the provider and method of delivery (1:1, small group, etc.) are also listed.

**Accommodations:** Examples include Assistive technology, preferential seating, access to an elevator, extra time on tests or in transitioning between classes. Your child may require a modified school day or a special area to eat lunch.

**State-Level Assessments:** The team will decide whether your child will participate in state-level assessments.

**Placement:** The last thing the team determines is the educational placement of your child. This includes a percentage of time the child will be in the classroom with typical peers. Your school is required to provide a free appropriate public education (FAPE) in the least restrictive environment (LRE) that is appropriate to an individual student's needs. "Least restrictive environment" means that your child with a disability should have the opportunity to be educated with non-disabled peers, to the greatest extent appropriate. This means that your child's school will attempt to provide the services and accommodations in your child's IEP within the school before considering an alternative placement.

Schools and parents often disagree over inclusion issues. You may feel that your child does not spend enough time with typical peers or, alternatively, that the time in the classroom is less productive than it would be in a more restrictive environment (i.e., an alternative placement). Try to work with your team to find the most appropriate placement for your child. You may have to advocate for more or fewer restrictions.

## Requesting a change to the IEP

Be clear about your concerns and put all requests, including any request for change, in writing. If the school disagrees with your request, you should receive a formal denial with an explanation. You may choose to request mediation that is available at no cost to you. In some cases, you may choose to proceed directly to due process, which may involve legal fees if you retain an attorney.

## What else can go in an IEP?

- Extended School Year (ESY) are programs for students who may experience regression in skills over the summer.
- Social skills for children who have difficulty developing relationships with their peers.
- Medical plan
- Transition plan by age 16 (see below)
- Behavior Plan (if needed)

If your child needs extra support around self-regulation, you can request that the school perform a *Functional Behavioral Assessment* (FBA) that tracks behavior patterns in order to propose alternatives to disruptive behavior. For relatively minor behavior issues, teachers and school social workers may be able to determine the cause, or function, of problem behaviors through observation. Where and what time of day do the behaviors occur? For a more severe behavioral disorder, the school should consult with a trained professional, such as a Board Certified Behavioral Analyst (BCBA), to conduct a more in-depth analysis of the cause of the behavior. A good behavior plan helps the student learn acceptable alternatives to problem behaviors. All staff that work with your child should be familiar with the behavior plan. As the parent, you can request any special training that can help you maintain consistency with the behavior plan in the home.

## Multi-year plan

If your child is unlikely to graduate on the usual timeline – after four years of high school or at age 18 – you may request a Multi-Year Plan when your child turns 14. The Multi-year Plan allows your child to attend school up to age 22 to complete the requirements for graduation.

## Transition plan

Every student on an IEP must have a transition plan as part of the first IEP by the student's 16th birthday. (*See Transition Timeline on page 10.*) A transition plan is a set of activities and goals tailored to the student for the purpose of preparing the student for adulthood. It is important to start early on transition planning, even if a student will stay in school until age 22. The goals can always be changed to reflect the changing interests and abilities of the student.

### Transition plans contain goals in the following areas:

- Post-secondary education
- Vocational training
- Employment, including supported employment
- Adult services
- Community participation
- Independent living skills, where applicable

Make sure your child's transition goals are realistic and relevant to his/her interests and ability. The danger lies in setting the bar too low for any student with a disability, and especially those with significant challenges. Everyone has the capacity to learn and should be given enrichment opportunities throughout their lifespan, not just in school.

A good place to begin planning for transition is through the MAPS process.

MAPS, or Making Action Plans, is a person-centered approach in which the plans for the future are guided by the student's hopes and dreams, preferences, interests, and needs. Family, friends and anyone with knowledge of the young person can participate. COACH is another good assessment tool for young people with significant challenges. Be sure to ask the team to explain what assessments are used to determine your child's transition goals.

## Parent role in special education

Parents are members of the IEP team and must be notified and invited in writing to all IEP meetings. You should be offered a copy of your Parental Rights at each IEP meeting. IEPs are reviewed yearly and the child is reevaluated a minimum of every three years. School teams often meet more frequently than once a year to review a child's progress. You may wish to arrange a regular meeting time with the team. Remember that you are the expert on your child and have a lot of wisdom to contribute. You have a right to be at the table and, when appropriate, your child can be there too.

## TIPS FOR PREPARING FOR TRANSITION TO ADULTHOOD:

- Make sure your child’s voice is heard, even if you have to interpret. No one should be making plans for your child without his/her input.
- Do not assume there are no post-secondary programs available to your child. Most colleges in Vermont offer support services or special programs to students with disabilities. There are also numerous continuing education programs and community classes, such as cooking, photography and yoga.
- Vocational interests and strengths should be evaluated through various assessment tools.
- Build in ways for your child to continue peer interaction after leaving school. After graduation, many young adults with disabilities lose their social network.
- Look for ways your child can connect with the community through volunteering, sports or recreational programs.
- Start teaching your child independent living skills at a young age: learning about safety, doing chores, learning about nutrition, money, etc.
- Some schools have access to model apartments where students can practice independent living skills, e.g., Montpelier, Addison County.

## How can parents be effective advocates?

When your child has a disability and is on a 504 Plan or an IEP, you will no doubt spend more time at school than parents of other children. Whether you find your school welcoming or intimidating, it is very important for you to be an active member of your child’s team. Schools may be the experts in education, but you are the expert on your child. The information you contribute will help the team determine the best way to provide your child with a successful school experience.

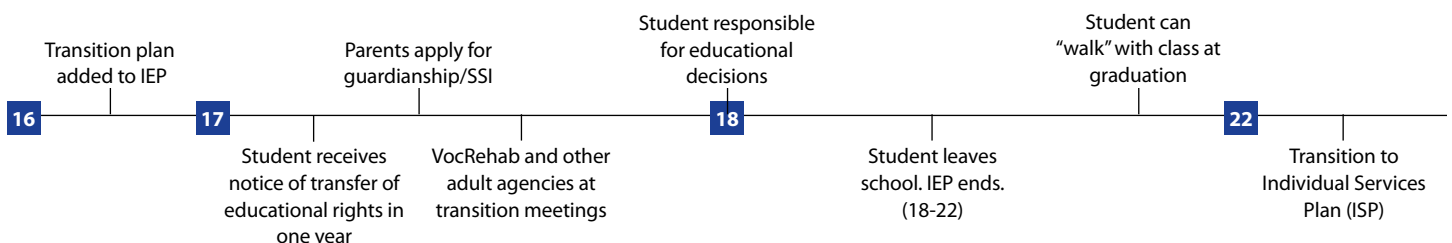
### TIPS TO HELP ENSURE AN EFFECTIVE MEETING:

- Familiarize yourself with your parental rights
- Understand your child’s IEP or 504 Plan
- Be sure you know the purpose of the meeting (Evaluation and Planning Team meeting? IEP meeting? Regular team meeting?)
- Make a list of points you wish to make
- Ask to have discussion points added to the agenda
- Talking about a child’s disability and requesting the services needed for an appropriate education can be emotionally draining if you do not feel heard. It can be helpful to take someone – a friend, relative or support person – with you to the meeting who can be another set of eyes and ears.
- Many problems stem from poor communication between school and home. You can improve your relationship with your child’s team by practicing these useful communication techniques:
  - Use good eye contact with speakers
  - Listen to speakers actively
  - Try not to interrupt
  - Use “I” statements to describe your feelings: “I worry that my child is not making more progress.”
  - Ask for clarification
  - Disagree respectfully

Transition plans are not provided under Section 504. Parents should work with the 504 coordinator and team to plan for the student’s future needs. 504 Plans remain in place after graduation, so a person on a 504 Plan may request accommodations for a disability at college or in the workplace. Complaints of discrimination under Section 504 can be directed to the Office of Civil Rights in Boston. (See *Resources*, page 25)

If you practice good communication skills, the team should follow suit. It is certainly worth a try.

### TRANSITION TIMELINE IN EDUCATION



\*18-26 – Males must register for selective service.





# Health

Many of us feel a sense of disorientation and loss when faced with the transfer of healthcare from our trusted pediatrician to adult healthcare services. After years of being deeply involved with our child's healthcare, we may find it difficult to step back as our children become more involved in making their own decisions. This is especially true because adult health care providers address issues of reproductive systems and family planning, which may be new territory for us. Your child now has an adult body requiring adult health care and specialists to address adult concerns. So take a deep breath and start preparing yourself and your child for transitioning to a new doctor. Below you will find some tips and recommendations from other parents who have walked this part of the journey.

## Finding the right provider

Although some pediatricians keep patients until they are 22 and leaving school, the general recommendation is to move a child to an adult practice at age 18. Still, maturity and experience are the best indicators of when your child is ready to make a successful transition. One difference between pediatric care and adult care is oversight. Pediatricians often follow up with patients regarding compliance with and reactions to medications, but adult providers may assume that our young adults are more capable of following a medication regime than they really are.

Finding a good fit for your child with an adult practice is the key to a smooth transition. Ask your pediatrician for recommendations and a referral. Remember that neighbors, friends, parent networks and organizations, and pediatric specialists may have helpful connections or experiences with adult providers. If possible, set up an "exploratory" appointment with a few providers to get a sense of how they relate to patients with disabilities. Your young adult should take part in the interview process to be sure he/she is comfortable with the new physician.



### TIPS FOR FINDING THE RIGHT PROVIDER:

- Invite your child's adult provider to transition team meetings at school.
- If that is not possible, make sure he/she has a copy of your child's IEP, or Summary of Performance if your child has already left school.

## Preparing your child

Even young children can learn the importance of taking good care of themselves. Start with small responsibilities that your child can take on, such as handing the prescription bottle to you, helping to fill a weekly pill dispenser or checking refill dates. Your child can keep a calendar, checking off when meds have been taken. Gradually increase responsibilities as the child is able. He/she can present the insurance card at the doctor's office and eventually may be able to make his/her own appointments.

## Insurance

Public and private health insurance is available for adults at age 18, but it can be quite expensive. Healthcare reform has allowed young adults to be covered on their parents' insurance plans until age 26. Your child may be eligible to stay on your plan as an adult dependent after he/she turns 26. However, having private insurance may limit your child's eligibility for public programs. Check with your insurance company about getting the necessary forms and medical affidavits. If approved, you will probably be required to have your child recertified every year. This process involves having a physician or psychiatrist certify that your child still has a disability – a sometimes sad exercise for parents of children with life-long disabilities.

Many young people with disabilities may already be in a Medicaid program, such as Dr. Dynasaur or Katie Beckett. These programs end at ages 18 or 19, so you will need to plan for a transition to a different program. Young people who are eligible for SSI will in most cases be eligible for Medicaid. For young people who do not qualify for SSI or adult services, finding coverage can be a challenge. Public health insurance is offered in a variety of plans. See the Resources section (Insurance) for more information.

## Mental health

Many teens and young adults suffer from some form of mental illness, especially depression and anxiety. Symptoms of bi-polar disorder, schizophrenia and other mental illnesses often become evident in adolescence. If your child begins to exhibit unusually challenging behavior in his/her mid-late teens, you may want to consider asking for a referral for a psychological evaluation.

### TIPS FOR MENTAL HEALTH:

- Psychological evaluations can often be done through the school as part of the initial or re-evaluation process for an IEP or 504 plan.
- You can request a Coordinated Services Plan (CSP), also known as an Act 264 meeting, through the school or your child's mental health therapist. The meeting convenes a partnership of professionals, often including the Department of Children and Families, as well as those who know your child, to brainstorm ways to better support the family and to avoid a crisis. A Parent Representative is also available to assist and support you. For information on this process, how to contact your local parent representative, or any questions concerning your child's mental health, contact the Federation of Families for Children's Mental Health of Vermont (*see Resources – Mental Health, page 25*) or Vermont Family Network.
- When young adults have physical or cognitive differences, deficits in social skills, and are diagnosed with a mental illness, adjusting to changes in their bodies and in social relationships can be complicated. It is a good idea to be proactive and get your supports lined up before puberty.

## Sexual health

Talking about sexuality with our children can be tricky, but it is all part of our responsibility as parents to teach our children independence, self-care, safety, and respect for themselves and others. Start modeling and teaching relationship skills and public vs. private behavior from an early age. Be clear and direct, using correct terms for body parts. Create house rules around respect for privacy (closing bathroom doors, no nudity in "public" parts of the house) and personal space (knocking, not touching others' belongings.)

Our children need to develop a sense of appropriate and inappropriate behavior for themselves and others when in the community. This knowledge can help lessen the possibility of misunderstandings when they are in public. It is also the foundation for the prevention of abuse. We can teach our children basic concepts about how to relate to others using the different types of relationships in our daily lives, from strangers to providers, acquaintances, friends and family. Learning how to interact appropriately in each relationship in terms of touching and words is important. Role-playing, scripts, and social stories can help us as we practice with our children.

All of us make mistakes throughout life, and we hope to learn from them! Our children and teens are no different. As parents,

we must remind ourselves that risk-taking is a part of growing up. Balancing the need to protect our vulnerable children and allowing them to take risks and fail is challenging for us. It is important that we talk clearly and directly with them about the lessons of a mistake. Our other children may make connections between behavior and consequences, but the teen with a disability may not.

As your child grows older, you may find yourself dreading the task of explaining physical changes to his/her body. The decision to provide your son or daughter with information and resources for birth control is a very personal one. Get help from your child's doctor, from books, online, and at VFN. The Green Mountain Self-Advocates (GMSA) holds an annual conference, which includes workshops on sexuality, relationships, independent living and decision-making. Activities with GMSA, Special Olympics, ARC or school teams and interest groups offer opportunities for practicing relationship skills. An excellent resource for parents of transitioning teens with any special need or diagnosis is "Autism Speaks Family Services Transition Tool Kit" 2011, a guide available to download at the Autism Speaks website.

## Internet safety and social networking

We have all heard of cases where people use the internet and social networking sites to bully, prey on, or violate others' dignity and safety. Our children, teens and adults with disabilities are particularly vulnerable to such attacks. Yet the web is such a useful tool for connecting with others, finding housing, employment and education. It would be a shame for our young people not to have access to the web. You can do a few things to minimize potential pitfalls.

### TIPS TO HELP ENSURE INTERNET SAFETY:

- Use parental controls to make certain sites off limits.
- Teach your child navigational skills that include safety concerns, "friending" rules and red flags.
- Make sure rules are clear and repeat them often. You may want to post the rules by the computer.
- Navigating various sites together presents the opportunity to practice responses to various scenarios that may arise.
- Check our resource section at the end of this guide for social networking sites specifically designed for individuals with special needs.

## Emergency planning

With all of our other worries, planning for emergencies (power outages, floods and storms, evacuations, natural or manmade disasters) may not be at the top of our priorities list. Does your child know where to go, what to do, or how to get assistance? Is your family prepared to live in isolation for days or a week, with sufficient food, water, and medicine?

Consider making family and individual emergency plans and keep them in an Emergency Management notebook. This way, you can keep all of your necessary information in one place: the daily needs of your child with a disability, names and contact numbers of family and providers, and other particulars about care in a different location. Notebooks and information about emergency kits are available through Vermont Family Network or the Vermont Departments of Health and Emergency Management.

### TIPS FOR EMERGENCY PLANNING:

- Help your child practice ways to communicate needs to safety service providers.
- If appropriate, have your child carry an explanatory card in his/her wallet or pocket when he/she is out in the community so people will know best how to communicate with him/her.
- Role-play appropriate behavior and language for them to use if stopped by police.
- Make sure they know their rights and that you know yours as a parent/legal guardian.
- For home emergencies, create a one-page instruction and contact sheet easily available to a respite worker or EMT arriving on the scene.
- It is a good idea to let police and fire fighters know about your child's disability and needs. That way they can know the best way to approach your child so that everyone stays safe and secure.

## Timeline for transition in healthcare

### By age 18:

- Complete a financial assessment, remembering that only the applicant's income is reviewed for SSI and health insurance. See the Insurance section of this guide for specifics.
- Finalize health care coverage.
- Check eligibility for SSI and apply online at [www.ssa.gov/ssi](http://www.ssa.gov/ssi)
- Decide whether guardianship (voluntary or involuntary), or an alternative, is necessary, and have documents signed. (See Resources for links.)
- Investigate adult developmental disabilities services, if applicable
- Prepare for transition to adult healthcare providers
- Create a portable healthcare summary and emergency page
- Have an emergency plan in place (for disasters or individual crises)

State and health agencies and other organizations are working on new guidelines for supporting better transitions in healthcare for youth. See Resources for helpful links to checklists, recommendations and educational resources on the web.



## Employment & Income

Getting a job is a rite of passage for most kids. If you are like most parents, you will want your adult child to find competitive employment that is meaningful and satisfying. However, the sad fact is that the unemployment rate for people with disabilities is 65% higher than for people without disabilities (ALLSUP Disability Study, July 2012), so getting a job can be a significant challenge. Many individuals with disabilities lose jobs they have worked hard to get due to issues with punctuality and attendance, not following through with responsibilities, not following instructions or personality conflicts. The more training and preparation we can give our children before they are employed, the better chance they have of being successful.

Planning for future employment should begin well in advance of when your child is ready to look for a job. If your child is on an IEP, he/she should have a goal related to employment in the transition plan, but you do not have to wait until then to begin the planning process. Early planning helps your child to build the necessary skills and attitude needed for any job and encourages him/her to begin thinking about work in a productive way. By setting early expectations at home, we can prepare our children for the world of work by helping them learn to take direction, to work with others, to respect their commitment to the job and to be flexible.



## Why is employment so important for my young adult?

Employment for people with disabilities is important on many levels.

### A job:

- Gets the person out of the house and helps to combat isolation, loneliness, and depression
- Can be a place to interact with others and make friends
- Provides income
- Can be a place to learn social skills and responsibility
- Gives a sense of purpose, accomplishment and structure to the day
- Encourages more independence



### TIPS ON RAISING A FUTURE EMPLOYEE:

- Start early teaching the soft skills involved in employment. Soft skills are valued personal traits that include getting to work on time, a good attitude, following through with responsibilities, ability to follow instructions, etc. Soft skills can carry over from job to job.
- Focus on your child's strengths and not on his/her challenges.
- Give your son/daughter household jobs to perform on a routine basis. Jobs can range from traditional household chores to chores that would better suit the individual's abilities. For example, an individual with mobility issues might be responsible for checking the weather on the computer every morning, looking up recipes, making a shopping list, or sorting mail.
- Combine daily, routine tasks during the week with chores that require following instructions on the weekend.
- Maintain high expectations over time to encourage your child to strive for more and to gain the confidence he/she will need. Create a chore chart that your child can check off as tasks are completed. This task can help build organizational skills.
- Consider paying for services. Your child may find the concept of money difficult, so it is helpful to draw the connection between task and reward. For example:  
*Katarina has moderate autism and rarely used cash. The concept of cash was difficult for her. Her parents gave her cash after her weekly chores and had her place it immediately into her piggy bank. After two weeks, her parents let Kat take cash from her piggy bank, go to the store and select a modest toy that she wanted. Kat handed the cash to the clerk. She gradually became comfortable with money transactions.*
- Take a look at your child's natural strengths and interests to get a sense of the sort of workplace setting that would work best. For example, does he/she like to be around people or prefer solitude? How about a preference for one repetitive task or, conversely, a variety? What is your child's communication style? Example:  
*Bob has Asperger's and enjoys being around people. A back and forth communication between individuals can be challenging for him; however, he loves to share his knowledge on subjects that he can really dive into. Perhaps Bob would make a terrific museum guide.*
- It is important to consider interests and hobbies, any future job must match your child's skill set. Interests may change and do not always lead to a good job fit. Someone who loves animals or children may not necessarily want a job working with animals or be temperamentally suited for work with children.
- Work with your school team to develop skills that are important for any job, such as filling out an application and interview skills. Make sure you have relevant and measurable goals in the IEP and transition plan to address, as appropriate, the following:
  - Personal hygiene
  - Punctuality and timeliness
  - Taking direction
  - Understanding responsibilities & using clarification skills
  - Basic social skills
  - Appropriate workplace behavior
- Practice the soft skills in the community through volunteer work. Although volunteering is not a long-term solution to paid employment, the experience can help build soft skills, create connections and add to a resume. Volunteering is also an opportunity to explore different types of jobs.



## How you can help your son/daughter find his/her first job

The best way to find a potential job for your child is to network, network, network. Many parents we know have found that relationships, not want ads, provide the most job opportunities. Make a list of people you know socially, through your church, volunteer work, workplace and businesses you frequent. Tell them that your son/daughter is actively looking for a job. If they do not know of any jobs, they may know someone who does.

**Develop a resume:** Every job seeker needs a resume. Your child can be creative about what he/she wants to include, such as work, volunteer experience, hobbies, and skills he/she is particularly proud of.

**Applications:** In preparation for filling out job applications, have your child practice completing a generic job application. Have it laminated or place it in a protective plastic sleeve. Your child can use this as a template for filling out future job applications.

**The interview:** You can help your young person practice interview skills through role playing. Encourage your child to focus on strengths, not challenges, and to avoid offering too much information. Talk about appropriate behavior and expectations, such as handshaking, eye contact and speaking clearly. Practice the basics repeatedly so that your child is comfortable. If you can, record your role plays with your child so he/she can watch, practice and repeat. You might also set up informational interviews with friends and colleagues to give your child first-hand experience. Finally, make sure your son/daughter has an appropriate outfit for an interview. Shop for clothes together and be sure your child likes them. Finally, help your child understand the importance of appearing clean and neat in the workplace.

## Who can help?

While we are focusing on what parents can do to help their child with a disability prepare for the future, it really is a team effort. If your child is on an IEP at school, the team will be instrumental in developing realistic and relevant goals to prepare for future employment. (*See Education – Transition Plan, page 10*) Make sure anyone with particular knowledge of your child is included on the team. Contact VocRehab Vermont to learn what they can offer your child. If your child qualifies for adult developmental or mental health services, he/she will have an employment counselor or have access to a job skills program. One relatively new program is Supported Employment. Contact your Designated Agency for more information.

## What about self-employment?

Some of our young people may find working for others to be a significant challenge. Self-employment may be an option for them. The benefits of self-employment include flexibility in time and place of work, pursuit of a talent or passion, and the creation of an enterprise in which family and friends can be involved. However, starting a business is not for everyone. Your child will need capital to get a business started and it might be difficult to find investors or to get a loan.

If you believe your child has a strong interest in starting a business, along with a commitment to seeing it through, you can help him/her get started by creating a viable business plan. What is the product or service? Who is the target consumer? How will the product be produced and marketed? With self-employment, there is a need to be flexible and income is not a certainty. Does your child have the organizational skills it takes to run a business, however small, or will he/she depend on others to help? If so, are those others committed to help for the long run?

For the right individual, self-employment can contribute to a sense of pride and accomplishment. Some examples of self-employment ventures that we know include baking cookies and dog biscuits, mixing and marketing granola, making dolls, doing barn and yard work and playing music at events.

Whatever work your child ends up doing, you will want to be an active participant – job coach, cheerleader, tear-dryer – in his/her success!



# Adult Services for People with a Developmental Disability

If your child has a developmental disability, you will need to plan for adult supports. Most of the time, a young adult's eligibility for adult supports is determined before he/she graduates. When your child is of transition age (16 and older), the school transition team should include a representative from adult services. The agency should be involved at least a year before your child is scheduled to graduate in order to plan for funding. However, you do not have to wait for the school to take action. You can request an intake appointment with your local Designated Agency and start the eligibility process at any time. Your child may receive many necessary services through his/her school program, but you may also be eligible for Flexible Family Funding, income-based funds, which can be used at your discretion. The following information can help you navigate the new terrain of adult developmental services.

## **How do you apply for adult developmental services?**

The first step is to contact your local Designated Agency and ask for the intake coordinator. Designated agencies are non-profit organizations which contract with the Agency of Human Services to provide services, including Developmental Disability Services. The agencies are organized by county or service area.

The intake coordinator will set up an appointment to meet with you and your child. According to law, the intake person must make the appointment within 5 days of your initial contact. The intake coordinator will gather information to determine whether your child is eligible for developmental services. This process may include an interview, examining school, medical

and treatment records, and review of your child’s adaptive functioning level, such as self-care skills, safety awareness, etc.

In order to be eligible for adult developmental services, a young adult will need to (1) meet the criteria for developmental disability, and (2) meet a “funding priority”.

## Step 1: Eligibility

Eligibility requires that the individual meet the definition of developmental disability under Vermont law. According to the Vermont Developmental Disabilities Act, a developmentally disabled individual is someone who: (1) has an IQ of 70 or below OR is on the autism spectrum, and (2) has adaptive functioning deficits.

Your documentation must show that your child’s disability existed by the time he/she turned 18. Do not confuse this with the date of diagnosis; it is not uncommon for individuals with autism to get a diagnosis at an older age. What is important is that there were documented signs that corroborate that the disability existed at childhood (by age 18). Also, note that no measurement of IQ is necessary for individuals on the autism spectrum.

Adaptive Functioning is measured by a questionnaire that is typically filled out by the parent or other caregiver. If your son or daughter received Personal Care Services, you may recall a questionnaire that you had to complete which included a wide variety of questions concerning how your son or daughter functioned in different situations and his/her level of independence. To be eligible for Developmental Services, the individual must score 70 or less on this questionnaire. Adaptive functioning can also be measured by interviewing the parents, an individual who knows the applicant well or who lives with the applicant, or the individual/applicant him/herself if possible.

### TIP:

- Risk and safety are important issues in looking at a young adult’s adaptive functioning. Throughout this Guide, we have encouraged you to focus on your child’s strengths, but now is the time to concentrate on areas where safety and risk are a concern.

## Step 2: Meet a funding priority

In order to receive a Home and Community Based Medicaid Waiver, individuals who are eligible for developmental services must also meet what is called a “funding priority”. The funding priorities are found in the Vermont System of Care plan, which

runs on a three-year cycle. The Home and Community Based Waiver has become greatly restricted since the System of Care Plan changed this funding priority in 2001. There are opportunities for public testimony when the Agency for Human Services (AHS) puts forth drafts of proposed changes for the System of Care Plan. For this reason, advocacy is extremely important in order to keep developmental services available for people in need.

If your child does not meet a funding priority, he or she may still be eligible for other services. Your Designated Agency can give you a description of possible services.

## How are adult services paid for?

In most cases, Medicaid will pay for adult services. If your child is found eligible and meets a funding priority, he or she must be eligible for Medicaid. Otherwise, he/she will be expected to pay for services based on a sliding scale. Some of the programs which may have provided Medicaid to your child will end by age 18 (Dr. Dynasaur) or age 19 (Katie Beckett).

### TIP:

- Be aware that a delay in services may occur until your child is on Medicaid.

For your child to be eligible for an adult Medicaid waiver, he or she must meet the financial eligibility criteria. Financial eligibility includes a low maximum allowable monthly income and a low countable resource limit. If your child holds excessive resources, you might consider a Special Needs Trust in order for him or her to meet financial eligibility for Medicaid (and SSI). A person who receives SSI checks will automatically be eligible for Medicaid.

## Budgets

Designated Agencies must budget well in advance in anticipation of need. At times funding may run out due to unexpected circumstances. In that case, your child may be placed temporarily on a waiting list.

## Adult mental health services

Adult mental health waivers through Medicaid can be difficult to get. If your son or daughter has a diagnosis of a major mental illness and is eligible for Medicaid, you should contact your local mental health agency. The Community Rehabilitation and Treatment (CRT) program, within each Designated Agency, may be able to help with therapy, case management and job support.

## TIPS:

- Contact the Designated Agency by your child's junior year in high school, even if you expect your son or daughter to stay in school until age 22. Designated Agencies must budget well in advance of when they anticipate a young adult will be entering the adult system. Make sure an agency representative is included on your child's transition team.
- Be aware that there is a gap between the ages of 18 and 19 where it is very difficult for an individual to get adult services, even if the person finishes high school. Services are more readily available once the person turns 19. Ask your agency about the Bridge Program, which offers case management on a time-limited basis during this period.
- Recognize that, unlike special education, adult services are not a federal entitlement. Every state has a great deal of flexibility in how and to whom to provide services for adults with disabilities. As a result, developmental services are frequently targeted for budget cuts. You can help by getting involved with systems advocacy and attending the public hearings regarding the System of Care Plan. As a parent, your advocacy can make a huge difference in the lives of many individuals. Your voice counts!
- If your child is on a multi-year IEP, encourage him or her to stay in a school program until age 22. You may find yourself in disagreement with the school, which may try to graduate your child once he or she has accrued the required credits. Keep in mind that it is equally important for your child to meet his/her transition goals. Staying in school as long as possible is an extremely important opportunity for your child to continue to learn job skills, academic and independent living skills while under an entitlement program.
- Remember that disability does not necessarily mean eligibility. Eligibility criteria differ between special education and developmental services. An individual with a significant disability who was on an IEP while in school may not be eligible for developmental services.
- Determine if your child is eligible for Medicaid. Even if your child is otherwise able to get services, the implementation will be delayed until he/she begins receiving Medicaid benefits. See Vermont Family Network's publication *6 Ways to Medicaid*.
- Be honest about your child's abilities when asked to complete the functional capacity assessment. The assessment is seeking information on what your child can and cannot do on his/her own. Many parents are tempted to 'defend' their child and exaggerate his/her abilities or others may try to minimize his/her abilities in

order to try to qualify for services. Your responses will be compared to records and responses from other sources.

- If your child has been on Medicaid, you probably know about the choice to manage your own funding. This is true for adult services as well. There are two ways to do this:
  - Self-management (by the self-advocate)
  - Family management – (by a parent, care-giver or guardian together with self-advocate)

In both cases, funding is dispensed through a fiscal agent. The self-advocate/family contracts for services with a Supportive Independent Agency based on the contents of the Individual Support Agreement (ISA). These might include case management, support with employment, community access, or independent living. Self- or family-managed waiver services can give you and your young adult more freedom of choice but it can be a time- and labor-consuming venture. For more information, contact Vermont Center for Independent Living (VCIL). Find their link in our Resources section.

## Thoughts on adult services

The world of adult services is very different from what your child may have experienced in school. Finding opportunities to pursue favorite activities (sports, music, etc.) that were part of the school day may be a challenge. There may be less engagement with typical peers, who have gone off to college or work. Leaving school will require your child to adapt to changes in routine, place and personnel. Make sure your young adult is an integral part of the transition planning process. Being actively involved can help him or her adjust more easily. You may find that, while you worry, he or she looks forward to a new phase of life with anticipation. This may be a good point to start letting go a little and not allow your fears and concerns dampen what can be an exciting time in any young person's life.





# Planning for the Future

## Supplemental Security Income (SSI)

Supplemental Security Income (SSI) is a monthly cash benefit for people with disabilities. SSI is intended for individuals with little or no income and resources. Because many of our adult children will fall into that category, it is worth looking into whether or not your child is eligible to receive SSI. SSI is also one of the gateways to Medicaid in Vermont: If your child receives at least \$1 of SSI, he/she will be eligible for full Medicaid.

To qualify for SSI, your child must (1) meet the financial criteria, and (2) be considered 'disabled' under Social Security rules.

### FINANCIAL ELIGIBILITY

If your child is under 18, your income and resources will be considered in determining eligibility. Once your child turns 18, your income and resources are no longer taken into account, even if your child continues living at home. At all times, however, your child's own income and resources will affect

eligibility for SSI. Local Social Security Field Offices process the intake information and determine your child's financial eligibility. The amount your child will receive in a monthly allowance will depend on several factors:

**Employment:** If your child receives SSI and gets a part-time job, the monthly cash benefit will be reduced accordingly. Your child (or you) must submit paystubs to the Social Security Administration and inform them of any changes in hours worked or if your child leaves the job. Failing to keep the SSA informed may result in your child having to pay back a portion of the allowance.

**Rent:** The amount of the allowance your child receives will be adjusted if he/she is living at home and receiving free room and board. In that case, you can check with your local SSA Field Office for guidelines on charging rent so that your child may receive the maximum cash benefit. If your child has an out-of-home living arrangement and pays rent, he/she will receive the maximum benefit.



**Resources:** Resources that add up to more than \$2000 (such as a bank account, savings bonds, stock shares, etc.) will disqualify your child. In this case, you may decide to spend down to the allowable limit, convert assets into a non-countable resource for SSI purposes, or use the assets to create a special needs trust. Transferring resources to another individual is not permitted.

## DISABILITY DETERMINATION

Once financial eligibility has been established, Disability Determination Services will examine evidence of your child's disability according to Social Security Rules. The type of evidence used to make this determination may include functional reports completed by parents or caregivers, special education records and teacher questionnaires, employer questionnaires and medical records. New evaluations and testing may be required.

### TIPS FOR SSI:

- When applying for benefits, be cooperative and respond quickly to letters and phone calls.
- Understand that the process of applying can be time consuming. If possible, avoid applying at a particularly stressful or busy time for your family, such as during the summer or near the holidays.
- Social Security needs documented evidence in order to render a favorable decision. Help Social Security get the evidence they need.
- Complete requests for more information (questionnaires).
- Contact third parties that have been asked to provide information and encourage them to process records and complete questionnaires promptly.
- If your son or daughter is in school, encourage your child's school to submit special education records and teacher questionnaires promptly to avoid a delay in processing the claim. Keep school vacations in mind when applying for benefits as this may cause a delay.
- Try not to reschedule appointments for further testing and evaluations.
- To maintain benefits, stay on top of further requests for information or documentation for periodic reviews.
- Consider charging room and board to your adult child who receives SSI while they live at home to maximize benefit amount. Be sure to keep accurate records of payments of room and board (copies of canceled checks).
- Consider establishing a Special Needs Trust in order to help your child qualify and maintain eligibility for benefits. Seek legal advice to be sure the documents meet legal requirements.

## Special Needs Trusts

The limit on allowable resources of SSI and Medicaid presents a problem for many parents of children with special needs. If we wish to leave money for our children for the future, we cannot do so without jeopardizing their benefits. Creating a Special Needs Trust can protect our children's assets while not affecting their benefit levels.

A Special Needs Trust is a legal document that provides protection in two ways. First, it allows us, or others such as grandparents, to leave funds for our children without having the funds counted against SSI or Medicaid eligibility. In a Third-Party Special Needs Trust, parents and other family members can add to the trust at any time and without limit. Second, the Trust provides a safety mechanism for the adult child by having Trustees become responsible for the day-to-day decisions on spending the money. Trustees have a legal responsibility to comply with the terms of the Trust and to act on behalf of the person with a disability.

## Wills

Every adult should have a will, but it is particularly important for parents of children with special needs. Whether your child is a minor or an adult under legal guardianship, your will is a place where you can appoint your successor. Finding the right person to take over guardianship of your child requires much thought and discussion. Whomever you pick – family, lawyer or other – that person will need access to a lot of information about your child. Consider preparing an information packet for the potential guardian to keep now and update it as needed.

Wills can redirect any possible source of inheritance away from your child into their Special Needs Trust. Remember, in the event that your son or daughter receives more than \$2,000 in assets, he/she will lose SSI, Medicaid and related benefits.

## Protections for vulnerable adults

Sometimes our children reach the age of majority (age 18) before they are able to look out for their own affairs. There are several legal safeguards we can put into place to protect their interests and well-being. Because these are legal documents, it is a good idea to get advice from an attorney on setting these safeguards up.

## GUARDIANSHIP

Once our children turn 18, they are responsible for their own financial, medical and legal decisions. They can sign legally binding contracts and make decisions on where they live and

whether or not to go to school. If you feel your child cannot make good decisions, you may wish to become the child's legal guardian. However, adult children under guardianship lose some rights and independence, so you should carefully consider all options before you make the decision to seek guardianship.

**Involuntary guardianship:** You will need to consider an involuntary guardianship when your adult child is either unwilling to go under guardianship or does not have a clear understanding or capacity to pursue a voluntary guardianship. When you seek guardianship over your child, you must be prepared to explain what alternatives you looked at and whether your child only needs help in making decisions in some areas, e.g., financial decisions.

### THE PROCESS IS AS FOLLOWS:

1. File petition/form in probate court in the county where your child lives. File no sooner than 4 months before the individual turns 18.
2. Pay the petition fee or request a waiver if you cannot afford it.
3. The Judge will order an evaluation of your child.
4. The Judge will appoint an attorney to represent your child's wishes. Your child is responsible for legal fees unless the attorney agrees to provide services pro bono (free of charge).
5. If necessary, the Judge will appoint a Guardian-ad-litem to determine what is in the best interest of your child and report findings to the court. The determination may or may not coincide with your child's wishes.
6. A hearing will take place and the judge will determine if your child is in need of guardianship.
7. As guardian, you will be required to submit yearly reports to the court.

**Voluntary guardianship:** Sometimes our adult children are aware of their need for assistance with their affairs. In this case, they may request a voluntary guardianship and select us as guardian. Once under guardianship, they will lose some freedom, as we would now have legal authority to make certain decisions for them.

The process is simpler in a voluntary guardianship. A court appointed attorney is not typically necessary nor does the judge order an evaluation. However, the judge would need to be satisfied that your child has a good understanding of the guardianship relationship and that he/she is seeking voluntary guardianship of his/her own free will. Once granted, your child can approach the court at any time to withdraw the guardianship. However, if you, as guardian, believe that your child should still be under guardianship, you could pursue an involuntary guardianship at that time.

## Other protections

Not all adult children with disabilities should be under guardianship. There are alternatives to guardianship that can provide additional support to adults with disabilities without affecting their independence. The following legal documents can help you support and protect your adult child:

### POWER OF ATTORNEY

Powers of Attorney allows you, the trusted "agent", to conduct business on behalf of your child. A Power of Attorney can grant you broad power, allowing you to handle the adult child's banking, buying and selling, bill paying and other personal affairs. You would show the Power of Attorney to banks, schools, car dealerships, mortgage companies, and others in order to handle your adult child's transactions.

A Power of Attorney can also be narrow in focus and have a time limit. For example, it can be in effect solely for school purposes until your child reaches age 22.

### ADVANCE HEALTH CARE DIRECTIVE

This document allows you to make health care related decisions for your adult child. The document can be broad or very specific.

### REPRESENTATIVE PAYEE

Your adult child can request that you receive and manage government assistance funds on his/her behalf. This is a common arrangement with SSI checks. You will need to keep these funds separate from your own (i.e., open a dedicated account.) Another party, such as a caregiver, lawyer or developmental services agency, can also be designated representative payee.

### CIRCLE OF SUPPORT

You and your child can create a Circle of Support made up of friends, family and anyone who shares your vision for your child's future and chooses to be a part of it. Making Action Plans (MAPS) is very useful in this process (see Education – Transition Planning).

Keeping our children safe and protected in adulthood, while allowing them as much independence and self-determination as possible, is a balancing act. Start planning the legal aspects of your child's future as soon as you can. And be sure to include your son or daughter in the process, as much as possible. Keep in mind the self-advocates' motto: "Nothing about us without us."

## Final thoughts

Parents are usually the best advocates for children with special needs. We work tirelessly to ensure that our children's lives are the best they can be. No one handed us a roadmap when our kids were diagnosed, so we often have to gather the pieces of the service and support puzzle ourselves. Sharing what we have learned from you, our Vermont Family Network families, and from our own experience is the best way we know of shining a light for others walking this path. We hope you have found this Guide helpful and informative.

# Resources

**Vermont Family Network** ..... 1-800-800-4005  
.....www.VermontFamilyNetwork.org

## EDUCATION

**Transition Coalition** provides information and resources.  
..... <http://transitioncoalition.org/transition/index.php>

**TRIPSCY** is an online transition resource housed at the Center on Disability and Community Inclusion, University of Vermont.  
..... [www.uvm.edu/~cdci/tripsy/?Page=TransHome.html&SM=TnsSubmenu.html](http://www.uvm.edu/~cdci/tripsy/?Page=TransHome.html&SM=TnsSubmenu.html)

**Kids as Self-Advocates (KASA)** includes information on education.  
..... 334-230-5441  
..... [fvkasa.org/resources/education.php](http://fvkasa.org/resources/education.php)

## EMPLOYMENT

**Jump On Board for Success (JOBS)** Program provides case management and employment support to eligible youth 16-21.  
..... 802-864-7423  
..... [www.spectrumvt.org/jobs](http://www.spectrumvt.org/jobs)

**The National Collaborative on Workplace and Disability**  
..... [www.ncwd-youth.info/Guideposts](http://www.ncwd-youth.info/Guideposts)

**VocRehab Vermont**..... <http://vocrehab.vermont.gov>

## GUARDIANSHIP

The Department of Aging and Independent Living includes information on guardianship and alternatives.  
..... [www.dail.vermont.gov](http://www.dail.vermont.gov)

## HEALTH

Find checklists, recommendations, and educational resources at the **National Health Care Transition Center** "Got Transition?"  
..... [www.gottransition.org](http://www.gottransition.org)

**National Healthcare Transition Center in Collaboration** with the American Academy of Pediatrics ..... [www.gottransition.org](http://www.gottransition.org)

**Kids as Self-Advocates (KASA)** includes healthcare information  
..... [fvkasa.org/resources/health.php](http://fvkasa.org/resources/health.php)

**Sexuality Resource Center for Parents** has a wealth of information and tips. .... [www.srcp.org/index.html](http://www.srcp.org/index.html)

## INSURANCE

Information and intake screening for multiple programs in Vermont is available by calling the **Vermont Health Access Member Services**. The Call Center will do a brief pre-screening for eligibility and will send you an application..... 1-800-250-8427 (TDD/TTY)  
..... 1-888-834-7898  
..... [www.greenmountaincare.org](http://www.greenmountaincare.org)

## INTERNET SAFETY

**Social Safety** provides practical tools to teach about internet safety.  
..... [socialsafety.wordpress.com](http://socialsafety.wordpress.com)

**Sexuality Resource Center for Parents** will link you several good sites  
..... [www.srcp.org/for\\_some\\_parents/developmental\\_disabilities/the\\_specifics/internetDD.html](http://www.srcp.org/for_some_parents/developmental_disabilities/the_specifics/internetDD.html)

## LEGAL

**Disability Law Project** represents Vermonters with disabilities  
..... 800-899-2047  
..... [www.vtlegalaid.org/our-projects/disability-law-project](http://www.vtlegalaid.org/our-projects/disability-law-project)

## MENTAL HEALTH

**The Balanced Mind Foundation**..... [www.thebalancedmind.org](http://www.thebalancedmind.org)

**National Alliance on Mental Illness Vermont**..... [www.namivt.org](http://www.namivt.org)

**A Practitioner-to-Practitioner Referral Resource** of Mental Health Practitioners in Vermont ..... [www.ptophelp.org](http://www.ptophelp.org)

**Strength of Us** is an online information and discussion forum for young adults with mental health issues ..... [strengthofus.org](http://strengthofus.org)

**VT Federation of Families for Children's Mental Health**  
..... [www.vffcmh.org](http://www.vffcmh.org)

## RECREATION

**Kids as Self-Advocates (KASA)** has information on dating, sexuality, etc.  
..... [fvkasa.org/resources/dating.php](http://fvkasa.org/resources/dating.php)

**Partners in Adventure**..... [www.partnersinadventure.org](http://www.partnersinadventure.org)

**Special Olympics Vermont**..... [www.specialolympicsvermont.org](http://www.specialolympicsvermont.org)

**Vermont Family Network** provides a comprehensive list of recreational resources in Vermont ..... [www.vermontfamilynetwork.org/i-need-help-with/developmental-disabilities/autism/camps](http://www.vermontfamilynetwork.org/i-need-help-with/developmental-disabilities/autism/camps)



## RESIDENTIAL OPTIONS

**The Department of Disabilities, Aging and Independent Living, Division of Disability and Aging Services**, maintains a list of providers of various types of residential living..... 802-871-3069  
....[ddas.vermont.gov/ddas-programs/programs-residential-alternatives](http://ddas.vermont.gov/ddas-programs/programs-residential-alternatives)

Check with your Designated Agency for local residential options.

**Heartbeet in Hardwick**, VT, is a community and licensed therapeutic residence that includes adults with developmental disabilities. Community members live and work together forming a mutually supportive environment that enables each individual to discover and develop his or her unique abilities and potential. .... 802-472-3285  
..... [www.heartbeet.org](http://www.heartbeet.org)

**The Whittle House** is a private respite, residential and day program that provides individualized support and educational opportunities that encourage the growth and independence of active young adults. We are the bridge from school to independence. .... 802-876-7007  
..... 802-238-8883  
email ..... [TheWhittleHouse@comcast.net](mailto:TheWhittleHouse@comcast.net)

## SELF-ADVOCACY

**Green Mountain Self-Advocates** is a state-wide organization. Contact them to locate a self-advocacy group in your area. .... [www.gmsavt.org](http://www.gmsavt.org)

**Kids as Self-Advocates (KASA)** provides information on civil rights, voting and much more <http://fvkasa.org/resources/civil.php>

## TRAVEL

**FAHC New Driver Program**..... 802-847-3140

**Kids as Self-Advocates (KASA)** includes travel information.  
.....<http://fvkasa.org/resources/transportation.php>

**Mobility International USA** has a comprehensive list of travel tips.  
..... [www.miusa.org/ncde/tipsheets/airlinetips](http://www.miusa.org/ncde/tipsheets/airlinetips)

**The Transportation and Safety Administration (TSA)** addresses questions about security concerns related to disability.  
..... 1-855-787-2227  
email ..... [TSA-ContactCenter@dhs.gov](mailto:TSA-ContactCenter@dhs.gov)  
..... [www.tsa.gov/travelers/airtravel/disabilityandmedicalneeds](http://www.tsa.gov/travelers/airtravel/disabilityandmedicalneeds)