



autism  
CONSORTIUM



# Transitioning teens with autism spectrum disorders

*Resources and timeline planning for adult living*



[www.autismconsortium.org](http://www.autismconsortium.org)

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## Introduction

For parents and guardians of children with Autism Spectrum Disorders (ASDs), the transition to adulthood can evoke feelings of uncertainty, unpreparedness, and fear – in even the most passionately loving, competent parents. You may have finally begun to feel comfortable with your child’s education and treatment, and now you must face an entirely new set of daunting challenges.

As parents, you have tremendous hopes for your children as they move through their adolescent years. You wish for their health, safety, and happiness; for their ability to develop meaningful relationships; and for their continued development and growth. You hope that as they become adults, they are able to make good choices and that they can live as autonomously and productively as possible. This particular part of the life cycle can be difficult for parents. Although you want to foster your children’s development and growth, you also don’t want to do so at the expense of their own hopes, well-being, and happiness.



Transition to adulthood is not a journey that happens overnight or in isolation, but it will happen, and it’s best to be prepared.

Children all function at different levels and will require varying degrees of care. These are some of the practicalities that as families, you will face. Questions will arise such as: “How do I separate?” “Can I trust him to other caregivers?” “Will she be able to live alone?” “Will he be able to hold a job and be financially independent?” “How will I navigate through this new maze of legal questions and state agencies?”

Transition to adulthood is an ongoing process that should begin in early adolescence and evolve throughout the course of your child’s life. Whenever possible, transition planning should begin with young adults identifying their own vision for their future. Those who know your adolescent best can form a supportive network to create a structured plan for accomplishing the next steps. As a group, you might want to consider these important questions: What makes your adolescent happy? What are their strengths? What obstacles might exist and what skills do they need to face them?

Creative thinking is often a huge part of this process, and you may have to adjust parts of your dream with what is possible. For adolescents and parents, you can plan, network, partner, ask

questions, and attend trainings and conferences so you can craft the best plan to capture the strengths of your adolescent and help them build the meaningful life that they want.

This guide is a tool, full of helpful resources and information that parents should know. Legal requirements discussed herein are based on Massachusetts state law. It focuses on children with ASDs and other cognitive and intellectual disabilities. It outlines critical timelines, eligibility criteria, important links, and other pertinent information. While this guide is meant for all parents, you may find as you read that some information is not pertinent to you. Our goal is to provide an overarching roadmap that you can adapt to your own adolescent's planning needs.

**While this new journey may be overwhelming, it is helpful to remember:**

- 1) This process is mostly defined.
- 2) You are not alone, and experienced parents and professionals are able to help.
- 3) Your early start with planning will serve you well.
- 4) You should feel that you can be as creative as possible.

Transition to adulthood is not a journey that happens overnight or in isolation, but it will happen, and it's best to be prepared.

We encourage you to remember the strengths that you bring into this process

You know your adolescent best and have been an ally and advocate through the years.

Knowledge of resources is empowerment.

Your family has already overcome innumerable transitions and will continue to do so.

For the most up to date information on resources visit  
[www.autismconsortium.org](http://www.autismconsortium.org)

## Middle and High School Education Planning

Parents devote enormous amounts of energy, time, and emotion into finding the right school programs, working with schools, and helping their children learn. Beginning around age 11, which is the time when children usually enter middle school, the focus of special education services should broaden to identify and develop skills for life after high school. The transition your child will make from school into adult life in the community is a long journey. Your child should be included as much as possible in this process and learn to develop self-advocacy skills (to develop his/her own vision, set goals, etc.). Advocates who specialize in transition will tell you that it is important to begin to think about this process as early as possible, to learn about the timelines and important steps you will need to make, and to develop a plan for your child's future so they can live as independently as possible and know how to access resources and community supports. Consider including the idea of "inter-dependence" in your adolescent's plan, which means being independent while remaining involved with your community.

A number of valuable resources and programs, detailed at the end of this chapter, are available for parents to participate in and learn about the transition process.

Massachusetts state law requires that high school special education departments use the Transition Planning Form (TPF) for all students with disabilities who are over 14 years of age. The TPF process includes development of measurable postsecondary goals based on age-appropriate transition assessments and a descriptive action plan to help the adolescent pursue these goals.

Transition planning may also include a "688 Referral," which should be made by the school two years before your child's graduation or 22<sup>nd</sup> birthday. This process will identify available community supports that might be needed after graduation and is described on the next page.



**The adolescent should be involved in transition planning meetings, and the plan should be updated annually.**

## TRANSITION PLANNING FORM—CREATED BY 14 YEARS OLD

- **Postsecondary Vision:** A collaborative description of the student’s strengths, preferences and interests, and postsecondary goals for the future (e.g., further training, employment, adult living, etc.).
- **Disability-Related Needs:** A description of the skills necessary for the student to achieve the vision above.
- **Action Plan:** Outlines how the student can develop self-determination skills and be prepared both academically and functionally to transition to post-school activities, and indicates how the IEP team and other community resources will help the adolescent develop the necessary skills.
  - Includes detailed description of specific high school coursework, employment opportunities such as job training, resume writing, vocational assessments, etc., and access to community-based experiences such as applying for government resources, managing money and transportation, and building social relationships.

## 688 REFERRAL—SUBMITTED TWO YEARS BEFORE GRADUATION OR TURNING 22

Massachusetts Chapter 688 (commonly referred to as the “Turning 22 Law”) is a law that requires a two-year planning process for young adults with severe disabilities who will lose their entitlement to special education at the age of 22, or at the time of graduation from high school, whichever comes first.

The purpose of the 688 Referral process is to identify the adult state agency that is most appropriate for providing assistance for your adolescent. Different eligibility guidelines will determine the agency most suitable to your adolescent based on his/her needs. These agencies may include the Department of Developmental Services (DDS), the Department of Mental Health (DMH), or the Massachusetts Rehabilitation Commission (MRC). Your child’s diagnosis, IQ, and functional abilities will factor into this determination. A more in-depth profile of these agencies is described in the “Public Benefits and Government Agencies” chapter.

It is important to note that a Chapter 688 Form is not a continuation of special education; rather, it is a single point of entry into the adult human service system and the services and supports that might be needed. It can be challenging when parents discover that these programs are not guaranteed and are subject to limited availability.

## WHO IS ELIGIBLE FOR CHAPTER 688?

Although many students will not qualify for a 688 Referral, initiate a discussion with your adolescent’s team about whether it is appropriate and if your child meets eligibility requirements.

### To be eligible for Chapter 688 services, a person must:

- 1) Be receiving special education paid for by the Commonwealth of Massachusetts

- 2) Need continuing habilitation services at the time of turning 22 or graduating from special education; and
- 3) Be unable to work competitively (without specialized supports) for more than 20 hours per week at the time of leaving school.

An individual is **automatically eligible** for Chapter 688 if **receiving SSI, SSDI, or registered with the Massachusetts Commission for the Blind**.

## WHEN SHOULD A 688 REFERRAL BE MADE?

Chapter 688 requires the school system to make the referral **at least two years before a student graduates or turns 22, whichever is earlier**. In order to facilitate the planning process, **DDS prefers to have the 688 Referral even earlier** than required by Chapter 688. DDS will take 688 packets or applications for adult eligibility as early as age 16. If your child receives services from DDS, you will need to ensure an adult application or 688 Referral is made or your child's services will be terminated at age 18.

Referrals that are made less than two years before graduation do not always ensure adequate planning time to assist a student in the most comprehensive way possible. Students or families who are concerned about the timing of a 688 Referral should contact both the school system and local adult agencies such as the DDS area office or MRC office. The age at which the adult agency becomes involved varies from town to town.

## IF A STUDENT IS ALREADY KNOWN TO DDS, IS A 688 REFERRAL STILL NECESSARY?

**YES.** Child eligibility standards for DDS services are different from adult eligibility standards. So, it is possible that a child who qualifies for DDS services might not qualify for adult services. Even though some individuals with intellectual disabilities receive DDS services as children, a referral should still be made. The 688 referral assists in identifying the number of individuals requiring services. DDS uses this information to request appropriate funding from the Executive Branch and Legislature.

## IMPORTANT ASSESSMENTS AND DOCUMENTATION

Assessments, or tests, are tools that give information about how your child performs in a variety of areas. There are many tests available that should be used in high school when preparing for a transition including psychological, vocational, and functional assessments. These assessments are important because they provide information about your child's current level of functioning, including the identification of interests and strengths. Assessment data serve as the common thread in the transition process and form the basis for defining goals and services to be included in the Individualized Education Program (IEP).

- **Psychological Testing:** Updated neuropsychological testing performed by a psychologist (either in-school or independently) will measure your child's cognitive abilities and include an IQ score (used

to determine to which adult state agency a referral will be made). Certain agencies have strict guidelines surrounding eligibility based on IQ testing. For example, DDS typically requires an IQ score of 70 or below in order to qualify for services, although an Appeals Court decision dated 7/23/12 has extended DDS eligibility to some individuals who have or who have ever had IQs over 70. The DDS hearing officer decided that the IQ score nearest to age 18 was most determinative and that the standard error of measurement – plus or minus five points – should not be applied.

- **Vocational Testing and Assessment:** Utilized to determine which career opportunities your child might excel at and enjoy. Often these can include real-life experiences (also referred to as job shadowing or situational assessments), interest inventories, employability tests, and others.
- **Adaptive Behavior/Daily Living Skills Assessments:** Help determine the type and amount of assistance that people with disabilities might need. This assistance might be in the form of home-based support services, special education and vocational training for young people, and supported work or special living arrangements such as Personal Care Attendants. They might evaluate your child's self-care and independent living skills such as dressing, cooking, or bathing, in addition to safety awareness skills.

Some assessments can be performed by school personnel, while others may necessitate contracting with outside agencies. The data gathered should inform both the transition plan and IEP goals and services. The transition assessment process will vary depending on the actual instrument(s) and procedures being used and various student characteristics. Although formal instruments might be easier and quicker to administer, they should be used primarily to verify observations of student behaviors and performances. Students should always be asked to verify results of both formal and informal assessments to determine whether their opinions, evaluations, and feelings confirm the results.

## MCAS AND GRADUATION REQUIREMENTS FREQUENTLY ASKED QUESTIONS

### What accommodations are available for the MCAS if my child is not able to pass the standard version?

Accommodations that are available for the MCAS may include: untimed testing, alternate test-taking environments, use of alternative augmentative communication devices, and other

## You may want to inquire about the following assessments for your child:

Some might be done as part of the eligibility determination process for agency services, some might be done by schools, and others will likely need to be covered by insurance:

Intelligence Testing

Situational Assessments

Individual Skills Inventory

Personal Interest Inventories

Safety Skills Assessments

Interviews with Family, Friends, Co-workers

Assistive Technology Assessments

Vocational/Functional Assessments

Adaptive Daily Living Skills

General and Specific Aptitude Tests

Temperament Inventories/Instruments

Career Maturity or Employability Tests

Self-Determination Assessments

Learning Styles Inventory

alternatives. However, MCAS accommodations cannot be different from those provided to the student on a regular basis. You might want to consider inquiring about the Alternate Portfolio Assessment; however, be advised that there are strict, specific eligibility criteria and many school districts are reluctant to allow for this.

### **If my child does not pass the MCAS, can s/he graduate\* with a regular high school diploma?**

Both the standard MCAS (with or without accommodations) and the Alternate Portfolio Assessment are held to the same high standard; both formats require a passing score to receive a competency determination for a state standard diploma. Students must pass 10th grade English and Math portions of MCAS (portfolio or regular) to satisfy competency determination to receive a state standard diploma. Students who do not pass both English and Math portions of MCAS remain eligible for transition services through their IEP and have many transition service options to consider. Students who do not pass MCAS and are not eligible for the portfolio assessment may be awarded a certificate of completion. Some colleges may accept these, depending on coursework and grades, while others will not. It is important to know that once a student has a certificate of completion, rules dictate that he may no longer earn a diploma.

### **If my child does pass the MCAS, is he required to graduate or can he remain in school until age 22?**

Each district's rules are different. Generally, along with passing MCAS, students must pass all local graduation requirements in your town/city. Find out what local requirements are in your district and talk about them at your Team meeting. Check to see if courses that have been waived (because the student is in special education) would be counted as credit toward "local graduation requirements." Parents may advocate that despite their child passing the MCAS, further transition goals and transition planning federal requirements have yet to be met on their child's IEP and warrant continued educational services until age 22. If you think that your adolescent has not met his IEP goals and is not ready to graduate, you should not sign the IEP with a proposed graduation date.

### **Can my child participate in the graduation ceremony if he is not receiving a diploma?**

Massachusetts law has been amended to ensure the right of a special education student to participate in graduation ceremonies even if he will not receive a regular diploma. Students must be informed of their expected graduation date (in their IEP) one year prior to that date.

## Important reminders

When your adolescent turns 18, he is considered an "adult" and is responsible for signing his own IEP. Some parents might be interested in seeking legal guardianship of their adolescent and the petition for doing so must be filed by his 18th birthday. To learn about what documentation will be required and associated timelines, refer to the "Guardianship" chapter.

You might want to explore applying for MassHealth Insurance for adult eligibility or private healthcare extensions (see "Public Benefits and Government" chapter).

At age 18, your adolescent may become eligible for SSI benefits (see "Public Benefits" section).

*\*Graduation is defined as exit from high school with a state standard diploma.*

## Resources

### Massachusetts Department of Early and Secondary Education and Planning

<http://asinfo.org/ZaJgY6>

### Massachusetts Transition Planning Form

<http://asinfo.org/SbwqH7>

### Federation for Children with Special Needs

The Schrafft Center

529 Main St., Suite 1102

Boston, MA 02120

(617) 236-7210

Fax (617) 572-2094

In-state toll free (800) 331-0688

Western Massachusetts

(413) 323-0681

[www.fcsn.org](http://www.fcsn.org)

### Transition Planning age 14-22

<http://asinfo.org/U2qMrP>

### A Guide of Specific Transition Tips

<http://asinfo.org/125vMN4>

### Planning a Life: Making the Most out of High School, A Transition Conference offered at different sites annually across Massachusetts

<http://asinfo.org/UeKzP4>

### Planning for Life After Special Education in Massachusetts: A Transition Services Online Manual

This online Transition Services Manual is written for parents and students who are advocating for better transition services, including social, vocational and independent living skills. The first edition was edited by the Disability Law Center (DLC) in partnership with the Federation for Children with Special Needs, the Institute for Community Inclusion, and Mass. Advocates for Children. The manual is now in its 2nd edition

<http://asinfo.org/UxZDLj>

### MCAS Alternate Portfolio Assessment

<http://asinfo.org/QVkJdZ>

### Massachusetts Curriculum Frameworks

[www.doe.mass.edu/frameworks](http://www.doe.mass.edu/frameworks)

### Massachusetts Comprehensive Assessment System

High School Graduation Requirements, Scholarships, and Academic Support Opportunities

<http://asinfo.org/QVtjBq>

## Guardianship

### WHAT HAPPENS WHEN MY CHILD TURNS 18?

After your child's 18th birthday, you are no longer his/her legal guardian. This is true even if he/she has a disability. According to the law, all persons 18 years old and older are presumed competent; that is, they are able to make decisions about healthcare, finances, and other important areas of life. This means your child is able to give "informed consent."

If you feel your child is unable to give informed consent, you may pursue one of various legal options to protect your adult child. One of the options a parent may seek is guardianship of an adult child.

The court makes the determination of your child's capabilities based on information you provide. The court may appoint an attorney to represent your child in the guardianship or conservatorship process if your child requests one or if the judge feels it would be in the best interests of your child to be represented.

### HOW DO I KNOW IF MY CHILD NEEDS A GUARDIAN?

- Carefully consider your child's specific strengths, vulnerabilities, needs, and best interests.
- Learn about guardianship and other legal ways of protecting your child. There are many different alternatives to full guardianship (e.g. healthcare proxy, limited guardianships). It might be helpful to attend a guardianship workshop to learn about all the options to make the most educated decision to suit your adolescent's needs.
- Speak with professionals who have worked with and know your child, such as teachers, school administrators and therapists or other professionals.
- Ask for advice from professionals who specialize in the field of guardianship.
- One possible starting point is to contact the Massachusetts Guardianship Association (MGA), a non-profit organization offering information and resources to individuals, families, and professionals pertaining to guardianship and conservatorship. You can contact the MGA through their website ([www.massguardianshipassociation.org](http://www.massguardianshipassociation.org)).
- **See additional resources at the end of this chapter.**

## What is Guardianship?

**Guardianship is a legal way to protect children who cannot:**

Care for themselves.

Make decisions (including healthcare decisions) that are in their own best interest.

If the court determines your child is incapable of handling his/her legal and personal affairs, it will appoint a **guardian**. A guardian can be the child's parents or another trusted adult.

If the court determines that your child is incapable of handling his/her financial affairs, it will appoint a **conservator**. A conservator and guardian can be the same person; however, **separate legal petitions** must be filed for these two roles.

Some guardians are limited to deciding treatment of a person who takes **antipsychotic medications**. These are commonly referred to as "**Rogers**" guardianships. If you think this may apply to your family's needs, it is advised to contact an attorney or another legal source, as there are separate requirements for documentation when anti-psychotic medication is involved. If your child receives services through the Department of Developmental Services (DDS), you may also receive advice or referrals from them regarding the Rogers guardianship.

THE PROCESS FOR ESTABLISHING LEGAL GUARDIANSHIP VARIES BY STATE. THE FOLLOWING IS INFORMATION FOR MASSACHUSETTS

## WHAT IS THE PROCESS FOR OBTAINING GUARDIANSHIP?

- An evaluation (**called a Clinical Team Report or a Medical Certificate, which are forms from the Massachusetts court that are available online**) of your child's capabilities and limitations completed by one or more licensed professionals (such as a physician, psychologist, or social worker). **The Clinical Team Report is the form for persons with intellectual disabilities (formerly referred to as mental retardation) and a Medical Certificate is the form for persons who are incapacitated but do not have a diagnosis of mental retardation/ intellectual disability.**
- **A court petition** (a form from the Massachusetts court also available online). If you are filing for conservatorship, you will also be required to file a Bond form.
- **Psychological Testing:** Rules may apply regarding the dates when your adolescent was last administered psychological testing, sometimes requiring **updated testing within six months**. It is best to inquire with your local probate court, the Department of Developmental Services (DDS), or an attorney regarding this and other required documentation.
- **Website information is listed at the end of this section.**



### To obtain guardianship, you will need:

An evaluation (clinical team report or medical certificate)

A court petition

Psychological testing

\*Website information is listed at the end of this section

## FOR ALL STATES

- All guardianship petitions ultimately come before the local probate court. **You should ALWAYS contact your local probate court for guidance and information.**
- **Most probate courts strongly encourage families to speak to a lawyer throughout the process.**
- Usually the process of obtaining guardianship for your child does not cost money. There is a fee required when you are applying for conservatorship. These fees may be waived or reduced if you provide evidence of financial need.
- It may be a family's responsibility to notify other interested third parties (including siblings or other family members) of the petition for guardianship.
- **Official notice of the petition for guardianship must be served (given) directly in hand to the proposed incapacitated person (person who will have a guardian) or protected person (person who will have a conservator).**

## MASSACHUSETTS PROCESS FOR OBTAINING GUARDIANSHIP AS OF JULY 1, 2009

There are different forms required to file for guardianship, depending on your child's cognitive abilities. Some courts allow guardianship petitions to be filed four to six weeks before the adolescent turns 18. Check with your local probate court about their policy.

A petition for guardianship of a person with mental illness or physical incapacity, but who does not have **an intellectual disability (formerly called mental retardation)**, must include a *Medical Certificate*.

- **This is the only form required if your child does not have an intellectual disability.**
- A Medical Certificate (available at your local probate court or online) must be completed and signed by a **registered physician, a licensed psychologist, OR a certified psychiatric nurse clinical specialist.**
- **A Medical Certificate must be dated within 30 days of the date the petition is filed.** In addition, a **Medical Certificate and the capacity/competency examination must be dated within 30 days of the hearing.** Thus, it is quite possible that an updated Medical Certificate might have to be procured prior to the permanent hearing because it can be difficult to get a court date within 30 days. This requires a second doctor's visit so that the doctor can fill out the medical certificate a second time. The doctor can refer to the initial certificate when preparing the second certificate. **Some physicians and professionals charge** for the time it takes to complete these documents.
- As of July 1, 2009, **the probate courts have been using more detailed Medical Certificates.** The new form requires that physicians need to state why a limited guardianship will not suffice and why a full guardianship is appropriate. Courts are favoring limited guardianships/conservatorships. Among other information, doctors must provide: clinical diagnosis; detailed description of cognitive and emotional functioning; an outline of every day functioning, and the level of care required.
- Finally, the Medical Certificate also assumes that **the individual (for whom guardianship is being sought) should be present at the hearing.** If the person cannot be present, **the doctor must explain why he cannot be present at the hearing.**

## CLINICAL TEAM REPORT

A petition for guardianship of a person with an *intellectual disability* must include a *Clinical Team Report (CTR)*, obtained either through your local probate court or online. **This is the only form required if your child does have an intellectual disability.**

- A CTR requires **three signatures** and should be completed by a registered physician, a licensed psychologist, **and** a licensed social worker, each of whom is experienced in the evaluation of intellectually disabled persons.
- **All three signatures must be obtained within 180 days of filing the initial court petition.**
- If a child receives special education services, the school team is often able to complete part of the CTR.
- If the Department of Developmental Services (DDS, formerly DMR) is involved, the evaluation may be referred to a contracted social worker and psychologist (for two of the signatures). These referrals can have lengthy waiting lists. DDS does not necessarily provide case management throughout the process, but has legal counsel available to help eligible clients.

## WHAT ARE MY RESPONSIBILITIES AS A GUARDIAN?

After being granted guardianship, **guardians are required to file a plan within 60 days**, including details like living arrangements and other services. **Guardians must also submit annual reports** detailing the incapacitated person's activities, living situation, prognosis and other details. The court system must monitor guardianships and conservatorships but has yet to announce a formal plan or system.

## CHANGES IN TERMINOLOGY

The Uniform Probate Code (UPC) are the laws that govern guardianship and related issues. As of July 2009, the law in Massachusetts changed to reflect the following changes in terminology, which provide more meaningful descriptions which are more consistent with the purpose of the statute:

**Guardians/Conservators:** Under the old statute, a guardian could be appointed over both the person and the property. Now under the UPC, guardians have authority over only the person and the conservator has authority over only the estate (property). The UPC has eliminated guardians of property. Guardians and conservators now have separate powers and responsibilities, and a separate petition must be filed for each.

## INCOMPETENT/INCAPACITATED/PROTECTED PERSON

Under the old statute, the court appointed a guardian or conservator if the person was found "incompetent." Now the court focuses on the person's functional limitations instead. Specifically, the court looks to the person's ability to process information and how that relates to their ability to make personal and financial decisions. A person who's been appointed a guardian is referred to as "incapacitated." An individual with an appointed conservator is deemed "a protected person."

**Incapacitated Person:** This is an individual who has a "clinically diagnosed condition that results in an inability to receive and evaluate information or make or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for health, safety, self-care, even with appropriate technological assistance."

**Ward:** The term "ward" used to relate to anyone who had a guardian or conservator. Now the term "ward" is limited to a minor who has a guardian appointed.

## WHAT ARE ALTERNATIVES TO OR VARIATIONS OF GUARDIANSHIP?

*Terms may vary by state*

**A Conservator** is responsible for handling your adolescent's financial resources.

**A Limited Guardianship** limits decision-making to certain areas, such as medical treatment. This can be tailored to fit your adolescent's needs by allowing your adolescent to make his/her own decisions in other areas, such as where to live, whether to vote, etc.

**A Temporary Guardian** may be appointed in an emergency situation when certain (personal only) decisions must be made immediately or if your adolescent's inability to make them is short term.

**A Temporary Conservator** may be appointed in an emergency situation when financial or estate related decisions must be made immediately or if your adolescent's inability to make them is short term.

**A Joint Bank Account** is an account that includes the names of two signors. You and your adolescent can have a joint bank account without having a guardianship or conservatorship. These accounts can be set up so that one owner can use or access the account or so that an additional signature is required on activity on the bank account.

**A Representative Payee** can be named to manage your adolescent's funds if your adolescent receives checks from Social Security.

**A Durable Power of Attorney** grants a person the legal authority to make legal and financial decisions on another's behalf. An adult can appoint another to act in this capacity only if he is capable of making an informed decision on the matter. That is, he must understand the consequences of delegating such authority.

**Advanced Directives and Healthcare Proxies** enable your adult child to designate a healthcare agent. This person is allowed to make healthcare decisions if your child becomes unable to make them. Similar to the Durable Power of Attorney, at the time your adult child appoints a healthcare agent, he must be capable of making healthcare decisions for him/herself.

**An Appointment of Advocate and Authorization** allows your adult child to designate an agent (person) to advocate on his/her behalf with administrative agencies such as the Department of Developmental Services (DDS), the Department of Human Services (DHS), Medicaid, and local authorities.

**A Trust** is a legal plan for placing funds and other assets in the control of a trustee for your child's benefit.

Any competent adult can name another person to make decisions on his/her behalf or to receive otherwise confidential health information. The Hospital has a "Delegation of Authority" form which may be appropriate. This authorization, to be legally valid, must be both voluntary and knowledgeable (with the person completing it aware of its consequences). Keep in mind that if your child is diagnosed with mental retardation or intellectual disability, they may not be considered "competent" to sign such forms.

Resources are listed for most states and may include organizations whose purpose is to represent adults who do not agree with the request for guardianship

*This information was derived from the **Guardianship: What happens when my child turns 18?** Booklet (2012 edition) written by the Social Work department at Boston Children's Hospital, with permission and from "Massachusetts Guardianship 2009" presented by Elizabeth Baum, Stephen Cohen, and Adam Nussenbaum.*

## Guardianship Flowchart

Does your child/young adult have an intellectual disability (clinically referred to as mental retardation)?

<http://asinfo.org/VCNAsc>

Yes, my child does have an intellectual disability.

- 1 Download a Clinical Team Report (CTR) Form.
- 2 Take CTR form to get an evaluation/signatures FROM ALL THREE OF THE FOLLOWING: Physician, Psychologist and Social Worker no more than 180 days before filing guardianship petition. Obtain evaluation/signatures as close to the child's 18th birthday as possible.
- 3 Call Department of Developmental Services and ask for assistance with Guardianship forms.
- 4 Call your local probate court and go over what you need to bring when you file the petition and to make sure you have the correct forms for your county.
- 5 Download and complete Petition to File for Guardianship.
- 6 File petition for guardianship with the completed CTR and Bond (MPC 801) at your local Family and Probate Court.
- 7 After you file the paperwork, the court will give you a **notice** that you must provide to your child showing that you are seeking guardianship. Depending on your family make-up, you may also have to provide notice to all interested parties over the age of 18.
- 8 You will receive a court date. The court expects your child to attend all court proceedings unless otherwise noted in the CTR.
- 9 If the court grants guardianship decree, the guardian must file a plan for the child/incapacitated person within 60 days and must file annual reports with the court.

## Guardianship Flowchart

Does your child/young adult have an intellectual disability (clinically referred to as mental retardation)?

<http://asinfo.org/VCNAsc>

No, my child does not have an intellectual disability.

- 1 Download a Medical Certificate.
- 2 Take the Medical Certificate for signature to ONE OF THE FOLLOWING: Physician, Psychologist, OR Clinical Nurse Specialist within 30 days of filing the guardianship petition.
- 3 Call your local probate court and go over what you need to bring when you file the petition and make sure you have the correct forms for your county
- 4 Download and complete Petition to File for Guardianship.
- 5 File petition for guardianship with the completed CTR and Bond (MPC 801) at your local Family and Probate Court.
- 6 After you file the paperwork, the court will give you a **notice** that you must provide to your child showing that you are seeking guardianship. Depending on your family make-up, you may also have to provide notice to all interested parties over the age of 18.
- 7 Make sure the Medical Certificate signatures are signed within 30 days of the court date. If they are not, another evaluation may need to be conducted.
- 8 After completing all the forms correctly, obtaining all necessary signatures, and completing all steps asked for by the judge, be present for court date.
- 9 The court expects your child to attend the proceedings unless otherwise explained by a physician in writing.
- 10 If the court grants guardianship decree, the guardian must file a plan for the child/incapacitated person within 60 days and must file annual reports with the court.

**REMEMBER**

- Call your local probate court and go over details. Some counties have their own forms.
- Many people hire a lawyer to help with this process. If you decide to do this, it is recommended that you retain a lawyer in the county where you are filing for guardianship, who is familiar with the county's court system.
- DDS lawyers can assist with Rogers' guardianships. Assistance may be in the form of advice or referrals.
- Filing to be a Conservator requires a different form. Guardians are in charge of only personal and medical decisions. Conservators handle a person's financial and legal matters.
- Additional forms may be required if your child takes anti-psychotic medication. Ask your local probate court about this process or, again, ask DDS for assistance.

**Massachusetts Resources****Mental Health Legal Advisor's Committee**

(800) 342-9092

[www.lawhelp.com](http://www.lawhelp.com)

**Massachusetts Probate and Family Court (various locations)**

(617) 788-6600

<http://asinfo.org/TuZMgi>

**Massachusetts Bar Association**

Lawyer Referral Service

(617) 654-0400

(866) 627-7577

[Masslawhelp.com](http://Masslawhelp.com)

**Volunteer Lawyers Project of the Boston Bar Association**

(617) 423-0648

[www.vlpnet.org](http://www.vlpnet.org)

**Massachusetts Uniform Probate Code**

(UPC or "the Code") Chapter 521 of the Acts of 2008

<http://asinfo.org/UxglWh>

**RESOURCES****Court Department Guardianship and Conservatorship**

Links to information and forms for guardianships of adults and children, and conservatorship of adults and children.

<http://asinfo.org/SOq1OT>

<http://asinfo.org/X659ST>

**BOOKS****Legal Planning for Special Needs in Massachusetts: A Family Guide to SSI Guardianship, and Estate Planning**

Barbara D. Jackins Esq.

<http://asinfo.org/Xjw8eM>

**Coming of Age in Massachusetts: A Legal Resource Guide,**

Frederick M. Misilo, Jr., Esq.

<http://asinfo.org/TY3jYS>

**WEBSITES FOR GUARDIANSHIP FORMS**

<http://asinfo.org/SThEmr>

**Petition to File for Guardianship**

<http://asinfo.org/UUpqNE>

**Plan for Guardianship/Annual Update Form**

<http://asinfo.org/TVjc04>

**The Massachusetts Guardianship Association**

[www.massguardianshipassociation.org](http://www.massguardianshipassociation.org)

**National Guardianship Association**

[www.guardianship.org](http://www.guardianship.org)

## Independent Living Skills

A large part of the transition process is assessing where your adolescent is developmentally and functionally relative to their independent living skills. This means looking at their knowledge, understanding, and ability to perform certain tasks, usually relating to self-care, problem-solving, decision-making, social awareness, and other areas. These assessments will help make determinations about what assistance or training they might need, if any, to live as independently as possible. The main domains of skill proficiency are: safety skills, daily living skills, time management, self-advocacy, work skills, social skills, health management, money management, transportation, and community navigation skills.

The following assessment tools have been developed to determine what areas of development need to be improved to allow for a smooth transition for young adults with special needs. It is important to have caregivers work with school, medical, and other involved community members to be a part of the assessment process to determine areas of strength and weakness and then ultimately develop a cohesive transition plan.

### The following are a few key questions you might want to consider when assessing independent living skills:

- 1) **Safety Skills:** Safety skills include knowing basic information (name, address, how to call 911), household safety (fire, gas smells, locks, emergency numbers), medical safety (doctors' numbers, when to seek medical attention), and physical safety (traffic rules, seatbelts, avoiding strangers). Statistics indicate that people with cognitive disabilities are at high-risk of being the victims of sexual and physical abuse. It is critical to keep this in mind when assessing safety skills.
- 2) **Daily Living Skills:** Daily living skills are also sometimes referred to as "Activities of Daily Living" or ADLs. These include hygiene, toileting, bathing, dressing, cooking, cleaning, laundry, shopping, using the telephone, and taking medications.
- 3) **Time Management:** Time management refers to the ability to understand time, be punctual, prioritize tasks, follow daily schedules, understand short-term versus long-term concepts, and be able to meet deadlines.
- 4) **Self-Advocacy:** Self-advocacy is an essential independent living skill. It includes feeling a sense of empowerment and the ability to take action in one's life, voicing concerns when problems occur, communicating needs effectively, asserting legal and personal rights, and having the ability to recognize and stand up for oneself when at risk of being taken advantage of or victimized.
- 5) **Work Skills:** Work skills overlap with many of the domains described in this section. They also include mastering skills relating to job searching, creating a resume, job interviewing, communicating effectively, learning to take initiative, exhibiting professional courtesy, and developing positive interpersonal skills.
- 6) **Social Skills:** This includes your adolescent's ability to make friends, communicate with people, recognize non-verbal cues, set and respect personal boundaries, and make safe choices about sexuality, as well as drugs and alcohol.

- 7) **Health Management:** This looks at your adolescents' ability to manage their own healthcare and includes scheduling doctor's appointments, understanding their condition, recognizing medical symptoms that need attention, awareness of mental health needs, medication management and adherence, healthy eating and exercising, and knowledge around tobacco, drugs, alcohol, and sexual health.
- 8) **Money Management:** This evaluates one's ability to understand money, spend within means, pay bills, receive change, use banking systems including credit and debit cards, and awareness of scams, etc.
- 9) **Transportation:** This refers to your adolescent's ability to travel from one place to another, whether driving, using public transportation, or walking. Assessments should consider safety and navigation skills, traffic awareness, passenger safety, and problem-solving.
- 10) **Community Navigation Skills:** This refers to knowledge and comfort around interaction in the community. For example, making purchases, interacting with others, asking for help, obeying the law, etc.

## SKILL BUILDING

After these assessments have been conducted, it can be useful to brainstorm ways of addressing and teaching needed skills or finding viable strategies to get around them. It is also important to train and practice these skills in real world settings where they occur.

There are many creative ways to teach skills and to help your adolescent integrate into the community and promote independence.

- **If you can teach the skill, teach it.** For example, if you can teach an adolescent to purchase something at a store and use money, teach them to do it.
- **If you can't teach the skill, adapt it.** If the adolescent cannot count change but can use a debit card appropriately, have them use a debit card.
- **If you can't adapt the skill, can you find some way around it?** If an adolescent cannot manage use of a debit card, can they use a gift certificate or prepaid card at a specific store?
- **If you can't find some way around it, teach the "non-disabled" world how to deal with it.** If an adolescent cannot master how to hand money to the cashier or wait for change, go to the local store that he will be using and get to know the manager and employees. Explain that you will be responsible for your adolescent, but ask them to help you augment his skill building, such as eye contact and social interaction, by having them address the adolescent and not you when it comes to check out. Practice a great deal at non-busy times and become familiar with all the employees. Explain your adolescent's disability and give them supportive and reinforcing prompts on how to help your adolescent. For example, they can try to prompt your adolescent—"Bobby, you need to take your change. Thank you!" That way, your adolescent is having an interaction with the cashier and learning how to begin to master the task of buying things.

\*\*\*Adapted from Peter Gerhardt Ed.D., President & Chair, OAR Scientific Council.

## Adolescent Autonomy Checklist

Transportation	PLAN FOR PRACTICE	ACCOMPLISHED
Read bus, subway, plane, and train schedules		
Identify correct mode of transportation to take		
Accurately calculate and pay for fare		
Safely board vehicle and exit vehicle		
Engage in appropriate passenger behavior		
Alert correct transportation person for stop if necessary		
Use safe and appropriate pedestrian skills (e.g., cross street, walk safely in parking lot)		
Read and respond appropriately to signs and traffic lights		
Identify and use landmarks as point of reference		
Access transportation information by phone/Internet		
Communicate verbal/written directions		
Time Management	PLAN FOR PRACTICE	ACCOMPLISHED
Use watch or clock to plan activities and get to appointments		
Set/use an alarm clock		
Utilize a calendar and/or appointment book		
Organize and establish priorities by order of importance		
Break down goals into manageable tasks (including seeking assistance if needed)		

Complete goals while following a plan		
Demonstrate awareness of relative length of time		
Identify basic needs including sleeping, eating, recreation, employment, and socialization, and schedule time for them		
<b>Health Management</b>	<b>PLAN FOR PRACTICE</b>	<b>ACCOMPLISHED</b>
Understand the difference between healthy and unhealthy food choices and habits		
Understand the health risks of using drugs, alcohol, and cigarettes		
Practice proper personal hygiene		
Understand how to use 911/local emergency numbers		
Understand basic First Aid (how to treat cuts, burns, bruises, etc.)		
Able to fill in a health and medical history form or ask for assistance		
Understand health insurance coverage and how to access benefits		
Understand own prescription medications (i.e., proper dosage, purpose, side effects and when to report any problems, how to refill)		
Aware of allergies and medication reactions		
Recognize symptoms of a cold, flu, fever, and other physical health issues		
Able to communicate any emotional health issues (e.g., stress, depression, or anxiety)		

Able to schedule and get to medical appointments (primary care, dentist, specialists)		
Attend regular health check-ups and dental visits		
<b>Money Management Skills</b>	<b>PLAN FOR PRACTICE</b>	<b>ACCOMPLISHED</b>
Understand basic financial terms (saving, spending, borrowing, taxes, debt, etc.)		
Describe what a budget is and give examples of expenses and income		
Read and interpret a pay stub		
Create a monthly budget		
Learn how to use a calculator to keep track of money		
Open a savings/checking account		
Use a checkbook and understand a bank statement		
Use a bank card at an ATM and how to pay for a purchase		
Maintain privacy around financial matters		
Be able to identify and protect oneself from a scam/fraud		
Consult with a trusted source around big financial decisions		
<b>Social Skills, Safety and Relationships</b>	<b>PLAN FOR PRACTICE</b>	<b>ACCOMPLISHED</b>
Use appropriate greetings		
Communicate appropriately with others, whether it be with gestures, sounds and/or use of augmentative communication devices		
Recognize verbal and non-verbal cues		

Identify problems and ask for help		
Assert oneself and appropriately express an opinion		
Show frustration tolerance		
Negotiate and compromise with others		
Is clean and neat in appearance, appropriate to situation		
Use polite words and understands social norms		
Demonstrate safety skills related to wandering, running away, or getting lost in a crowd		
Carry personal identification and know when to use it		
Know how to use local 911 and under which circumstances		
Know the difference between friends, acquaintances, and strangers		
Understand and exercise personal boundaries (e.g., identify appropriate and inappropriate places to touch another person)		
Understand "personal" conversational topics and appropriateness of sharing with others		
Differentiate between private and public locations		
Demonstrate how to tell a trusted person if treated inappropriately by someone		

## Resources

### ASSESSMENT TOOLS

#### Home Skills Checklist/Table A

**The University Of Washington  
Division Of Adolescent Medicine  
Adolescent Autonomy Checklist**

<http://asinfo.org/TbU1qA>

#### The Youth Transition Survey

Is an eight-page self-assessment tool for youth

<http://asinfo.org/11gITrB>

### HELPFUL WEBSITES FOR TRANSITIONING YOUTH WITH SPECIAL HEALTHCARE NEEDS

**Adolescent Health Transition  
Project Center on Human  
Development and Disability,  
University of Washington**

[www.depts.washington.edu/healthtr](http://www.depts.washington.edu/healthtr)

#### Got Transition: National HealthCare Transition Center

A national resource for healthcare professionals, families, youth, and state policy makers focusing on a young adult's transition from pediatric to adult healthcare.

[www.gottransition.org](http://www.gottransition.org)

(603) 228-8111

#### Transition to Adult Healthcare: A Training Guide in Two Parts

Offers a guide with separate sections for parents and teens about transitioning into adulthood.

<http://asinfo.org/XjPbWa>

#### Smooth Transitions

Booklet to help transition people with special needs from teen to adult.

[www.smoothtransition.us](http://www.smoothtransition.us)

#### Teens Health: Answers and Advice

Helps teens looking for information and advice about health, relationships, and growing up.

[www.teenshealth.org](http://www.teenshealth.org)

#### Family Village

Provides a forum for families on varied topics, including career interest inventories, employment, health, civil rights and legal information, transportation, programs and supports for youth and young adults.

[www.familyvillage.wisc.edu](http://www.familyvillage.wisc.edu)

### TOOLS FOR INDEPENDENCE

#### Autism Speaks Toolkit

<http://asinfo.org/118Unlg>

## Postsecondary Education

Many adolescents, with support from their families, want to go on to postsecondary education but do not know where to begin. For those with disabilities, the college experience may present some unique challenges. A first step is to find out what types of programs exist, and what will be the best match for the student, academically, geographically, socially, and in relation to their independent living skills.

It is important to keep an open mind, think creatively and do your research. Some colleges and universities have programs tailored to meet the needs of students with disabilities. Perhaps your adolescent may want to begin with community college or a specialized training program. Some schools may allow a student with interest in one particular subject to take one class at a time, audit classes or take online coursework. Each adolescent's needs and ability to manage the various and complex demands of postsecondary education will differ. Thus, it is important for the adolescent, parent, and high school team to think together and craft a plan that addresses important issues such as: identifying supportive staff in the postsecondary setting, considering disclosure of the student's disability, and preparing tools and accommodations that may be helpful toward creating a successful experience.

### TIPS AND RECOMMENDATIONS

- 1) Speak to your adolescent about their goals and dreams and begin the planning process early. Plan for college as soon as possible in the adolescent's IEP.
- 2) Include developing the academic, social, and independent living skills necessary to succeed in college in the adolescent's Transition Planning Form (TPF) (see the chapter about "Middle and High School Education Planning").
- 3) Consider a college internship program, which provides individualized social, academic, career, and life skills instruction for students to obtain the skills necessary to inspire independence and healthy social functioning. See [www.collegeinternshipprogram.com](http://www.collegeinternshipprogram.com) for more information.
- 4) Prepare thoroughly for visits to prospective colleges with your adolescent. **Speak to the Office of Disabilities as well as the Director of Admissions about your adolescent and his/her specific needs.** Your adolescent should **observe a class** and, in some cases, potentially **spend the night** at the school. See what resources are available, such as **peer mentoring, modified academic plans, and other services.**
- 5) When applying to colleges, **your adolescent may want to mention his or her disability on the application and also mention it to the professors after being accepted.** Colleges cannot discriminate based on disabilities. If your adolescent wants to disclose his or her disability, it may pave the way for more comprehensive and thoughtful planning. Parents

can help the student strategize about when and how to disclose one's disability to teachers. By educating teachers and informing them about their disability in advance, your adolescent may feel more empowered to ask for help when needed.

- 6) If a student wants to, parents can help their adolescent **obtain documentation** of their disability and share it with college administrators and teachers. As a group, **discuss what kinds of interventions and accommodations are appropriate**. Some teachers may need some psycho-educational assessments pertaining to your adolescent's disability. Try to keep lines of communication open and encourage your adolescent to take the lead in educational planning. Discuss the possibility of creating a helpful one-page document that describes your adolescent and his needs, which can be used at his/her discretion to give to appropriate staff.
- 7) Work with your adolescent on self-advocacy skills, such as recognizing his own needs, communicating those needs effectively to the appropriate people, and taking problem-solving initiatives such as using adaptive equipment (laptop, electronic organizer, etc.) in class or reaching out for support to professors and other school personnel.
- 8) Remember that unless your **adolescent signs** a Family Educational Rights and Privacy Act or FERPA (obtained at your postsecondary institution), you cannot communicate with the school about how your adolescent is doing. In some cases, families of adolescents with disabilities prefer that the adolescent's support system stay in contact to monitor progress and help facilitate a successful experience for the adolescent. Discuss this issue with your adolescent and make the decision about signing a FERPA form together.
- 9) **If your adolescent is living away from home in a dormitory, they may want to request a private room**. For example, some people are extremely sensitive to external stimuli (light, sound, etc.). For those students, it may be helpful to ask to be placed in a "study floor" or "quiet dorm" if possible. Create a relationship with the dorm's Resident Advisor (RA) staff that your adolescent can access if needed. RAs can be helpful in assisting the student transition into a new environment and provide guidance around social issues that may arise.
- 10) Your adolescent should **seek career counseling** as soon as possible. Selecting a career path and finding a job after graduation can be challenging for all students, and even more so for those with disabilities. It can be helpful to come up with a list of strengths and interests to share with career counselors, so that they can provide some direction in terms of courses, volunteer, and internship opportunities.
- 11) Your adolescent should keep the contact information of a **personal counselor** nearby for times of stress. Many issues that arise during the college experience can be daunting and it is therefore important to have contact with the university counseling department or a local mental health therapist who can be supportive during stressful times.

- 12) **Find a local medical provider** familiar with your adolescent's disability and access their services, so that any special medical needs can be attended to while away at school. Assess your adolescent's ability to attend to their own healthcare needs and adhere to their medical regimen (e.g. taking medication, refilling prescription, being aware of medication interaction with alcohol) so that you can make necessary accommodations as necessary.
- 13) To help develop a social life, encourage your adolescent to join an activity to meet people with similar interests. There are numerous clubs, organizations, and teams at colleges that may resonate with your adolescent's specific strengths and interests and provide satisfying social, as well as recreational opportunities and experiences.
- 14) **Consider online classes.** If the classroom environment is too stressful or cannot meet the adolescent's needs, online courses may be a better alternative. Keep in mind that online courses require self-motivation and discipline. If this may be more challenging for your adolescent, stick to typical classes.
- 15) Encourage your adolescent to seek out available academic supports within their institution. This may include tutoring centers, writing workshops and other services offered by the Office of Disability Services.
- 16) It is always wise to have a backup plan. Some students may begin college and then realize that their plans may need to be redefined or adjusted, or that greater supports are necessary to ensure success. Be flexible and recognize that there are many options for higher learning, and the best one for your particular adolescent will be unique to him.

## Resources

### Asperger's Association of New England- AANE

[www.aane.org](http://www.aane.org)

### Think College!

A program sponsored by the Institute for Community Inclusion, with an online tool to search for specific programs for students with disabilities.

[www.thinkcollege.net](http://www.thinkcollege.net)

### Going to College

A Resource for Teens with Disabilities: An interactive, video-based web site designed for high school students to learn more about themselves and the college experience from teenagers who have gone through the process.

[www.going-to-college.org](http://www.going-to-college.org)

### Project C3: Connecting Youth to Communities and Careers

Website with database called "Disability Friendly Colleges."

<http://asinfo.org/UXIcPM>

### LD Online

Website for students with learning disabilities and ADHD.

[www.ldonline.org](http://www.ldonline.org)

### Legal Rights Information About Auxiliary Aids and Services for Postsecondary Students with Disabilities

[www.ed.gov/about/offices/list/ocr/docs/auxaids.html](http://www.ed.gov/about/offices/list/ocr/docs/auxaids.html)

### Information on Preparing for College

[www.ldonline.org/indepth/college](http://www.ldonline.org/indepth/college)

### The Health Resource Center

Postsecondary programs and summer pre-college programs for individuals with disabilities.

[www.heath.gwu.edu](http://www.heath.gwu.edu)

### Assistive Technology Website

<http://asinfo.org/ZE8wpL>

### Colleges with Programs for Students with Learning Disabilities

<http://asinfo.org/VM0AMA>

### Legal Rights for Accommodations for Individuals with Disabilities

<http://asinfo.org/SFCQ1j>

### The 411 Disability Disclosure: A Workbook for Youth with Disabilities

[www.publications.iowa.gov/4778](http://www.publications.iowa.gov/4778)

### EducationQuest

Provides free college planning services to students with disabilities and addresses self-advocacy, entrance exams, choosing a college, admission and financial aid, rights and responsibilities etc.

[www.educationquest.org/free.asp](http://www.educationquest.org/free.asp)

### Association on Higher Education and Disability

[www.ahead.org/about](http://www.ahead.org/about)

### The National Center for Learning Disabilities: "Transition to College: Strategic Planning that Ensures Success"

<http://asinfo.org/UY0gcz>

### College Readiness Assessment

<http://asinfo.org/T2AiXS>

### Free Articles on Postsecondary Transitions

<http://asinfo.org/UDxD5x>

### Scholarship Information

#### Special People in Need

500 West Madison St.

Suite 3700

Chicago, IL 60661-2511

#### The Anne Ford Scholarship for College-Bound Students with Learning Disabilities

381 Park Avenue South, Suite 1401

New York, NY 10016

(212) 545-7510

Fax (212) 545-9665

(888) 575-7373

### For Kids with Autism Spectrum Disorders

#### Ahead

Offers \$500 book scholarships to qualified students who have autism or Asperger's Syndrome.

#### CVS/All Kids Can Scholars Program

Administered by the Autism Society of America, this program awards \$1,000 scholarships to qualified individuals with autism to pursue an accredited postsecondary educational or vocational program of study.

#### The Schwallie Family Scholarship Program

Provides \$3,000 scholarships for qualified students who have autism or Asperger Syndrome to attend college, a university or a trade, technical or vocational school.

## Employment

Finding meaningful employment is an important endeavor for most people as they enter adulthood. When planning for individuals with special needs, it is important to think broadly and creatively and to give due time to the extra preparation and training that may be necessary. Employment can come in a variety of forms. As your adolescent enters the working world, keep in mind that trials and errors will be a part of the process. Flexibility is essential and exploration should be encouraged as many young adults will find that their needs and interests will change over time.

The practical steps of an employment search will be different for each teen. Some adolescents will go directly from high school to a job. For others, this transition involves linking them first to supports such as job coaching. Other adolescents will go on to further their education past high school.

Encourage your adolescent to become their own advocate in the employment process. You can help your teen think about channeling their interests, strengths, and talents into a job and finding ways to learn about career possibilities and opportunities. They can connect with and learn from others who have entered the job market. Families can encourage their young adult to discuss their plans with guidance counselors, teachers, and other medical providers. All adolescents will benefit from paying close attention to the development of their job skills and experiences.

### ENVISIONING EMPLOYMENT

- **Use Person Centered Planning:** PCP is a term that refers to a process that brings a group of friends and associates together to help a person develop a plan for their future. The group comprises the individuals who know the person best. Using their shared knowledge, the group tries to paint a comprehensive picture of the person—their likes, strengths, abilities, and future goals. This picture can become the basis for developing an employment plan, with the adolescent leading the process and identifying their interests, needs, and preferences. It's meant to be a creative and positive process with both brainstorming sessions and concrete steps once the goals are decided.
- **Use your community networks and connections to identify and develop vocational experiences.** Talk to neighbors, friends, acquaintances, and others who know your child well and can help you identify potential part-time and summer employment opportunities, such as walking a neighbor's dog or mowing lawns. Also consider exploring volunteer opportunities.



**Begin thinking about work early.**

**Children can learn about working as early as preschool by watching family members and helping out at home.**

- Incorporate activities into your home, school, and community that build on strengths and develop new skills.
  - **School Activities:**
    - Talk to teachers about potential work opportunities and ask them how your adolescent can become more involved in your community (for example, volunteering in a community service organization at school);
    - Participate in your school’s career exploration and vocational programs with guidance from school staff; and
    - Explore and build on interests and hobbies through various school activities
  - **Home Activities:**
    - Consider assigning paid chores at home (for example, washing the family car, doing yard work, helping with laundry);
    - Ask school staff about potential home-based activities your young adult can do that parallels or reinforces vocational skills being taught at school;
    - Include your young adult in banking and shopping activities so they can learn budgeting and money management skills;
    - Introduce your young adult to community resources such as the YMCA or public library, and create opportunities for social interactions or volunteer work there;
    - Support your young adult in learning how to use public transportation and increasing independence in planning trips and using public transit;
    - Offer opportunities at home to develop leadership skills and build self-esteem (for example, identifying and planning a weekend family outing); and
    - Encourage and nurture hobbies and interests which can lead to the development of job-related interests and skills.
- Contact **family advocacy and employment support organizations** such as Advocates for Autism of Massachusetts (AFAM), Massachusetts Families Organizing for Change (MFOFC), the National Collaborative on Workforce and Disability for Youth, and the Institute for Community Inclusion to learn more about community and state agencies. (See the resource section at the end of this chapter for contact information.)
- Research companies online that are disability-friendly as possible options for employment or volunteer opportunities.
- Understand that employment services can include: **resume preparation, job placement assistance, and employment counseling, as well as job coaching, travel training, and benefits management.**
- Consider a **vocational assessment** for your adolescent as a way to clarify work-related interests, abilities, and strengths.
- Remember that **work experience can be helpful for all teens and youth, not only** students who are planning to go to college.

## PREPARATIONS DURING HIGH SCHOOL

- **Identify early on the supports and services that your adolescent will need** in order to succeed in the workplace.
- Involve your adolescent in the transition planning process by having him/her **attend school meetings and review the IEP**. Legally, he has the right to attend beginning at 14 or earlier if determined appropriate by the IEP team.
- **Beginning at 14, annual transition planning** must be included in the IEP (see instructions about the Transition Planning Form earlier in this chapter). At this early stage, transition planning focuses on developing **measurable postsecondary goals** that are based on transition assessments, a course of action that includes transition service needs and a course of study that will help the student achieve these identified goals.
- **At least two years prior to the student leaving high school (due to graduation or turning 22), a 688 Referral may have been made** and the team must continue to focus on necessary transition services. **This is when any identified linkages to other agencies should be identified and potentially included in the IEP process** (for example, to agencies such as DDS or MRC, etc.). **The school has to submit the 688 form, but it is always good for parents to be aware of timelines so they can remind the school if necessary.**
- Remember that transition services must be based on your adolescent's strengths, preferences, and interests. Consider the following when planning transition services: **instruction, employment, community experiences, post-school adult living and where appropriate, functional vocational evaluation, and daily living skills.**
- Ask your school about **local work training programs** that can help provide support, job coaching, and training to the adolescent.
- Encourage your adolescent to participate in voluntary **internships** in order to learn about possible job opportunities and to develop job skills.

## CHOOSING TYPE OF EMPLOYMENT

- Adolescents with special healthcare needs and disabilities can and should be encouraged to work so as to promote their independence and productivity.
- Employment scenarios can vary widely, however some general options may include:
  - **Individual-Community Employment:** This is the most typical type of employment. It is an integrated, individual placement where young adults work at a job in the community. They are hired and managed by the employer directly and earn similar wages and benefits as fellow employees. Individuals can receive support as needed, via job coaches, a fellow staff member, or a disability employment agency, etc. Over time, the goal is for the young adult to develop increased independence and for support to gradually diminish.
  - **Group Community Placement:** Group community placements are usually organized by disability employment agencies that place groups of three to ten individuals in an employment setting, such as a warehouse or supermarket. The group works together onsite with supervision from a staff person at the disability employment agency. Usually, there is a contract between the disability employment agency and the employer. Often,

the employer will pay the agency a fee, and the agency will pay the workers. Other times, the agency will pay the employer and the employers will, in turn, pay the workers.

- **Sheltered Workshops:** In this model, employers contract with disability employment organizations that exclusively place individuals in a facility-based setting, such as a factory, and often consist of assembly line or piece work labor in a segregated arrangement where all employees have disabilities. Employees are paid based on their productivity. During this past decade, there has been a shift away from this model and an effort to employ persons in community based employment.
- **Customized Employment:** As defined by the Office of Disability Employment Policy (ODEP), Customized Employment is a “flexible process designed to personalize the employment relationship between a job candidate and an employer in a way that meets the needs of both. It is based on an individualized match between the strengths, conditions, and interests of a job candidate and the identified business needs of an employer. This approach includes careful planning and support. For more information, [visit \*\*http://asdinfo.org/T5WMIK\*\*](http://asdinfo.org/T5WMIK)

## EMPLOYMENT AND LAWS AND BENEFITS

- Contact the **Social Security Administration or the Department of Public Health** about programs that may offer **financial assistance**.
- Learn about the state regulations and legal protections that exist regarding employment for people with disabilities. Contact your local Social Security Office to learn about the impact of earnings on your son or daughter’s benefits and **to learn about Social Security work incentives** (see “Going to Work: A Guide to Social Security Benefits and Employment for Young People with Disabilities,” published by the Institute for Community Inclusion).

## For more information:

### **Institute for Community Inclusion/UCEDD**

#### **UMass Boston**

100 Morrissey Blvd.

Boston, MA 02125

(617) 287-4300

Fax (617) 287-4350

TTY: (617) 287-4350

Email: [ici@umb.edu](mailto:ici@umb.edu)

*\*\*See ICI's "School Days to Pay Days/Employment Planning Guide for Families of Young Adults with Intellectual Disabilities"*

[www.communityinclusion.org/school-days](http://www.communityinclusion.org/school-days)

### **Massachusetts Rehabilitation Commission**

MRC is the state agency that helps individuals with disabilities live independently and go to work. The agency is responsible for Vocational Rehabilitation Services and Independent Living Services, among others.

600 Washington St

Boston, MA 02111

(800)-245-6543

(Voice/TDD) or (617) 204-3600

[www.state.ma.us/mrc](http://www.state.ma.us/mrc)

### **Pathways to Employment for Youth with Disabilities**

A program of Jewish Family & Children's Services

1430 Main St.

Waltham, MA 02451

(781) 647-5327

<http://asinfo.org/V9GHUN>

### **Department of Developmental Services**

500 Harrison Ave.

Boston, MA 02118

(617) 727-5608

Fax: (617) 624-7577

Email: [info@state.ma.us](mailto:info@state.ma.us)

[www.mass.gov/dds](http://www.mass.gov/dds)

### **Social Security Administration**

10 Causeway St.

Boston, MA

(800) 772-1213

[www.ssa.gov](http://www.ssa.gov)

### **National Collaborative on Workforce and Disability for Youth**

Making the connection between youth with disabilities and employment

[www.ncwd-youth.info](http://www.ncwd-youth.info)

### **Advocates for Autism of Massachusetts (AFAM)**

217 South Street

Waltham, MA 02453

(781) 891-6270

Contact: Judy Zacek

[www.afamaction.org](http://www.afamaction.org)

### **Massachusetts Families Organizing for Change (MFOFC)**

P.O. Box 61

Raynham, MA 02768

Tel: (508) 824-6946

Fax: (508) 824-6946

[www.mfofc.org](http://www.mfofc.org)

### **School Days to Paydays**

An employment Planning Guide for Families of Young Adults with Intellectual Disabilities

<http://asinfo.org/U3jyhW>

### **The Road Forward: A Guide to Transition Planning from the Massachusetts Office of Health & Human Services**

For English go to:

<http://asinfo.org/TSUCMe>

For Spanish, Portuguese, Chinese, Haitian-Creole, and Russian, go to:

<http://asinfo.org/15QsSh3>

## Healthcare

Parents of children with special healthcare needs and disabilities need to plan, connect, advocate, and find information on behalf of their child. Planning ahead is very important and makes a difference.

This chapter on healthcare transition explains important issues and lists practical steps that should be addressed. The chapter discusses two aspects of healthcare transition. The first aspect is the need for **increased responsibility** by the adolescent for his/her own healthcare. The second is the need for families to **plan for the transfer of care** from the pediatric provider to the adult provider.

- Begin early, but plan over a period of time. Make a plan that is specific to your adolescent and his/her special healthcare needs and developmental understanding.
- If your adolescent has a special healthcare need or disability significant enough to interfere with his/her ability to make financial and medical decisions, you will need **to file a petition to the court to maintain guardianship or initiate conservatorship at 18 years old**. For more information, go to the “Guardianship” chapter.
- Talk to your child about their disability **in a way that they can understand**. Work with their primary care provider to choose the key points and figure out how to make them clear.
- Assess your child’s knowledge about their own healthcare needs and ability to communicate with others about them.
- **Depending on the family and adolescent’s preference**, it may be helpful for the provider to suggest that the **doctor and adolescent meet privately to discuss topics such as physical and mental health (including safety concerns, substance abuse, and sexuality)**.
- Help your adolescent, if able, to understand the importance of the **medication** s/he takes (i.e., do they know the name, the proper dose, how to refill, etc.).
- Encourage your adolescent **to make his or her own healthcare appointments** and work with your child to ensure s/he **understands the routines** of visits (i.e., checking in with front desk, showing the insurance card, waiting until being called, and how to checkout). Go through a “practice run” with your adolescent.
- If your adolescent is verbal, encourage your adolescent to **prepare for doctor visits by writing down questions in advance**. He or she might want to keep personal health notes and records.
- Begin teaching your adolescent about their **insurance coverage**.
- Discuss with your primary care provider when you should **consider transferring your adolescent’s care to an adult provider**. Consider also the potential need for specialists such as psychiatrists, neurologists etc.
- **Talk to other families and young adults with similar special healthcare needs and disabilities** to help you identify appropriate adult providers for your adolescent and their unique needs.
- Consider the hospital where you would want your adolescent admitted in the future, if need be, and whether the adult provider you have chosen is affiliated with that hospital.
- **Schedule an interview visit with potential adult providers** before transferring your adolescent’s care. If possible, encourage your adolescent to call and schedule the visit.

- Ask your primary care provider to **transfer your adolescent's medical records** prior to transfer of healthcare to the adult provider.

## MASSHEALTH/MEDICAID

### Medicaid in Massachusetts is called MassHealth:

There are many different types of MassHealth. Eligibility for a particular MassHealth program is determined by family income and family size, as a percent of the federal poverty level, and whether or not you have a family member with a disability. Disability is determined by the federal criteria on the Social Security Administration (SSA) website.

Medicaid covers most necessary medical services, such as those provided by physicians, hospitals, clinics, long-term care facilities, medical equipment suppliers, and therapists. This also includes X-rays, prescription drugs, and eyeglasses.

### MASSHEALTH FOR YOUNG PEOPLE WITH DISABILITIES WHO WORK

Two types of MassHealth benefits may be available to young people with disabilities who get SSI or SSDI and who want to work: MassHealth Standard and MassHealth CommonHealth.

#### MASSHEALTH STANDARD

This program automatically gives health coverage to SSI recipients. Young people who are not on SSI may apply separately for MassHealth Standard. To be eligible for MassHealth Standard, a person must have a low income. However, there is no asset (resources) limit for MassHealth Standard benefits that are requested separately from SSI benefits.

#### MASSHEALTH COMMONHEALTH FOR WORKING ADULTS

This program covers adults age 18 through 64 who are over the income limit for MassHealth Standard but meet the same disability standards and work at least 40 hours per month. CommonHealth covers most of the same benefits as the MassHealth Standard program. CommonHealth Working members pay a monthly premium that increases as their income goes up. There are NO income or asset limits for the CommonHealth Working program. There is also a MassHealth CommonHealth program for people who are not working. People in the CommonHealth Non-Working program pay a substantial one-time deductible, in addition to a premium if they are over age 18.

You must complete a Medicaid application and submit proof of the information the Division of Medical Assistance (DMA) requests. For further information, you can contact the DMA at (800) 841-2900 • [www.medicare.gov](http://www.medicare.gov) or call (800)-Medicare.

## ARICA FOR AUTISM INSURANCE COVERAGE

### What is the autism insurance law?

Massachusetts is one of many states with a law requiring health insurers to cover specified services for the diagnosis and treatment of autism spectrum disorders. The law is called ARICA (An Act Relative to Insurance Coverage for Autism) and went into effect on January 1, 2011 (or on the day in 2011 that your insurance plan renewed).

Although ARICA calls for insurance providers to cover medically necessary autism treatment, not all Massachusetts insurance plans are required to comply with it. Plans that are not subject to ARICA include MassHealth and “self-insured” (also known as ERISA) plans. However, it is sometimes possible for individuals who have coverage under these plans to obtain ARICA-mandated benefits. If you are covered by a plan that isn’t subject to ARICA, please refer to the specific information in the following Frequently Asked Questions (FAQs), prepared by the Autism Insurance Resource Center, a division of New England INDEX/UMass Medical School Shriver Center.

### What does ARICA do?

ARICA requires health insurers in Massachusetts to provide coverage for the diagnosis and treatment of Autism Spectrum Disorders. You can find the full text of the law [here](#).

### When does ARICA go into effect?

ARICA went into effect January 1, 2011, but implementation is based on each policy’s specific renewal date. If you have insurance under a policy that is subject to ARICA (see below), the coverage must be provided when the policy renews on or after January 1, 2011, meaning it will go into effect the date that your company’s insurance plan renews annually.

### What types of policies does ARICA cover?

Massachusetts legislation can only affect certain types of healthcare policies, so coverage under ARICA will depend on the type of policy you have. Private insurers, employees and retirees under the state plan, hospital service plans, and HMOs are all required to comply with the mandate. Self-funded plans are regulated by ERISA – which is federal law. This includes many of the state’s largest employers. ERISA plans are not subject to state laws and not required to provide coverage under ARICA.

### How can I find out if I have coverage under ARICA?

Contact your employer to verify that your policy is subject to the new law, and if so, what annual date your group policy renews. Even if your company is regulated by ERISA they may, as practice, comply with state laws. In addition, there is language in the recently enacted federal healthcare reform that will eventually cover autism treatment. If you are covered by an ERISA plan, please contact the Autism Insurance Resource Center at (781) 642-0248 for additional information and assistance in advocating for coverage with your company.

## Are individuals or family members covered for services under MassHealth or CommonHealth?

These plans are not subject to the new law, but consumers should know the following:

- MassHealth may cover co-pays and deductibles for some ARICA-mandated treatments covered by private insurance.
- The Premium Assistance Program can help subsidize purchase of private insurance policies and policies through Commonwealth Choice that will cover ARICA.
- Families covered by MassHealth with children under age 9 can also apply for the Massachusetts Children's Autism Medicaid Waiver through DDS. Note: This is a limited program with specific application windows; check with DDS for more information.
- In certain cases, consumers may be able to access some treatments through the Early Prevention, Screening, Diagnosis and Treatment (EPSDT) Program.

## Is there a limit to the amount of the coverage?

No. The diagnosis and treatment of Autism Spectrum Disorders will not be subject to any annual or lifetime dollar or unit of service limitation on coverage which is less than any annual or lifetime dollar or unit of service limitation imposed on coverage for the diagnosis and treatment of physical conditions.

## Is there an age limit to this coverage?

There is no age limit.

## How are education services affected?

ARICA does not affect educational services provided under an IFSP, IEP or ISP. Insurers are not required to pay for in-school services. Conversely, under IDEA, schools may not require parents to access private insurance for services that are part of FAPE.

## The FAQs are also available in the following languages:

[ARICA FAQs: Spanish \(PDF\)](#)

[ARICA FAQs: Vietnamese \(PDF\)](#)

For further information about ARICA, please contact an Autism Insurance Resource Center Information Specialist at 781-642-0248 or [info@disabilityinfo.org](mailto:info@disabilityinfo.org), or visit [www.disabilityinfo.org/arica/](http://www.disabilityinfo.org/arica/)

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## Resources

### Family Ties

Family TIES (Together in Enhancing Support) of Massachusetts is a statewide information and parent-to-parent support project for families of children with special needs and chronic illness. It is a project at the Federation for Children with Special Needs.

Massachusetts Department of Public Health

Donovan Health Building, 3rd Floor

5 Randolph St.

Canton, MA 02021

(781) 774-6736

[www.massfamilyties.org](http://www.massfamilyties.org)

### Family Voices

The national advocacy organization speaks on behalf of children with special healthcare needs.

(505) 872-4774 or

(888) 835-5669

[www.familyvoices.org](http://www.familyvoices.org)

*Provides an online parent discussion forum for parents to network and share resources regarding health care.*

### Massachusetts Family-to-Family Health Information Center (a project of the Federation for Children with Special Needs)

If you need assistance completing your MassHealth application, consider calling this resource. The center offers free technical assistance pertaining to MassHealth and other health care financing option for families.

(800)-331-0688, ext. 210

<http://massfamilyvoices.org/F2FHIC.html>

### National Healthcare Transition Center "Got Transition"

[www.gottransition.org](http://www.gottransition.org)

For more information:  
Family to Family Healthcare Information Center (800) 331-0688, Ext. 210

## Housing

Thinking about where your adolescent or adult with disabilities will live can be a stressful issue full of uncertainty. Many questions include: What are my options? What if he or she cannot live alone and take care of themselves? Will my adolescent be well-cared for and happy? Who will pay for it?

Adults with disabilities live in a range of environments that can include completely independent living situations, shared living arrangements, supported group homes, and more restrictive residential settings. Planning early for this process is very important and requires a great deal of research, networking, and preparation. If your son or daughter has more cognitive and intellectual disabilities, they may qualify for services through the Department of Developmental Services (DDS) as an adult. However, unlike educational services, DDS services depend on available resources and are not entitlements. If your adolescent does not receive housing assistance through DDS, you have other options such as public housing and private-pay group living arrangements.

Multiple housing options exist and it's important to remember that each individual will have different needs and choices. The following is a guide for parents as they begin the process.

### To Determine Housing:

#### STEP ONE: ENVISION AN IDEAL SETTING FOR YOUR ADOLESCENT WITH DISABILITIES

All parents want their children to be safe and happy as adults. It can be helpful for parents to try and envision what environment would be best as they begin to think about adult living situations. Where would your adolescent thrive? Do they prefer the country or city? What are their transportation options? How important is living in close proximity to the family? In general, there are six residential options for adults with disabilities: Living:

- 1) Independently in the community.
- 2) At home with the family (with consideration to long-term needs).
- 3) In homes or apartments (alone or shared) with services that come in and check on residents (assistance with bill paying, personal care, cleaning, etc.).
- 4) With supervised living arrangements. Programs often referred to as “group homes” provide housing, meals, case management and other services with 24 hour on-site supervision.
- 5) In a home-sharing or shared-living scenario — an option that pairs a person with disabilities with a live-in caregiver or companion in exchange for room and board or a stipend.
- 6) In “dorm-style” facilities, such as a nursing home or residential setting.

## To Determine Housing:

### STEP TWO: IDENTIFY YOUR ADOLESCENT'S SPECIFIC NEEDS AND ABILITIES

The next step is to identify your adolescent's life skills to figure out what supports will be needed to make the living situation workable. Key among the skills young adults will need to live independently is the ability to manage finances, shop, cook, clean and manage personal hygiene. Families should also work closely with their special education team to ensure that their adolescent enjoys opportunities to develop the independent living skills identified in their IEP as the most important to prioritize. See the "Independent Living Skills" chapter for a more comprehensive list of important considerations.

### STEP THREE: DETERMINE YOUR IDEAL SETTING

Once parents and their adolescent have identified an ideal living situation, the next step is to determine whether such a setting already exists or whether the family will have to create the setting. Many parents have explored creating their own unique options such as co-investing in a group home with other parents and adolescents. Some are funding or developing supportive living situations; others are envisioning and creating work/home settings in towns, cities, and rural areas.

Often, information about adult living situations in your state is available through the Department of Housing and Urban Development. In Massachusetts, DDS may also offer some guidance and support around housing resources. In addition, you can explore options available through nonprofit agencies such as Autism Housing Pathways ([www.autismhousingpathways.net](http://www.autismhousingpathways.net)), Advocates, Inc. ([www.advocatesinc.org](http://www.advocatesinc.org)), Living Independently Forever, Inc. ([LifeCapeCod.org](http://LifeCapeCod.org)), Jewish Family & Children's Service (<http://asdinfo.org/15iX8zW>), and 3LPlace ([www.3lplace.org](http://www.3lplace.org)). Do your homework to determine what's available. It is important to network with other families!

### STEP FOUR: HOW TO GET SPECIFIC

Once you've imagined your ideal setting and determined your adolescent's appropriate needs, research housing options that meet those criteria. If getting funding through DDS, a Service Coordinator may offer a list of places to tour. If this is not the case, consider private options. For all settings, parents and adolescents can take an official tour and narrow down their options. While you are researching, look carefully at:

- Staff turnover (if relevant to the housing option).
- Any reports of abuse.
- The quality of individual caregivers.
- The quality of facility conditions.
- Level of staff support (for ex: round the clock staff availability).
- Length of the wait list.
- Medication policies (is psychotropic or stimulant medication allowed in the specific facility).

## FINANCIAL ASPECTS OF HOUSING

### DDS or DMH Funding

In Massachusetts, the Department of Developmental Services (DDS) and/or the Department of Mental Health (DMH) can provide supportive housing for some individuals who are not capable of living independently (see the “Public Benefits and Government Agencies” chapter).

The determination of whether you will receive DDS funding for housing is based on multiple assessments, primarily an instrument called the MASSCAP (see the “Public Benefits and Government Agencies” chapter) as well as IQ testing. If it is determined that your adolescent will need funding for supported housing, DDS may offer financial assistance. This is not always possible and depends on the current budget and available resources.

If you meet eligibility requirements and funding is available, there are multiple options for housing.

DDS usually contracts with non-profit agencies that are responsible for supervising the living arrangements. Generally, these are the most commonly used living arrangements. Here are some of the most common living arrangements:

### Supported Living

Homes or apartments (alone or shared) with service providers that come in and check on residents (for example: assist with bill paying, personal care, house cleaning, etc.). This is considered a “supported living” arrangement and typically serves people who do not need 24-hour supervision or support. These options can be privately or publicly funded.

### Supervised Living

Programs often referred to as “group homes” provide housing, meals, case management, and other services with 24-hour onsite supervision. Typically there are two–five residents living together in a house or in an apartment that is owned by a provider agency contracted through DDS, DMH, or operated privately.

### Shared Living or Home-Sharing

This is an option that pairs a person with disabilities with a live-in caregiver or companion in exchange for room and board or a stipend. These options may also be funded through contracts with DDS or DMH.

### “Dorm-style”

These are larger facilities, such as a nursing home or residential setting.

## SECTION 8 HOUSING

Section 8 housing is a federal assistance program that helps low-income Massachusetts residents pay for their housing. In this program, people can either receive a voucher, which they use to get an apartment at a discounted rate, or they can move into an apartment complex that is exclusively

reserved for tenants receiving Section 8 assistance. A person may apply to either voucher program (see below), either to each program separately or to several programs simultaneously. Individuals can apply to any programs that have an open waiting list. However, they can only receive one type of assistance.

The waitlist is usually longer for voucher programs. Different factors can influence your place on the waitlist. For example, individuals with disabilities will be prioritized along with other populations, such as homeless individuals, veterans, and families with young children. Despite the prioritization, waitlists tend to be many years long. For more information about waitlists and housing availability, please contact your local housing authority.

### Section 8 Tenant-Based Vouchers

With a Section 8 tenant-based voucher, a family or an individual may choose their own apartment. The apartment must be safe and clean, and the rent must be reasonable. Families usually pay 30 percent of their income for rent, and the Section 8 program pays the rest. If the family moves, they may use their voucher for a different apartment.

### Section 8 Project-Based Vouchers

With a project-based Section 8 voucher, a family must live in a specific Section 8 subsidized housing unit. These subsidized housing units are privately owned, but the owners get help from the government in return for low rents. Families usually pay 30 percent of their income for rent and utilities, and Section 8 pays the rest. If the family moves, the voucher goes to the next family that rents that apartment and there is no assistance provided for the person moving out.

Unfortunately, Section 8 has incredibly long waitlists. Your adolescent must wait until turning 18 before they can apply for Section 8 housing. Waitlists vary, but sometimes can be up to ten years or more. Many individuals live at home while they are on the waitlist. Also, it is highly advised to check-in annually to ensure that your adolescent's name remains on the waitlist.

#### Metropolitan Boston Housing Partnership

125 Lincoln Street, 5th Floor, Boston, MA 02111

(617) 859-0400 or (800) 272-0990

[www.mbhp.org/index.asp](http://www.mbhp.org/index.asp)

#### The Metropolitan Boston Housing Partnership

Is a non-profit agency that assists families and individuals in their search for safe and affordable housing. Contact them for help with the Section 8 process or with any other housing-related questions. They also offer other helpful services and resources, such as information about home modification programs, utility discounts, home buying assistance etc.

For more information, see [www.massresources.org](http://www.massresources.org), or contact: <http://asinfo.org/14rTof8> or [www.massresources.org/adult-family-care.html](http://www.massresources.org/adult-family-care.html)

## FOR ADOLESCENTS LIVING AT HOME AND OTHER PRIVATELY FUNDED LIVING ARRANGEMENTS

If your young adult continues to live at home and has Mass Health, they may qualify for a Personal Care Attendant (PCA) hours. A PCA is someone who can help your young adult perform activities of daily living (such as bathing, dressing, and feeding). For more information, see the “Public Benefits and Government Agencies” chapter.

Placements are also available at privately run living facilities, such as group homes. Nonprofit community agencies often run these programs and provide a residence, meals, supervision, and transportation and host social events. Residents are grouped according to diagnosis and their independent living skill competencies; i.e., some residences have 24-hour supervision, while others are staffed only during select hours.

Some families are able to purchase and staff private apartments or homes. They can team up with other parents or do it independently. Sometimes, DDS may provide the staff for the home. There are agencies that specialize in these kinds of housing arrangements. One primary resource is the Specialized Housing Company: [www.specializedhousing.org](http://www.specializedhousing.org). (617) 277-1805. See resources section at the end of this chapter for more specific information.

Autism Housing Pathways (AHP) is a Massachusetts-based organization that provides information, support, and resources to families who seek to create secure, supportive housing for their adult children with disabilities. For more information, see [www.autismhousingpathways.net](http://www.autismhousingpathways.net) or call 617-893-8217.

Other organizations to explore: [www.31place.org](http://www.31place.org) or [www.sagecrossingfoundation.org](http://www.sagecrossingfoundation.org).

## Resources

### Massachusetts Rehabilitation Commission Home Modification Program

State-funded program providing loans for access modifications to homes of adults with disabilities.

27 Wormwood Street

Boston, MA 02210

(617) 204-3600

[www.mass.gov/mrc](http://www.mass.gov/mrc)

### MASS ACCESS: The Accessible Housing Registry

A free program that helps people with disabilities find rental housing in Massachusetts, primarily accessible and barrier free housing. The database tracks accessible and affordable apartments throughout the state, maintaining information about their availability.

[www.massaccesshousingregistry.org](http://www.massaccesshousingregistry.org)

### Arc/Massachusetts

See housing guide titled "Building a Future: Strategies on supported housing for young adults with intellectual and developmental disabilities."

<http://asinfo.org/VOYOu3>

[www.arcmass.org](http://www.arcmass.org)

### Mortgage and Home Loan Help Guide

<http://asinfo.org/Y8lBCc>

### INDEPENDENT LIVING CENTERS IN MASSACHUSETTS

These are private, nonprofit, consumer-controlled, community-based organizations providing services and advocacy by and for persons with all types of disabilities. Their goal is twofold: to create opportunities to promote independence and to assist individuals with disabilities to achieve their maximum level of independent functioning within their families and/or communities.

#### Berkshire County

##### Ad-Lib, Inc.

215 North St.

Pittsfield, MA 01201

(413) 442-7047

TTY (413) 442-7158

##### Stavros Center for Independent Living, Inc.

200 Old Farm Road

Amherst, MA 01002

Voice/TTY (413) 256-0473

[staff@stavros.org](mailto:staff@stavros.org)

#### Metropolitan Boston

##### Boston Center for Independent Living

60 Temple Place, 5th floor

Boston, MA 02111

(617) 338-6665

TTY (617) 338-6662

[www.BostonCIL.org](http://www.BostonCIL.org)

#### Worcester County

##### Center for Living and Working

484 Main Street, Suite 345

Worcester, MA 01608-1874

(508) 798-0350

[www.centerlw.org](http://www.centerlw.org)

#### Cape and Islands

##### Cape Organization for the Rights of the Disabled

1019 Iyanough Rd. #4

Hyannis, MA 02601

Voice/TTY (508) 775-8300

[www.cilcapecod.org](http://www.cilcapecod.org)

#### Southeastern Mass.

##### Independence Associates

141 Main St. 1st Floor

Brockton, MA 02301

Voice/TTY (508) 583-2166

[www.iacil.org](http://www.iacil.org)

##### Southeast Center for Independent Living

Merrill Building

66 Troy Street

##### Roxbury, Dorchester, Hyde Park, Jamaica Plain, Roslindale, Mattapan, West Roxbury

##### Independent Living Project

Multicultural Independent Living Center

22 Beechwood Street

Dorchester, MA 02121

(617) 288-9431

TDD (617) 288-2707

[www.milcb.org](http://www.milcb.org)

## Resources (Cont.)

### Metrowest

#### Metro West Independent Living Center

280 Irving St. #401

Framingham, MA 01702

(508) 875-7853

[www.mwcil.org](http://www.mwcil.org)

### Northeastern Mass.

#### Northeast Independent Living Program

20 Ballard Rd.

Lawrence, MA 01843

Voice/TTY (978) 687-4288

[www.nilp.org](http://www.nilp.org)

### Fall River and New Bedford

#### Southeast Center for Independent Living Merrill Building

66 Troy Street

Fall River, MA 02721

Voice/TTY (508) 679-9210

[www.secil.org](http://www.secil.org)

### Independent Living Center of the North Shore and Cape Ann

27 Congress St. Suite 107

Salem, MA 01970

Voice/TTY (978) 741-0077

[www.ilcnsc.org](http://www.ilcnsc.org)

*This information is provided by the Massachusetts Rehabilitation Commission*

- Regional Housing Agencies (RAAs) provide both Section 8 and housing counseling state-wide. The website [www.masshousinginfo.org](http://www.masshousinginfo.org) provides detailed housing information and a directory of RAAs for your region.
- In addition, a number of Local Housing Authorities (LHAs) also participate in a centralized waiting list for Section 8 assistance administered through 86 LHAs state-wide. For more information, visit: <http://asinfo.org/T53AVD>

For the most up to date information on resources visit  
[www.autismconsortium.org](http://www.autismconsortium.org)

# Day Habilitation Programs

## DAY REHABILITATION PROGRAMS

Some adults with disabilities attend structured programs during the day where they work on a variety of functional and vocational skills and enjoy recreation and social opportunities with others. These Day Habilitation programs (Day Habs) programs usually take place at non-profit community agencies with employed staff and are typically funded by Medicaid or sometimes by DDS or DMH. Goals may focus on improving communication skills, personal care, leisure and gross motor skills, as well as socialization skills in the community. Activities may include: exercise, community experiences, volunteer opportunities, art and music therapy, food preparation, and learning to attend to personal care needs. For information on specific programs, speak to your young adult's Service Coordinator at your state agency's local area office, such as DDS ([www.mass.gov/DDS](http://www.mass.gov/DDS)) or DMH ([www.mass.gov/DMH](http://www.mass.gov/DMH)). Clients must be Medicaid-eligible ([www.mass.gov/masshealth](http://www.mass.gov/masshealth)).

Many adults with developmental disabilities require specialized support to achieve community inclusion. Day Habs programs provide individualized support for adults of all ages, including those with complex medical needs. These programs combine medical monitoring including nursing and ancillary supports such as; physical, occupational and speech therapies with assistance with daily living skills training and active community involvement. There are also day programs for individuals who have significant mental health issues and who meet criteria for the Department of Mental Health ([www.mass.gov/dmh](http://www.mass.gov/dmh)).

## RECREATION

Recreation is more than planned programs that happen in a park or gym. It can be any activity that helps a person to explore or relax or have fun. Recreation can occur in the home or in a community setting. For the adolescent with special needs, recreation is especially important. The physical and emotional benefits of relaxation, social connections, and staying active in different ways can help to create a more fulfilling and joyful life.

Families can assist their adolescent in finding recreational opportunities. This can come in the form of structured activities or can also be as informal as hanging out with a peer in a relaxed setting.

### Here are some tips to help you explore suitable recreation opportunities:

- Highlight your adolescent's strength and interests by noticing what excites him/her.
- Remember that "fun" is a personal experience. Fun for your adolescent may be different than for someone else. For example, an activity like bowling may be fun for one person but confusing, loud, or uncomfortable for another person. Recreation and leisure should be FUN for everyone involved. If your adolescent does not enjoy it, it does not create an incentive for them to participate in it.
- Make friendships a priority. Adolescents benefit from sharing their lives with others in their peer group.
- Include recreation in transition planning. Make this a subject for your team IEP/ISP meeting.

- Discuss with your adolescent's primary care physician any health-related limitations your adolescent may need to consider when planning recreational activities.
- Identify your adolescent's need for accommodations.
- Encourage your adolescent to try out new and different activities.
- Explore organizations such as the local YMCA to see if the recreational activities available are a good fit for your adolescent. Inform staff about adaptations or accommodations your adolescent might need to participate in recreation activities.
- Remember to coach your son or daughter when they try new things. Helping them prepare for new experiences that require new skills or unfamiliar social expectations is important to increase the likelihood that s/he will enjoy their recreation time.
- Ask other parents about successful recreational experiences. Work with other parents to create new ones where they don't exist.
- Check out the school or local library for fliers on adolescent activities in your community. Surf the Internet for groups dedicated to common interests and recreational group outings. Review Internet safety with your adolescent and have an open dialogue about meeting new people safely and appropriately.
- Check out calendars of agencies that serve persons with similar disabilities for local events (Asperger's Association of New England, local Arcs, Special Olympics, etc.).
- Let your young adult take the lead as a teacher with something they are good at doing. If video games or trivia are a specialty, ask them to teach you or other peers how to do something. By giving your adolescent a leadership opportunity, they can feel like an expert and not like they are always being subjected to "programs".
- Review safety tips with your adolescent and ensure mutual agreement and understanding. These can include: Internet meet ups, rules for touching, peer pressure, emergency preparedness, etc.



## Resources

### THERAPUTIC RECREATION OPTIONS AND IDEAS

Below are some of the local organizations and programs that provide physical and activity and social opportunities for individuals with special needs

#### **Ability Plus, Inc.**

Their mission is to offer increased access to athletic and recreational opportunities for persons with physical and/or cognitive disabilities that will create freedom, promote independence, support inclusion, and help those individuals and their families discover their full social, mental, and athletic potential.

[www.abilityplus.org](http://www.abilityplus.org)

#### **All Out Adventures**

This agency promotes health, community, and independence for people with disabilities and their family and friends through outdoor recreation.

[www.alloutadventures.org](http://www.alloutadventures.org)

#### **AccessSport America**

A national non-profit, this organization, inspires higher function and fitness for children and adults living with

disabilities through high-challenge sports and training.

[www.accessportamerica.org](http://www.accessportamerica.org)

#### **The Arc of Massachusetts**

The specific section under Community Services, Recreation and Leisure has information and highlights important resources. Many of the local Arc Chapters have Recreation Departments and provide structured social and recreational programs.

[www.arcmass.org](http://www.arcmass.org)

<http://asdinfo.org/ZaKXor>

<http://asdinfo.org/XOCTsV>

#### **Massachusetts Special Olympics**

The mission of Special Olympics Massachusetts (SOMA) is to provide year-round sports training and athletic competition in a variety of well-coached Olympic-type sports for individuals with intellectual disabilities.

[www.specialolympicsma.org](http://www.specialolympicsma.org)

#### **Massachusetts Department of Recreation, Universal Access Program**

This program is dedicated to providing outdoor recreation opportunities in

Massachusetts State Parks for visitors of all abilities. Accessibility to State Parks is achieved through site improvements, specialized adaptive recreation equipment, and accessible recreation programs.

<http://asdinfo.org/URUhud>

#### **YMCA**

Check with your local area YMCA to ask about specialized programs.

[www.ymca.net](http://www.ymca.net) (national site)

[www.ymca.net/find-your-y/](http://www.ymca.net/find-your-y/) (local)

#### **Kids In Disability Sports**

Lowell, MA

[www.kidsindisabilitysports.com](http://www.kidsindisabilitysports.com)

#### **The Bridge Center**

The Bridge Center is a fully-accessible 20+ acre campus located in Bridgewater, MA that offers year-round, summer camp, and equine assisted programs for children, teens, and adults with special needs.

[www.thebridgectr.org](http://www.thebridgectr.org)

## Public Benefits and Government Agencies

### A BEGINNER'S GUIDE TO MASSACHUSETTS STATE AGENCIES, HEALTH INSURANCE, AND SOCIAL SECURITY

As your child enters adulthood, he or she may be eligible for certain services and benefits. The following is a basic guide to help clarify what those services and benefits are and how to access them.

#### DEPARTMENT OF DEVELOPMENTAL SERVICES (DDS, FORMERLY DMR)

In Massachusetts, the Department of Developmental Services (DDS) supports children and adults with intellectual disabilities, including autism spectrum disorders within rules and regulations that can be difficult to understand. DDS offers an array of specialized services and supports for eligible adults, that may include service coordination, community residential support, facility support, community day support, individual support, employment support, and family support services (which may include home-based respite). **Because adult eligibility for DDS is determined (or re-determined if your adolescent previously received services) at 18 years of age**, it is always best to be as prepared as possible by having all the required documentation. As an applicant or guardian, you are responsible for obtaining all relevant information needed to determine eligibility.

#### How to Apply

- 1) Complete an application form and fax or mail to the Regional Eligibility Coordinator that your town belongs to (you can find your local office at <http://asinfo.org/UaSz7t>).
- 2) Once the application is received, you will be contacted by the Regional Eligibility Coordinator from your local DDS office to schedule a face-to-face meeting to begin the process of determining eligibility.
  - **Basic criteria for meeting eligibility:**
    - A) Adults 18 years or older who have intellectual disabilities (IQ of 70 or below and limitations in adaptive functioning in at least two skill areas).
    - B) People whose permanent primary home is in Massachusetts.
    - C) People who need assistance to live and work in the community.
  - Specifics of determining the eligibility will be based on standardized tests (intellectual and functional assessment), which are assessed by DDS. The information that you may be asked for includes: (1) the applicant's functional abilities, (2) family information, (3) Social Security number, (4) insurance information, and (5) other legal documents such as guardianship decree, birth certificate, and immigration papers. In addition, you or your family member will be asked to give DDS permission to get records, such as school records, psychological test reports, and medical records that will be used by the Regional Eligibility Team in making a decision.
- 3) You will get a formal, written decision within 60 days stating that the applicant is either eligible or ineligible or that a decision has been deferred.

- A) If eligible, you will be contacted by the Service Coordinator to continue the process.
  - B) If ineligible, you may file for an appeal and the information will be provided to you about the process.
  - C) If deferred, you will be told to provide further information to complete the eligibility process.
- 4) Once your young adult is deemed eligible for the service, their documents will be sent to your nearest local office.
- A Service Coordinator from your local office will contact you and help with the process of providing extra information that the office may need. The Service Coordinator will also present your case to the administrators and the directors of the office for determination of services.
  - Once your case is presented, the administrators and the directors will determine whether you will receive the services.
- 5) **Community-Based Services Waivers:** Massachusetts provides home and community-based services through the federal Medicaid Home and Community-Based Services (HBCS) waiver program. This program allows Massachusetts to use funds that would have been used to pay for institutional care, for a wide variety of home and community-based services for individuals who lived in institutions or were at risk of entering institutions. **Services include in-home and community-based services such as personal care, transportation, supported employment, adaptive technology, housing modifications, and respite.** The services you get depend on your needs. Waiver participants and their families help design their own service plan and can choose their own service providers. For more information related to the waiver, please visit the DDS website, [www.mass.gov/dds](http://www.mass.gov/dds). For information about the Intellectual Disabilities Waiver, call: (617) 727-5608.

## Important to know about DDS:

- A) **Gaining the eligibility is just a first step; it opens the door to accessing the services but does not guarantee the services.**
- B) The decision about whether your young adult will receive services is made on a case-by-case basis by the administrators and directors of your local DDS office, depending on their funding availability and the severity of the needs.
- C) Your Service Coordinator will guide you through the process.
- D) Advocacy by the Service Coordinator may be a key to gaining access to the services.
- E) Often times with large agencies such as DDS, workers assigned to your adolescent's case may change. This can be challenging and requires you to stay well-informed throughout the process by keeping good records and paying attention to all contact personnel.

## DDS IN HIGH SCHOOL

For students who receive a 688 Referral to DDS, the role of the Transitional Agency (TA) is delegated to the DDS Area Office that covers the town of the responsible local school system.

### What is a DDS Transition Coordinator?

A Transition Coordinator, sometimes called the “688 Coordinator”, is a case manager who works at the local DDS Area Office. The Transition Coordinator’s caseload consists of individuals ages 18-22 who have been found eligible for adult supports through DDS. The Transition Coordinator is the primary link to information and assistance from DDS during the transition from special education to adult life. The Transition Coordinator will help the individual and family understand what DDS can offer and assist with identifying and securing requested supports, subject to MASSCAP (Massachusetts Comprehensive Assessment Process) prioritization for those supports. Soon after graduation or when an individual leaves school and transitions into adult supports, an individual’s case will be transferred to an adult Service Coordinator within the Area Office.

### What is an ITP?

The Individual Transition Plan (ITP) is the document that specifies what kinds of support the student/family is requesting upon leaving special education. It is a DDS document and is different than the Transitional Planning Form completed by the high school when your child is 14. The Transitional Agency (usually, but not always DDS) arranges and chairs a meeting or meetings in order to develop the ITP. The ITP meeting is normally held about one year before the student is ready to leave school, and typically involves the student, family members, school personnel, and other individuals who know the student well. The purpose of an ITP meeting is to develop a plan that includes the interests, skills and needs of the student. The ITP does not contain specific goals and objectives, or identify specific provider agencies. The ITP functions as more of a “blueprint” of the student’s requested support needs. Supports identified in the ITP are not guaranteed and do not create an entitlement; they are subject to prioritization, appropriation and availability. The DDS Transition Coordinator conducts the meeting and writes the ITP. DDS’s Central Office reviews the plan and sends it to the individual or guardian for approval.

### What is the MASSCAP (Massachusetts Comprehensive Assessment Profile)?

The MASSCAP is an evaluation used by DDS that determines what level of care an adolescent with disabilities will need as an adult. In particular, it addresses the question of who needs DDS funded residential supports, 24 hours per day, seven days a week. For more information about the MASSCAP, visit: <http://asinfo.org/VnUwdZ>

## MASSACHUSETTS REHABILITATION COMMISSION (MRC)

The Massachusetts Rehabilitation Commission (MRC) assists individuals with disabilities with living and working independently. MRC provides vocational rehabilitation services, community services, and assistance with eligibility determination for the Supplemental Security Income (SSI) federal benefits programs for Massachusetts citizens with disabilities. MRC also serves as an adult agency

for some students that are found eligible for 688 plans in high school. MRC serves people with all types of disabilities except those who are blind (please contact Massachusetts Commission for the Blind for further resources).

**MRC's Vocational Rehabilitation (VR) Program** assists individuals with disabilities in obtaining and maintaining employment. The Vocational Rehabilitation Program helps individuals with disabilities who want to go to work. MRC will work with the person to:

- Work with the special education team to develop their IEP and receive vocational rehabilitation counseling;
- Plan for a career, identify college and vocational training choices and help with financial aid applications;
- Participate in paid work experiences and on-the-job training;
- Get training to achieve work goals;
- Work with employers or colleges to ensure that needed reasonable accommodations, assistive technology, and other supports are received;
- Find a job that matches the individual's interests and needs.

To be eligible for VR services from a State VR agency, a person must have a psychiatric or physical disability which severely limits one's ability to get or keep a job, and have a desire to work.

### Eligibility Process for MRC

- Call or visit your local MRC-VR office ([www.mass.gov/mrc](http://www.mass.gov/mrc) or (800) 245-6543).
- Attend an orientation and bring the VR checklist.
- Arrange a meeting with a VR counselor to develop goals, identify strengths and limitations, and design a plan (paperwork will be collected).
- Decide whether to apply.
- If the decision is yes, the VR Counselor makes eligibility determination and will gather information from your young adult's physicians, therapists, hospital, and other medical records, will get a self-report from your young adult, and will get information from the Social Security Administration.
- A decision will be made within 60 days of applying.
- If found eligible, your young adult will receive a letter assigning a "priority category" (based on the significance of the disability).
- If found in the "top priority," your young adult is eligible for the full range of MRC services.
- If not found in the "top priority," your young adult will receive referral and information services only. You may appeal this assignment.
- Please note that sometimes there are waitlists for programs.

### Financial Need

The MRC-VRS Program will ask you about any income your young adult has to determine whether they can assist with paying for any services. If your young adult is dependent on you, your income may also be considered.

## Understanding the Role of DDS and MRC in High School Transition Planning

For students with more significant impairments, a 688 Referral can be made in high school. Most students with autism spectrum disorders who do not have global developmental delays may not receive a 688 Referral. If a 688 Referral is made, an adult agency is identified to continue supporting the individual's care beyond high school. This will be referred to as the Transitional Agency (TA) or the lead agency and is the agency that the local school system feels will best meet the student's future needs as an adult. The TA is responsible for assisting the individual in planning to move from special education services into adult life. There are different criteria that dictate which agency is most appropriate for each individual. DDS is one such agency. Other Transitional Agencies include the Department of Mental Health (DMH) and the Massachusetts Rehabilitation Commission (MRC).

## MRC IN HIGH SCHOOL

If the lead agency is MRC (Mass Rehab Commission), they may provide services before your child exits high school. Each branch of MRC operates differently, and some cities/towns can provide services before graduation or leaving school, while others may require that the adolescent finish high school before starting services. The following programs are offered by MRC to high school students.

### Supported Living Program

MRC will work with special education departments to coordinate services for students who will be graduating and needing supported living services. Students can choose the supported living provider with whom they wish to work and should begin meeting with them during the last six months he/she is in school. The case coordinator will help with such things as finding accessible housing and hiring appropriate Personal Care Assistants (PCAs).

### Who is Eligible for Supported Living?

#### Any individual who:

- Is exiting from a 766 educational program and has not reached the age of 22;
- Is their own legal guardian;
- Has a severe physical disability with a mobility impairment;
- Has a 688 Individual Transition Plan (ITP) that includes supported living services;
- Is ineligible for comparable services from another Executive Office of Health & Human Services (EOHHS) State agency, such as DDS, DMH, Massachusetts Commission for the Blind, or the MRC Statewide Head Injury Program (SHIP).

### How to Apply for Supported Living:

Any individual who meets the above guidelines and would like to receive case coordination services through the Turning 22 Supported Living Program should call the T22 Services Coordinator at (617) 204-3626.

*It is extremely important to make the referral early so an Individual Transition Plan (ITP) can be scheduled before the student graduates.*

### **Transition to Adulthood Program (TAP)**

The MRCT22 Independent Living Program contracts with six Independent Living Centers (ILCs) to provide early intervention to students with disabilities, regardless of the type of disability. Students receiving TAP services attend public, private, and residential schools throughout Massachusetts. Experienced skills trainers, who themselves have a disability, provide advocacy, skills training, and peer counseling to young people with disabilities in their school setting.

Students learn skills and self-confidence to better prepare them for independence. Exposure to adult peer role models, as well as skills training, helps students learn how to take on the responsibilities of living independently in the community of their choice. The ILC staff coordinates with supported living staff at the time of transition to the community and on an ongoing basis, as needed.

### **Who is Eligible for TAP Services?**

#### **Any individual who:**

- Is aged 14-22 and enrolled in special education with a severe disability and is ineligible for services from another Massachusetts state agency; and
- Desires to learn independent living and self-advocacy skills;
- After eligibility is determined, the individual will be asked to choose a provider with whom they will work. That provider will assess the individual's need for supported living services and evaluate the number of hours needed per week to support the individual. Case coordination services will then be provided.

### **How to Apply for Transition to Adulthood Program**

If a student is interested in receiving independent living skills training through TAP while he/she is in school, please contact the T22 Program Coordinator, at (617) 204-3626, who will make the referral to the appropriate Independent Living Center. Currently, there is funding for only six ILCs in Massachusetts, but it is hoped that funding will be expanded to include additional ILCs in the future.

### **ADULT FAMILY CARE (ADULT FOSTER CARE)**

Adult Family Care (AFC), also called Adult Foster Care, is a program for adults with disabilities who need daily help with personal care, but want to live in a family setting rather than in a nursing home or other facility. AFC adults live with trained paid caregivers who provide daily care, meals, companionship, personal care assistance, and 24-hour supervision. Caregivers may be family members (but may not be a legally responsible relative) or non-family members and may be individuals, couples, or larger families.

Currently, caregivers receive up to \$18,000 in reimbursement per year from MassHealth to provide care to MassHealth members who otherwise would need institutional care. Service providers, through agencies who contract with MassHealth including a social worker and registered nurse, train the caregiver and provide ongoing support.

### To be eligible for Adult Family Care:

- You must be 16 years of age or older.
- You must be unable to live alone because of a medical, physical, cognitive, or mental health condition.
- You must need daily assistance with one or more activities of daily living (ADLs).
- You cannot require full-time skilled nursing care.
- You must be willing to live with your caregiver.
- You must be eligible for MassHealth or be able to pay privately.
- Your caregiver cannot be your spouse or another relative legally responsible for you. (Note: For a minor child, the caregiver cannot be a parent)
- You must be approved for Adult Family Care by a physician and an Aging Services Access Point (ASAP).

## SUPPLEMENTAL SECURITY INCOME (SSI) PROGRAM

The Supplemental Security Income (SSI) program pays benefits to adults and children with disabilities who have limited income and resources. See Understanding Supplemental Security Income for an explanation of SSI benefit payment rates at:

[www.socialsecurity.gov/ssi/text-understanding-ssi.htm](http://www.socialsecurity.gov/ssi/text-understanding-ssi.htm)

### How to apply

Call (800) 772-1213 to make an appointment to apply for SSI benefits, visit your local Social Security office in person, or submit an application online.

### Eligibility

Eligibility is based on meeting both income and disability criteria.

- Income criteria: Even if you are age 18 or older, your legal guardian's income (not full, but a portion of it) will be factored in under the resource category. Each resource that you have will be calculated as "countable" and "not countable" to determine the amount of benefits you can receive (check this website to see an example of how they calculate the amount you receive [www.ssa.gov/ssi/textincome-ussi.htm](http://www.ssa.gov/ssi/textincome-ussi.htm)).
- Disability criteria: An individual age 18 or over is considered "disabled" if he or she has a medically determinable physical or mental impairment that impacts the ability to gain substantial income and has lasted longer than 12 months.

## Determination

The time frame for decision-making is about three to four months after the application is submitted.

## Important to Know about SSI:

If you meet the requirement, you are most likely to get this benefit.

There is no waitlist for this program.

The primary criteria for eligibility determination is whether your disability is severe enough (12 months or longer) to not allow you to work.

Do not wait to apply. If you think you may be eligible for SSI, you should apply right away.

The SSI office will need to see original documents and does not accept photocopies. They will return the original documents to you.

Try to keep a copy of all the information you send. Keep track of the dates you send information, talk to staff, as well as the name of the Social Security employee with whom you spoke.

BenePlan is a program that provides comprehensive benefits assessment, planning, and assistance to SSI and SSDI (Social Security Disability Insurance) beneficiaries, their families and service providers in Massachusetts. For more information, visit [www.beneplan.org](http://www.beneplan.org) or contact (877)YES-WORK.

## PERSONAL CARE ATTENDANT (PCA) PROGRAM

### What is PCA Program?

The PCA Program is a MassHealth program that helps people with permanent or chronic disabilities keep their independence, stay in the community, and manage their own personal care by providing funds (not the actual PCA) to hire Personal Care Attendants (PCAs). The PCA consumer (the person receiving PCA services) is the employer of the PCA, and is fully responsible for recruiting, hiring, scheduling, training, and, if necessary, letting go of PCAs.

*FOR MORE INFORMATION ON HOW TO APPLY TO MASSHEALTH SEE THE HEALTHCARE CHAPTER.*

### Who is a Personal Care Attendant (PCA)?

A personal care attendant (PCA) is a person who is recruited and hired by you to physically assist in performing activities of daily living (ADLs). You may hire one or more PCAs, as necessary, to meet your needs. Your PCA must be 1) legally authorized to work in the United States and have a Social

Security number; 2) able to understand and carry out directions given by you; and 3) willing to receive training and supervision in all PCA services from you.

**A PCA CANNOT be your:**

- Spouse
- Child
- Son-in-law or daughter-in-law
- Parent or foster parent or step parent
- Surrogate
- Legally responsible relative

**Who is a surrogate?**

If you cannot independently manage your PCA program, you may have the help of a surrogate. The surrogate is often a family member but may be any other person you choose who has the ability to manage the program. A surrogate can assist you with managing any part of the PCA program with which you have difficulty, but a surrogate does not necessarily run your PCA program for you. When you apply for PCA services, your Skills Trainer will determine whether you are able to manage the program independently, what skills training you will need to learn how to manage the PCA program, and whether you will need any help from a surrogate.

**What are ADLs and IADLs?**

**ADLs (activities of daily living) are:**

- Mobility/transfers
- Taking medications
- Bathing or grooming
- Dressing or undressing
- Eating
- Toileting

**IADLs (instrumental activities of daily living) are:**

- Laundry
- Shopping
- Housekeeping
- Meal preparation and clean-up
- Transportation to medical appointments
- Maintaining adaptive equipment

If an individual needs help at night, PCA time can be approved for Night Attendant services.

*\*Behavioral supervision is not part of the PCA program, such as dealing with self-injurious behaviors, pica (eating non-food objects), bolting and other safety issues.*

## Eligibility

You may apply for PCA program if:

- 1) You have or are eligible for MassHealth Standard or CommonHealth.
- 2) You have approval from your doctor for PCA services.
- 3) You have a chronic or permanent disability that prevents you from performing your own personal care.
- 4) You have a need for physical (hands-on) assistance with at least two of seven activities of daily living (ADLs) (i.e. bathing, dressing, etc.).

## For More Information

**Autism Commission**

<http://asdinfo.org/XKePSI>

## Financial Planning

Families who have children and other dependents with special needs, no matter what age or disability, have many serious questions about how best to provide for their future well-being—not only lifetime care, but quality of life. As a parent or caregiver of a person with special needs, you face uncommonly difficult planning decisions regarding their future well-being. The most important of these is how to provide for future care and services after you are gone.

Special needs financial planning is different from traditional financial planning, where you typically plan for buying a home, raising a family, college education expenses, or retirement. Financial planning for individuals with special needs requires planning for two generations because many adult children with disabilities will need support throughout their lives, long after their parents have died.

Some of the common concerns a financial planner can help your family properly address are how to use various financial and legal tools to preserve your child's eligibility for government benefits (for example, SSI), address financial concerns of residential options, and maximize the use of both public and private resources, among other considerations.

The following is by no means a comprehensive outline for financial planning, but is meant to be a jumping off point for more in-depth exploration.

### The Letter of Intent

The Letter of Intent is not a legally binding document, but it is one of the most important documents you can prepare for the future well-being of your child. If you have entrusted a sibling, friend, relative, trustee, or organization to look after your child when you are gone, you can help guide them by providing them the knowledge that only you, as a parent, possess.

Sample topics might include:

- Biographical and family information
- Medical history
- Important people
- List of advisors
- Location of important documents
- Personality traits and preferences
- Personal care information

### Estate Planning and Finding a Lawyer

Lawyers are usually necessary because estate planning is very complicated. To find a lawyer with expertise in special needs estate planning, ask other parents for references or check with a local advocacy agency such as the Arc or the National Academy for Elder Law Attorneys (NAELA).

## Wills

A will explains how your estate will be distributed after you die. A will can name a guardian for your child and provide a roadmap for loved ones on how you would like things handled (for more questions about guardianships/conservatorships, see the “Guardianship” chapter). Most experts recommend that your will should prevent your estate’s assets from going directly to your child with disabilities because assets over a certain amount can disqualify your child from receiving government benefits, such as SSI or Medicaid. Instead, there are special planning techniques that can be used to safeguard your child’s eligibility for government benefits. Creating a will allows you to have a voice in these important decisions and will prevent courts from making determinations about your child’s personal and financial affairs.

## Trusts

A trust is a legal agreement in which a person called a “trustee” is named to hold property or assets for the beneficial use or enjoyment of another person, called the “beneficiary.” The grantor (in this case, the parent) is the person who established the trust. Keep in mind that a “trustee” and a “guardian” are not the same thing. Trustees oversee trusts; guardians oversee personal and legal decisions.

After selecting a trustee, the grantor writes a “letter of intent,” which is not legally binding but provides a guide for your child’s caregivers or the courts on how you would like your child to live after you are gone. There are three components—a medical history of your child, practical advice (includes housing, services needed, daily care requirements and names of advocacy organizations), and a description of your hopes and dreams for your child’s future.

## Special Needs Trust

Many well-intentioned parents don’t realize that an inheritance may affect their child’s ability to access state and federal benefits. A special needs trust offers families a reliable way of safeguarding their child’s eligibility for benefits, while also providing for additional needs not covered by the government. A

### Special needs trusts typically provide for:

- Eye glasses
- Annual independent check-ups
- Transportation (including vehicle purchase)
- Equipment
- Training programs
- Maintenance
- Education
- Insurance (including payment of premiums)
- Rehabilitation
- Entertainment
- Electronic/computer equipment
- Trips and vacations
- Athletic training and competitions
- Companion services/health home aide
- Other items to enhance self-esteem
- Medical/dental care
- Cash/stocks
- Personal property and real estate property
- Benefits from a life insurance policy

special needs trust enables a trustee to pay for items and services beyond the bare necessities the government provides. It can pay for everything from a ball game, to movie tickets, to vacations, to private rehabilitation. Your trustee will use the guidance from your letter of intent to help discern rightful expenditures. Likewise, the trustee can legally be held accountable for their financial decisions and must act in accordance with your letter of intent.

Encourage grandparents or other relatives who may want to leave a bequest to your child, to leave it to their special needs trust.

### **Funding a Special Needs Trust**

In order to amass sufficient money to fund a special needs trust; you can contribute different assets, some of which may be available only after your death. Work with a reputable financial planner to strategize for these savings. Ideas include life insurance, standard government benefits, savings and investments, retirement funds, assistance and inheritances from friends and family members, home or rental property, and military benefits. If you have listed your child with special needs as a beneficiary for any policies, accounts, or assets that transfer according to the terms of a contract, and not the terms of your will, change the beneficiary designation to the special needs trust.

### **Planning Today for Tomorrow**

Expenses when having a child with special needs can be substantial. It can be hard to find the means to cover your child's immediate needs, let alone save for the future. That said, it is important to think in the long-term. Your financial planner can help you estimate current expenses versus what's needed as savings toward the future and advise you accordingly. Your financial planner can also provide guidance around savings, investments and life insurance policies, which will accrue over time.

### **Sibling Considerations**

Often times, your child's siblings will assume some of the responsibility for the care and decision-making for your child with special needs after you are gone. This requires open, frequent, and anticipatory discussions about the future with everyone involved.

Information provided by Met Life and the National Endowment for Financial Education and Easter Seals.

## Resources

### **The Special Needs Alliance**

[www.specialneedsalliance](http://www.specialneedsalliance)

### **The MetLife Center for Special Needs Planning**

<http://asdinfo.org/WfM3NQ>

### **Mass Mutual Financial Group**

<http://asdinfo.org/12a44Ag>

### **Special Needs Financial Planning**

A Division of Shepherd Financial Partners

<http://asdinfo.org/X8yoDZ>

## BOOKS

### **Managing A Special Needs Trust; A Guide for Trustees**

by Barbara Jackins, Esq., Disabilities books, 2010

### **The Special Needs Planning Guide: How to Prepare for Every Stage of Your Child's Life**

by John W. Nadworny, CFP, ChFC & Cynthia R. Haddad, CFP, Brookes Publishing, 2007

<http://asdinfo.org/W31feu>

### **Special Needs Trusts: Protect Your Child's Financial Future**

by Stephen Elias, Esq., Nolo Publishing, 3rd edition, 2009

### **Legal Planning for Special Needs in Massachusetts: A Family Guide to SSI, Guardianship, and Estate Planning**

By Barbara Jackins, Esq., AuthorHouse, 2010

## Transitions Timeline

The suggested timeline provided here should be modified according to your adolescent's development and the needs and preferences of your family. Some areas of transition planning can take up to ten years for completion; therefore, the checked boxes indicate rough estimates for when individual steps can be addressed.

Education	Ages 11-13	Ages 14-16	Ages 17-19	Ages 20-22
Begin to discuss your child's future and include them in the planning process. What does s/he want? What are his/her goals? What steps need to be taken to achieve these goals?	✓	✓	✓	✓
Call DDS or other appropriate agency to learn about services.	✓	✓	✓	✓
Call for Transitions meeting at AGE 14. Develop Vision Statement on IEP. Can ask DDS or other adult agency to come. Complete Transition Planning Form. Should include participation of state agencies and/or needed links. Remember child has legal right to be present and participate in the planning meetings required by special education law.		✓		
Ask about MCAS and graduation requirements.	✓	✓	✓	✓
Look into available assessments (vocational, functional behavioral, etc.) and arrange for the school to test your child or hire outside agency to complete assessments.		✓	✓	✓
Integrate transition needs into the IEP.	✓	✓	✓	✓
Review and update Transition Planning Form annually.		✓	✓	✓
688 Form should be completed within two years of exiting school, or turning 22, depending on your child's situation.	✓	✓	✓	✓
Continue dialogue with state agency and any appropriate resources.		✓	✓	✓
Network with other parents about resources and the transition process.	✓	✓	✓	✓
At age 16, begin discussing guardianship and the transfer of parental rights. Call the local probate court to learn about guardianship. Arrange for necessary testing assessments before filing the petition for guardianship.			✓	

At age 18: Hold IEP meeting. Request DDS/MRC attend. Remember the student has the right to make all decisions as related to special education programs at age 18, unless the family has petitioned the court for guardianship or the student has chosen to share or delegate decision-making to a parent.

✓ ✓

Son/daughter, parents, & DDS/MRC invited to all IEP meetings.

✓ ✓

Ask about MCAS and graduation requirements.

✓ ✓ ✓ ✓

Remember entitlement to special education services ends when the adolescent graduates, withdraws from high school, or reaches age 22.

✓ ✓

Visit potential workshops, day programs, and vocational programs in the area.

✓

If child is going onto postsecondary education, visit colleges and programs. Arrange for meetings with teachers, deans, and the Office of Disabilities. Discuss issues relating to disclosure of disability with your child. Assess your child's ability to self-advocate (does he/she feel empowered to ask for help, do they know when they need help, etc.) and focus on building these skills.

✓ ✓ ✓

Assess daily living skills and functional abilities to ensure child is prepared for a more independent environment.

✓

Guardianship	Ages 11-13	Ages 14-16	Ages 17-19	Ages 20-22
Consider guardianship needs by age 18. Research and plan for testing, paperwork and any potential legal fees.	✓	✓	✓	✓
If pursuing guardianship, rules may apply regarding the dates when your adolescent was last administered psychological testing, sometimes requiring updated testing within six months. Inquire with your local probate court, or the Department of Developmental Services, or an attorney about the requirements in your area. If necessary, arrange for your child to get updated testing prior to their 18th birthday. There can be long waits for this, so speak to your providers when your child is 16 to allow enough time for scheduling.		✓	✓	
If pursuing guardianship, prepare petition and get appropriate evaluations from necessary providers. Petition cannot be filed until child's 18th birthday and all signatures for CTR (Clinical Team Report) must be obtained within 180 days of filing the petition if child has an intellectual disability (formerly known as mental retardation). If child does not have an intellectual disability, a Medical Certificate must be filed within 30 days of filing the petition and also within 30 days of the court date (NOTE: May require TWO examinations because of 30 days rule).	✓	✓	✓	✓

Housing	Ages 11-13	Ages 14-16	Ages 17-19	Ages 20-22
Identify your child's specific needs and abilities to determine what level of support they will need. Discuss housing with the adolescent if possible and plan together.	✓	✓	✓	✓
Consider financial arrangements in the event that they do not receive government funding or encounter a Section 8 waitlist.	✓	✓	✓	✓
During the 688 process, make sure the adult agency is performing the necessary assessments (i.e. MASSCAP for DDS housing)			✓	✓
At 18, explore subsidized housing, and Social Security benefits and complete applications for waitlists.			✓	
If approved for housing by DDS, begin exploring options.			✓	✓

Postsecondary Education	Ages 11-13	Ages 14-16	Ages 17-19	Ages 20-22
Envision an ideal setting for your adolescent. Research existing programs.	✓	✓	✓	✓
If child is going onto postsecondary education, visit colleges and programs. Arrange for meetings with teachers, deans, and offices of disabilities. Discuss issues relating to disclosure of disability with your child. Assess your child's ability to self-advocate (does s/he feel empowered to ask for help, know when help is needed, etc.) and focus on building these skills.			✓	✓
Consider an overnight visit in a dorm room for your child when exploring a preferred school.		✓	✓	✓
Identify other supports that may be needed in close proximity to chosen college (e.g., medical, mental health services, etc.).		✓	✓	✓
Research and identify social and recreational opportunities in the college setting.			✓	✓
Discuss the issue of signing a FERPA (Family Educational Rights and Privacy Act) form with your child. Parents will not have permission to communicate with the college if the adolescent does not sign a FERPA, so it can be helpful to discuss this issue as a family proactively and make the decision together.			✓	✓
Obtain documentation for accommodations if necessary.		✓	✓	✓
Seek career counseling early in the college experience.			✓	✓

Employment	Ages 11-13	Ages 14-16	Ages 17-19	Ages 20-22
Begin envisioning employment as early as age 14 and include it in the IEP transition meetings.		✓	✓	✓
Begin thinking about different kinds of employment, routes to employment, such as higher education and technical training, or supported employment.	✓	✓	✓	✓
Begin exploring community vocational opportunities and become familiar with vocational services, even if further education is planned. Consider vocational assessments that help identify strengths and begin exposing your adolescent to different types of work environments to see what preferences they may have.		✓	✓	✓
Begin dialogues about the importance of early work experiences and job-related skills, such as resume preparation and interviewing. Discuss practical issues relating to working and job expectations.		✓	✓	✓
Contact local and state agencies involved in employment services.		✓	✓	✓
Contact the Social Security Administration to learn about and plan for financial aspects of employment, such as work incentives.			✓	✓

Healthcare	Ages 11-13	Ages 14-16	Ages 17-19	Ages 20-22
Depending on your family preference, your son/daughter may meet privately with physician for part of office visit.	✓	✓	✓	✓
Determine if son/daughter understands his/her health condition, medications and insurance coverage. Keep copies of all reports/tests.	✓	✓	✓	✓
Parent and physician may begin to provide anticipatory guidance around fitness, nutrition, sexuality, relationships, substance abuse, and smoking with the child.	✓	✓	✓	✓
If able to, the adolescent can begin to schedule and keep track of own medical appointments, prepares own list of questions, etc.		✓	✓	✓
Parents can initiate a discussion with provider about transfer to adult healthcare provider. What is the healthcare plan for the adolescent as an adult?		✓	✓	✓
Parents can start networking and identify potential adult providers. This process can take time, so it can be useful to start early.		✓	✓	✓
Parent and child interview adult providers.			✓	✓
Current provider can begin communicating with selected adult provider.			✓	✓
Provider can transfer medical records			✓	✓
Provider and parent should assess adolescent's competence around making medical, financial, and other independent decisions and determine whether there is a need for guardianship/conservatorship by age 18.			✓	✓

Recreation	Ages 11-13	Ages 14-16	Ages 17-19	Ages 20-22
If your adolescent will attend a Day Rehabilitation Program, research different options and consider transportation required.			✓	✓
Discuss in-home and community recreation options.	✓	✓	✓	✓
Develop strategies, in conjunction with professionals to foster friendships and avoid social isolation.	✓	✓	✓	✓
Consult with your physician and disclose healthcare information to the appropriate parties if anything may affect the adolescent's ability to participate in recreational activities.	✓	✓	✓	✓
Focus on your adolescent's strengths and interests and remember that recreation has to be fun!	✓	✓	✓	✓
Miscellaneous	Ages 11-13	Ages 14-16	Ages 17-19	Ages 20-22
Begin thinking about long-term financial plan. Contact a lawyer to create will and special needs trust.	✓	✓	✓	✓
Research and apply for insurance and government benefits such as SSI (see the "Financial Planning" chapter).	✓	✓	✓	✓
Consider transportation issues (such as public transportation for people with disabilities known as The Ride).			✓	✓

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## LOCAL

### Arc Mass Resources:

Found at [www.arcmass.org](http://www.arcmass.org)

- The Arc Massachusetts Transition from School to Adult Life – Timeline (new): which is a general time line ages 13-22 <http://asinfo.org/XEc6A5>
- Transition from School to Adulthood: Planning for a Future <http://asinfo.org/TXEGaY>
- Building A Future 3rd Edition A Handbook for Families <http://asinfo.org/VOq2Sf>
- Planning for a Good Life: For parents of Adult Children with Disabilities <http://asinfo.org/WBn8AK>
- Tools for Tomorrow Pocket Guide <http://asinfo.org/14rVf3v>

Passport to Independence: A Manual for Families <http://asinfo.org/XiZTfN>

“The Road Forward: A Guide to Transition Planning” from the Massachusetts Office of Health & Human Services <http://asinfo.org/TSUCMe>

*Coming of Age in Massachusetts A Legal Resource Guide:* by Frederick M. Misilo, Jr., Esq.  
[http://ftwlaw.com/legal\\_resources.php](http://ftwlaw.com/legal_resources.php)

## NATIONAL

National Center on Secondary Education and Transition [www.ncset.org](http://www.ncset.org)

*It's Time to Transition: A Workbook for Young Adults, Their Families, and Their Medical Providers* by Dr. Laura Pickler, 2006 <http://asinfo.org/VrMrXq>

Autism Speaks Family Services Transition Tool Kit <http://asinfo.org/118Unlg>

*Life Journey Through Autism: A Guide for Transition to Adulthood* by DANYA International, Inc; OAR; SARRC; 2006 <http://asinfo.org/WExejC>