

Important Transition Information Every Family Should Know

Transition Information Fact Sheets

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Transition Information Fact Sheets

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Developing a Vision

A “Vision” for a young person’s future after high school is based on that person’s interests, aspirations and dreams. It is helpful to start thinking and developing a realistic Vision for the future during the teen years. Parents, siblings, teachers, friends, and other interested parties can help and support the young person to develop a Vision.

It is important that goals, objectives, and strategies developed on the Individualized Education Program (IEP) during later school years support the Vision. The Vision is a starting point and can be revised over time.

Things to consider when developing a vision

List the person’s strengths, interests, and accomplishments.

COMMUNICATION

- » What is the person’s communication style?
- » How does the person respond in social, familiar, and unfamiliar situations?
- » Does the person use technology or an assistive device to communicate?
- » How does the person respond to changes in routine?

HOME

- » Where will the person live?
- » With family, in shared living, with a housemate, in a house or apartment?
- » What would be the ideal living arrangement?
- » Would an urban, suburban, or rural setting be preferred?
- » Should the environment be lively, quiet, or predictable?
- » What supports are needed and what resources are available?
- » Does the person use or need any equipment to be successful?
- » Do medical factors play an important role?

DAY

- » What does the person want to do after graduation?
- » Where does the person want to work?
- » What work schedule is possible?
- » What would an ideal day look like?

COMMUNITY

- » What does the person like to do for fun?
- » Where, with whom, and how often will the person go to restaurants, hairdresser/barber, grocery store, library, clubs, parks, museums, etc.?
- » What does the person do on weekends and other periods of free time?
- » What opportunities are there to connect with the community through volunteering, clubs, gyms, and other local activities?

TRANSPORTATION

- » How will the person get from place to place?
- » Can the person walk, take the bus or public transportation, use ADA transportation, ride with family or friends?

RELATIONSHIPS

- » Who are the person’s friends?
- » What relationships could be strengthened?
- » Where will the person socialize and meet new people?

These are just a few questions to get started. The Vision will be developed over time as more questions about the future are asked and answered. When beginning to implement the Vision, the team should consider personal resources and networks, community opportunities, and public benefits in order to bring the Vision to life.

Person-Centered Planning

What is Person-Centered Planning?

Person-Centered Planning (PCP) is a process used to help people with disabilities create a vision and a plan for the future based upon the person's unique interests, hopes and dreams. A Person-Centered Plan is best done prior to transition, as it can help to develop the transition plan, but can be done at any time in a person's life.

A PCP team must include the person and may also include parents/family members, teachers, peers, caregivers, and community members. Participants must be committed to taking action to make sure that the strategies and outcomes discussed in planning meetings are implemented. A trained PCP facilitator is typically identified to facilitate the process.

This team meets regularly to identify opportunities for the person to develop relationships, participate in the community, increase decision making, and develop the skills and abilities needed to achieve these goals.

THE FIRST STEP IN THE PLANNING PROCESS: THE PERSONAL PROFILE

1. Develop a history or personal life story of the person. Things such as background, critical events, medical issues, major developments, important relationships, etc., may be shared.
2. Describe the quality of the person's life, considering community participation, community presence, choices/rights, respect, and competence.
3. Preferences of the person. Things the person enjoys doing, as well as things they do not like at all.

The personal profile is best discussed prior to the PCP meeting so the participants have time to reflect on what is shared. The meeting may use graphic symbols in place of words to help stimulate creativity and encourage participation across all areas of life.

THE NEXT STEP: THE PLANNING MEETING

1. Identify a PCP facilitator and the "person-centered" team members.
2. Review the personal profile. Give the group the chance to make additional comments and observations.
3. Identify ongoing events that are likely to affect the person's life.
4. Share visions for the future. Through brainstorming, participants are challenged to imagine ways to increase opportunities.
5. Identify obstacles and opportunities. Identify things that can make the vision a reality.
6. Identify strategies. Outline action steps for implementing the visions.
7. Identify action steps that can be completed within a short time and who is responsible.
8. Identify the services the person would benefit from.

FOR A PLAN TO BE SUCCESSFUL, IT IS BEST IF:

- » People have a clear and shared appreciation of the talents and capacities of the person.
- » People have a common understanding of what the person wants.
- » The group agrees to meet regularly to review activities.
- » The group includes a strong advocate or family member, ensuring that the interests of the person are being met.
- » The group includes a person committed to making connections to the local community.
- » Multiple team members assume responsibility for specific tasks.

Additional resources: www.pacer.org/tatra/resources/personal.asp

Letter of Intent

A letter of intent (LOI) is an optional, written document that families create to provide details about a person's life: past, present and future. It is not a legal document, but provides invaluable written guidance to those who will most likely provide care, support, and/or oversight for the person in the future.

A letter of intent and/or a person-centered plan are your family's personal plan for your loved one with intellectual/developmental disabilities. The PCP and LOI help those who support the person to be on the same page when planning and coordinating the person's supports.

Development of the LOI should include the person as much as possible, and reflect that person's unique preferences and needs in every aspect of life. It should include:

Summary and Vision:

A brief summary of the person's life to date and general thoughts, hopes, and dreams.

Family History:

Provide information on birthdays, locations, and other important history for family members. Include favorite stories, memories, and feelings about the person.

Daily Routines:

Include typical daily routines, favorite foods, music, activities, and events or tasks. Share details about abilities to assist with tasks such as doing the dishes, making the bed, grocery shopping, etc. It is equally important to include strong dislikes or other "non-negotiables."

Medical/Health Care:

Share a medical history/health care plan, current/preferred doctors, therapists, hospitals, and frequency and purpose of medical and therapy appointments. List current medications, including how and why they are taken. Describe all medications that have not worked or have caused adverse reactions.

Benefits, Financial & Legal:

Include benefits the person receives or is wait-listed for, including Medicaid, Medicare, SSI/SSDI, Supplemental Nutrition Assistance Program (food stamps), housing assistance, and banking or special needs trusts. Include contact information, identification numbers, renewal processes, and dates.

Employment:

Describe types of work and environments the person may enjoy, such as supported employment, volunteer opportunities, or a day program. List any companies that may be of specific interest to the person.

Residential Environment:

Describe the person's living arrangements now and what might be the best future alternative. Consider level of supervision, location, male/female housemates or roommates, etc.

Social Environment:

Describe social activities the person enjoys, such as sports, dances, movies, friendships, relationships, community experiences, vacations, and modes of transportation. Indicate spending money and any limitations or support that is needed.

Spirituality/Religious Environment:

Specify the person's beliefs, customs, and place of worship. Identify religious leaders who may be familiar with the person, and indicate whether religious participation is of interest and important to the person.

Behavior Management:

Describe current behavior management: what works and what doesn't.

Final Arrangements:

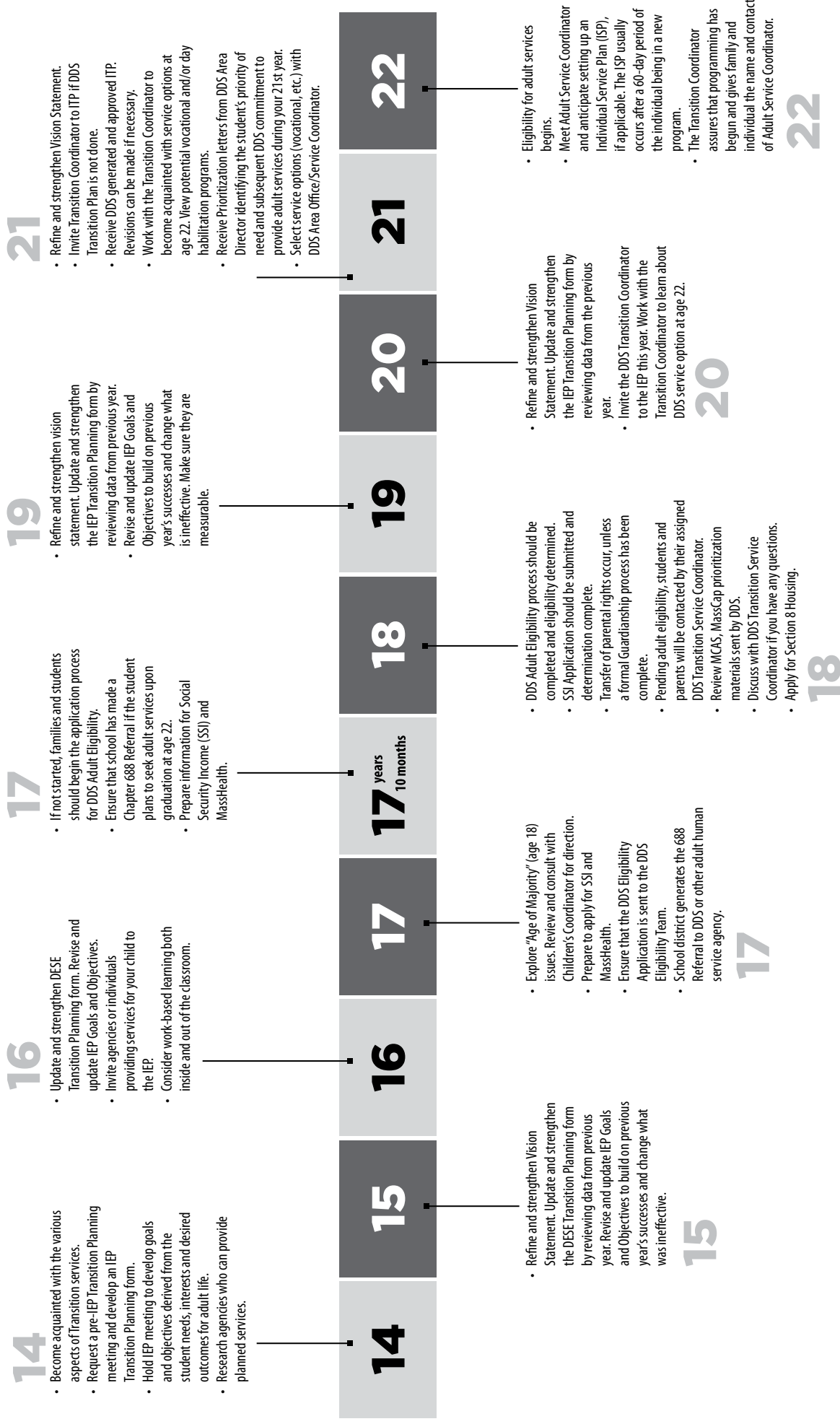
Share any planned services such as a funeral, cremation or burial, or customs.

There are numerous sample LOI formats available. Here are two examples:

- » <http://theemarc.org/footprints-for-the-future-184.html>
- » <http://midmoelderlaw.com/forms/LetterofIntent.pdf>

Remember, this is the beginning of a process that continues throughout a lifetime.

Transition Timeline



Student's Role in Transition

In Massachusetts, transition begins at age 14. This is a natural time in the life of a student when the focus is on planning for the future.

For all students, but especially for those with more significant disabilities, support often comes from the family, advocates, and school personnel. This fact sheet addresses the student's role, but is intended to acknowledge the additional support provided by other individuals to assist in the transition process.

The suggestions below fall into three different environments: education, home, and community. There is some overlapping, as many skills can be taught in multiple settings and by multiple individuals.

Education

- » Learn your personal learning style (how you learn best and what accommodations you will need).
- » Become aware of options for further education through your guidance counselor/special ed teacher (or workplace coordinator).
- » Identify course requirements for middle school, high school, and post-high-school programs.
- » Complete interest and career inventories/assessments.
- » Begin career exploration, including visiting employment sites.
- » Understand the purpose of your Individualized Education Program (IEP) and Transition Planning Form (TPF), and assist in the development of both.
- » Take part in informational interviews or job shadowing.
- » Learn to use public transportation.
- » Join a club or organization in your school or community.
- » Be able to explain your abilities and disabilities and any accommodations you might need.
- » Learn and practice how to make informed decisions.
- » Participate in self-advocacy training.
- » Find out about your educational rights.
- » Start financial planning, budgets, money management.
- » Learn about acceptable intimate/sexual behavior. Talk with people you trust.
- » Explore technology to enhance learning.

Home

- » Learn to act and dress for a variety of social situations.
- » Start financial planning, budgets, money management.
- » Learn to order and dine in restaurants.
- » Learn how to plan recreation and leisure activities, where, when, cost of transportation.
- » Learn to schedule medical and dental appointments.
- » Learn the names and purposes of the medications you take.
- » Learn to recognize an emergency and how to use 911 for assistance.
- » Begin learning skills you'll need for independent living.
- » Learn to use public transportation.
- » Explore technology to enhance learning.
- » Get an ID card and learn when and how to give out personal information.
- » Establish exercise routines.
- » Develop personal care skills, including hygiene, knowledge of health needs, private and public behavior.
- » Learn about acceptable intimate/sexual behavior. Talk with people you trust.
- » Develop housekeeping and cooking skills by participating in chores at home.
- » Learn responsible use of social media.
- » Familiarize yourself with the local bank and learn to perform banking operations.

Community

- » Get a Social Security card.
- » Make friends and establish relationships.
- » Learn public transportation and alternatives such as reduced rates.
- » Learn to make clear to others your interests, wishes, and needs.
- » Volunteer in community.
- » For males, register for selective service at age 18.
- » Register to vote at age 18.
- » Visit work sites to learn about jobs.
- » Participate in community activities.
- » Join community offerings like a church, club, coffee house, etc.

Family's Role in Transition

In Massachusetts, transition begins at age 14 and continues until a student leaves the school system for the adult world. It is an ongoing process.

The role of the family in the transition process is essential. Parents and guardians are the providers of information to schools and agencies; they know their children better than anyone else. Parents play a major role on the Individualized Education Program (IEP) team in helping to develop a vision for their child's future. They help to develop post-secondary goals and objectives that will enable their children to become as independent as possible before leaving school. They teach, model and guide their children to adulthood, and assist them in becoming part of their communities.

The suggestions below fall into three different environments: educational, home, and community. The purpose is to enable families to understand the scope of transition.

Educational

- » Transition begins at age 14. Participate in creating the Transition Planning Form with the school.
- » Develop a partnership with the school system, and actively participate on the IEP team.
- » Help your child develop advocacy skills to participate in his/her IEP.
- » Become familiar with federal and state laws about transition.
- » Schedule interest inventories and vocational assessments.
- » Identify IEP goals that will capture interests, vocational opportunities, post-secondary education, and independent living skills across settings.
- » Understand the Chapter 688 process and eligibility for adult service agencies.
- » Make sure your child has volunteer experience, internships, and real work experience.
- » Maximize independence by fading supports.

Home

- » Learn about person-centered planning.
- » Focus on self-determination skills: choice making, decision making, problem solving, goal setting, self-management.
- » Encourage independence in all areas of life, including self-care activities, money management, and travel in the community.
- » Talk about the value of work, and teach behaviors that develop employment potential.
- » Assist in good grooming skills, and emphasize the importance of physical activity.
- » Help children think about and envision their future.
- » Assist your child in understanding his/her disability and medical needs.
- » Investigate requirements for SSI, MassHealth, and other government benefits.
- » Plan for future needs and assets, including personal finances, wills, and trusts.

Community

- » Share your vision for your child's future.
- » Network with other families, community groups, and advocacy groups.
- » Attend transition-related workshops, fairs, and conferences.
- » Provide opportunities for your children to see people at work in different settings.
- » Identify the human service and provider agencies and understand the work that they do.
- » Encourage relationships and nurture friendships.
- » Use Family Support Centers and understand the work that they do.
- » Explore volunteering and connections to community activities.

Tips for Maximizing the Educational Process

Transition Process

- » Special education is an entitlement until age 22.
- » Transition begins at age 14 in Massachusetts, or earlier if determined by the Individualized Education Program (IEP) team.
- » It's important to learn the young person's rights and responsibilities from federal and state laws around transition.
- » The years between 18 and 22 should focus on a broad range of functional life skills across all settings, such as work, social, community safety, and travel training.
- » The age of majority in Massachusetts is 18.
- » Be sure your child's school submits a 688 referral at least two years before he or she leaves school.

Family Role

- » Parents and guardians are essential and active members of the IEP planning team.
- » Share as much information as possible about your child with the IEP team.
- » Build a positive relationship with your child's teacher and IEP team.
- » Think about ways your child can participate in the development of his/her IEP in a meaningful way.
- » Request that written assessments and evaluations be provided at least two days prior to the IEP meeting in order to prepare.
- » Get to know your child's Department of Developmental Services (DDS) coordinator, and communicate about individual and educational changes and developments.
- » Learn about and access the range of programs, services, supports, and accommodations available for young people with disabilities.
- » Attend parent workshops on transition.
- » Apply for SSI/MassHealth when your child is 18 years old.
- » Consider assisting your child to apply for Section 8 and other subsidized housing programs.

School Role

- » The Transition Planning Form (TPF) is not a legal document and is separate from the IEP.
- » The Vision, Goals, and Objectives should reflect your child's life at age 22 or when he or she leaves school. They should cover educational, vocational, and community experiences, independent living skills, and social skills.
- » The Post-Secondary Vision, Goals, and Objectives must be transferred from the TPF to the IEP for implementation.
- » Make sure the emphasis on the IEP is on post-school goals that will make the biggest difference in the child's life.
- » Interest surveys and vocational assessments should be done regularly by school personnel starting from age 14 to determine strengths, interests, and preferences.
- » Parents/guardians may request that evaluations and assessments be done by an independent evaluator.
- » No later than 30 days after receipt of an IEP, a parent can reject part of or the entire IEP.
- » Make sure travel training is addressed while the child is still in school.
- » Discuss shared and delegated decision-making authority with the child, and document this in the IEP.

Federal and Massachusetts Laws on Transition

Federal Law: Individuals with Disabilities Education Act (IDEA) – 2004

The purpose of IDEA is to ensure that all children with disabilities have available to them a free appropriate public education (FAPE). FAPE emphasizes special education and related services designed to meet children's unique needs and prepare them for further education, employment, and independent living.

One specific component of IDEA is related to "Transition Services." This means a coordinated set of activities for a child with a disability that:

1. Are designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including postsecondary education; vocational education; integrated employment (including supported employment); continuing and adult education; adult services; independent living or community participation;
2. Are based on the individual child's needs, taking into account the child's strengths, preferences, and interests; and
3. Include instruction, related services, community experiences, the development of employment and other post-school adult living objectives and, when appropriate, acquisition of daily living skills and functional vocational evaluation.

WHAT THIS LAW MEANS TO YOU

Each Individualized Education Program (IEP) starting at age 16 must include:

1. At least one appropriate, measurable postsecondary goal based upon age-appropriate transition assessments in each of the following areas: training, education, employment, and, where appropriate, independent living skills; and
2. The transition services and school work needed to assist the child in reaching those goals.

Massachusetts Law Chapter 285 of the Acts of 2008 (section 2 of c.71B)

Beginning at age 14 or sooner if determined appropriate by an individualized education program team, school-age children with disabilities shall be entitled to transition services and measurable postsecondary goals, as provided under the federal Individual with Disabilities Education Act. 20 USC sec. 1400.

WHAT THIS LAW MEANS TO YOU

Although the federal law states that transition activities start at age 16, Massachusetts starts transition services at age 14.

Massachusetts Law Chapter 688, "Turning 22" Law (Chapter 71b, Section 12c)

A disabled person who has been receiving special education shall be eligible, subject to appropriation, upon graduation from high school or upon attaining the age of twenty-two, whichever occurs first, to receive habilitative services. The education authority which is responsible for the education of a person with a disability shall, with the consent of such person or his parent or guardian, at least two years before such person attains the age of twenty-two or at least two years before such person's graduation, whichever first occurs, determine whether such person may need continuing habilitative services and notify the bureaus of transitional planning of the name and address of such person, the record of the special education services being provided to such person, and the expected date of termination of such services.

WHAT THIS LAW MEANS TO YOU

It is the responsibility of the local school system to make a Chapter 688 referral for adult services for each student needing continued services upon leaving special education. The referral must be made while the student is still in school and should be made at least two years in advance of graduation or turning 22.

A 688 referral is needed even if a student is already known to the Department of Developmental Services (DDS) and eligible for adult services. The school system can send the 688 referral directly to the adult service agency best suited to serve the individual as an adult.

If DDS is the designated agency, the referral can be sent directly to the Area Office that covers the referring school system. If the school system is unsure which agency would best serve the individual, the referral can be sent to the Bureau of Transitional Planning at the Executive Office of Health and Human Services for assistance.

Eligibility for Chapter 688 is broad and does not guarantee eligibility for DDS or any other specific adult human service agency.

Chapter 688 / Turning 22

WHAT is Chapter 688?

Chapter 688 is a law enacted in 1983 to provide 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 law creates a single point of entry into the adult human service system.

WHO is eligible for Chapter 688?

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

- » Be receiving special education paid for by the Commonwealth of Massachusetts
- » Need continuing habilitative services at the time of turning 22 or graduating from special education, *and*
- » 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, receiving SSDI, or registered with the Massachusetts Commission for the Blind.

HOW is a 688 referral made?

- » Only the local school system, also known as the Local Education Authority or LEA, can make a 688 referral. The referral must be made while the student is still in school. The local school system typically decides which adult human service agency, referred to as the Transitional Agency, might best meet the student's needs as an adult, and sends the referral directly to that agency. If an individual is being referred to the Department of Developmental Services (DDS), the referral typically is sent directly to one of the DDS area offices.
- » If a student or parent believes that a 688 referral has not been made, they should contact the special education department at the school, or the director of special education services for the school system. Although there is only one Transitional Agency for each student, multiple adult agencies can plan and provide services.

WHEN should a 688 referral be made?

- » Chapter 688 requires the school system to make the 688 referral 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 earlier than required by Chapter 688. DDS suggests that referrals be made at age 18 to coincide with DDS adult eligibility age requirements. Referrals that are made less than two years before graduation do not afford adequate planning time to assist a student in the most meaningful way possible.
- » Students or families who are concerned about the timing of a 688 referral should contact both the school system and the local DDS area office, if they feel DDS would likely become the Transitional Agency.

IF a student is already known to DDS, is a 688 referral still necessary?

- » Yes. Even though some individuals with an intellectual disability receive DDS services as children, a 688 referral still should be made. The 688 referral starts the formal DDS transition planning process for the individual student.

WHAT is the "SPED DATE" and why is it important?

The special education date ("sped date") is the date on which a student is planning to leave special education and school. Typically, the sped date is either the student's expected date of graduation or 22nd birthday. The sped date is used in the 688 referral process as the reference date for planning. Students

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leaving on short notice in advance of the sped date specified on the 688 referral may not have the benefit of adequate planning time to assist with a smooth, well-planned transition.

WHAT happens if a student leaves school without a 688 referral?

If a student leaves school without a 688 referral being made, he or she is not eligible for specialized planning through 688. The student can still apply to DDS or other state agencies serving adults at any time, as any citizen could.

WHAT if a 688 referral is made to DDS and the person is found ineligible for DDS?

When a 688 referral is made to DDS, DDS determines if the student is eligible for adult supports through the agency. If the person is eligible for 688 services but is not eligible for DDS services, DDS transfers the case to the appropriate state agency for 688 planning assistance.

If an individual with a 688 referral is found ineligible for DDS adult services, the Regional Eligibility Team sends a complete package of material for the ineligible person to DDS Central Office in order to complete the transfer. In addition to supporting material, a copy of the 688 referral and the DDS ineligibility letter are included in the transfer packet. The transfer will be completed by the Central Office and sent to the appropriate agency.

In order for a 688 referral to be transferred to another agency, there must be at least six months lead-time before the student leaves school.

WHAT are the benefits of the 688 process for individuals eligible for DDS adult services?

- » The 688 process ensures that the student is working with DDS before exiting school.
- » The 688 process specifies a referral timeline that allows for sufficient planning to support a smooth transition to adult supports.
- » The Individual Transition Plan (ITP) enables DDS to understand the student's needs and to begin programmatic and fiscal planning.
- » By specifying an individual's needs before exiting special education, the individual, family, and DDS can plan together.

WHAT is the role of the DDS 688 transition coordinator?

The 688 transition coordinator is a case manager who works at the local DDS Area Office. Once a student is determined DDS adult eligible, a transition service coordinator will be assigned.

The coordinator is the student and family's primary link to assistance from DDS during the transition process from special education to adult life. He or she visits the student's program and assists in identifying future community supports that are consistent with the individual's vision and ITP.

The 688 transition coordinator also chairs the ITP meeting and develops the written ITP which identifies future adult community support service needs for the student.

DDS Adult Eligibility

Individuals can be determined eligible for adult services through the Department of Developmental Services (DDS) if they have significant limitations in adaptive functioning and one or more of the following diagnoses:

- » Intellectual Disability
- » Autism Spectrum Disorder
- » Prader-Willi Syndrome
- » Smith-Magenis

In order to receive services at age 22 or later, adult eligibility must be completed, even if the individual has been determined eligible for children's services. It is best to begin the adult eligibility process around age 18 in order to provide maximum planning time for adult services. Adult services do not begin prior to age 22.

When to Apply:

Around age 18.

Where to Get an Application:

ONLINE

Go to www.mass.gov/dds.

Under "Related Links," click on:

1. Application for Eligibility
2. Application for Eligibility Forms
3. Application Form for Adult Eligibility

Download the form, complete it, and mail it to your regional office. Cities and town pages are included with the application to help you identify your regional office.

BY PHONE

- » Call your DDS regional office:
- » Central West Region: 413-284-5045
- » Metro Region: 781-314-7513
- » Northeast Region: 978-774-5000, ext. 850
- » Southeast Region: 508-866-5000

IN PERSON

- » Visit any area office, family support center, or autism support center for assistance.

Criteria for DDS Eligibility Based on Intellectual Disability

- » Must live in Massachusetts
- » Must have a diagnosis of an intellectual disability (originates before 18)
- » Must have significant limitations in adaptive functioning

What to submit for an application based on intellectual disability:

1. All available intelligence/cognitive/psychological testing reports
2. Early Intervention Plans
3. IEP and related assessments
4. Adaptive Behavior Assessment System (ABAS) or Vineland II
5. Individual Family Support Plan
6. 504 Accommodation Plan
7. Medical, developmental, and specialty assessments
8. Hospital reports (if applicable)

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Criteria for DDS Eligibility Based on Autism Spectrum Disorder

- » Must live in Massachusetts
- » Must have a primary diagnosis of Autism Spectrum Disorder determined by a qualified professional (manifests before 22)
- » Must have significant limitations in adaptive functioning

WHAT TO SUBMIT FOR AN APPLICATION BASED ON AUTISM SPECTRUM DISORDER:

1. Autism Diagnostic Testing results:
 - » Gilliam Autism Rating Scale (GARS)
 - » Gilliam Asperger's Disorder Scale (GADS)
 - » Childhood Autism Rating Scale (CARS)
 - » Autism Diagnostic Observation Schedule (ADOS)
2. All available intelligence/cognitive/psychological testing reports
3. Diagnostic reports of diagnosed developmental condition
4. Most recent IEP and related assessments

For All Applications, Submit:

Please submit copies only, do not submit original documents.

- » Birth certificate
- » Social Security card
- » Health insurance card
- » Guardianship decree (if applicable)
- » Proof of domicile as necessary

All requested documentation may not apply to each individual.

Eligibility Determination

Once all the paperwork has been submitted, you will be contacted by an eligibility specialist to set up an intake interview. This is a face-to-face interview. The location will be determined by the eligibility specialist and the individual and family.

All the materials and information will be reviewed by the regional eligibility psychologist. The applicant or guardian will be notified in writing of the eligibility determination. There is an appeal process if the applicant is found to be ineligible.

Supports for Adults with Autism Spectrum Disorder

Background

The Department of Developmental Services (DDS) has provided supports to children with autism and adults with autism who met the department's eligibility criteria for intellectual disability. In 2010, the legislature established an Autism Commission to investigate the needs of individuals with autism spectrum disorders (ASD), including those who did not meet the criteria for DDS as related to intellectual disability. After extensive study, the Autism Commission developed a comprehensive report that identified a number of priorities, findings and recommendations.

The Massachusetts Autism Commission Report, issued in March 2013, identified a number of priorities, including:

- » Expand the eligibility for DDS so that individuals with autism who have higher IQ scores and substantial functional limitations have access to services.
- » Ensure that individuals with autism with co-occurring mental health conditions have access to services from the Department of Mental Health.
- » Expand insurance coverage for treatment for individuals with autism.
- » Increase employment, housing, educational, and health care options for individuals with autism.
- » Determine the number of people with autism in Massachusetts and their needs by consistent data collection.

Autism Omnibus Act

In 2014, the governor signed the Autism Omnibus Act into law in order to expand supports and services to individuals with autism living in Massachusetts. This legislation establishes a permanent Autism Commission to oversee the implementation of autism services. It also creates the opportunity for families to establish tax-advantaged accounts to use for their family member with a disability. It requires the Board of Elementary and Secondary Education to revise educator licensure to provide a mechanism for special education teachers to achieve Autism Endorsement through mastery of specialty training and skills. Insurance coverage to cover services for individuals with autism is expanded as a result of this legislation.

What does this mean for DDS?

Eligibility for supports through DDS has expanded. The criteria for children and for adults with intellectual disability have not changed. Eligibility for adults with ASD, Prader-Willi Syndrome, and Smith-Magenis Syndrome has been added. Provision of adult services begins at age 22.

IQ (Intelligent Quotient) is not a criteria for individuals with ASD and Prader-Willi Syndrome. Individuals with these diagnoses can be eligible without having an intellectual disability. In order to be determined eligible for ASD services, an individual will need a verified diagnosis by a qualified professional, and for Prader-Willi a genetic testing result. The qualifying disability must manifest prior to age 22 and be determined to continue indefinitely.

In addition to the diagnosis, the individual must have substantial functional impairments in three or more areas of seven major life areas. The major life areas are self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency.

What will happen after eligibility?

After an individual has been determined eligible, he or she will be contacted by a DDS assessor who specializes in conducting the Supports Intensity Scale® (SIS). The SIS is a standardized assessment tool that will help in service planning. The individual will also be referred to the DDS Area Office closest to that person's home for assistance with planning and services.

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In the event that the individual has a 688 referral and is under 22, the planning requirements of Chapter 688 will be met. Using a person-centered planning process, the individual will receive assistance from a DDS Service Coordinator to determine service needs, preferences and options. The Service Coordinator will help the individual locate and arrange supports.

Services provided by DDS are dependent on availability and funding. It is anticipated that some individuals can be supported on existing service models, while other individuals will need and benefit from new services and or/individualized options. The Autism and Family Support Centers funded by DDS are also available to provide information, support, and resources to individuals and families.

What services will be available?

Community Developmental Disability Services will be made available and include the following types of services: employment/day services; individual supports to assist individuals who may be living more independently; support services for assistance both in-home and in the community, such as adult companion, individualized home supports, behavioral supports and consultation, and peer support; and family support services for individuals living with their families, including respite, family training, and flexible funding. Individuals have the option to receive services from traditional providers or can choose one of the self-directed service options, the Participant-Directed Program or Agency With Choice Program.

Ongoing Development

With experience it is expected that our understanding of the support needs of this new, diverse population of adults with ASD will continue to evolve. DDS is committed to the ongoing development of services to be able to provide quality supports and assistance relevant and responsive to the needs of this group of individuals. This will involve additional education and training and strong partnerships with providers, individuals and families, and other stakeholders.

MASSCAP and Prioritization

What is MASSCAP?

MASSCAP is the Massachusetts Comprehensive Assessment Process. It consists of two components: the Inventory of Client and Assessment Planning (ICAP), and the Client and Caregiver Assessment (CCA).

MASSCAP provides a consistent and fair process across the state. Combined with professional judgment, it helps determine an individual's needs for services and the priority for services with consideration of health and safety factors. Both the ICAP and CCA are conducted through interviews without the individual present.

Inventory of Client and Assessment Planning (ICAP)

The ICAP is a standardized, proprietary instrument that assesses the functional skills and behavioral limitations of an individual. It is conducted through an interview process with an informant who has current knowledge of the individual's everyday functioning. Often, the informant is a family member. In some cases where the individual is placed out of the home, the informant is a current caregiver.

The ICAP assessment is usually completed during the intake and eligibility process by the Department of Developmental Services (DDS) eligibility specialist. The ICAP process results in a score from zero to 100, with lower scores typically suggesting greater needs for supervision and support. The ICAP can be reviewed or redone in the event of significant changes in the individual's needs or functioning.

Client and Caregiver Assessment (CCA)

The CCA is a tool developed by DDS to understand the resources available to the individual, including the family caregiver's capacity to provide care in the home. This capacity may be impacted by factors such as age, physical and mental health, the number of caregivers in the home, the number of dependents the caregiver is responsible for, and the capacity of the caregiver to provide a safe, supervised environment.

The CCA assessment does not result in a numeric score, but does provide a valuable summary of the caregiver's capacity to provide ongoing supervision. Typically, the CCA is conducted by a member of the area office MASSCAP team. It takes place in the home of the caregiver prior to planning for services for the individual.

Changing Needs

The ICAP, CCA, or both can be re-administered any time that DDS area office staff recognize that the individual or caregiver has experienced significant changing needs.

Prioritization

An individual is prioritized only for services that have been requested. Services can be requested during the eligibility process for adult services, or later as the individual and family work with the 688 transition coordinator.

Prioritization for comprehensive 24/7 residential supports requires a thorough review of health and safety factors during the MASSCAP process. An individual's priority status can be appealed, but the MASSCAP and its components are not subject to appeal.

Prioritized services do not begin until a student turns 22 or special education entitlements have ended. Family support services may be available while a student is still in school.

Supports Intensity Scale (SIS)

What is the Supports Intensity Scale?

The Supports Intensity Scale® (SIS) is a person-centered assessment for adults with intellectual and developmental disabilities. It is an individualized assessment, using a positive, strength-based approach, which provides a way to measure the types of supports individuals will need in their daily life.

The SIS is used across the country and around the world, and the Department of Developmental Services (DDS) is beginning to implement it here in Massachusetts. The assessment is administered by certified assessors, and is statistically established, reliable, valid, and fair.

Who receives a SIS assessment?

At this time, individuals found newly eligible for DDS with Autism Spectrum Disorder, Prader-Willi, or Smith-Magenis will be contacted in order to participate in a SIS assessment. In addition, individuals with intellectual disability who will be transitioning from special education to adult services may also be contacted to participate in a SIS assessment.

How is the SIS assessment administered?

A SIS assessment is conducted by a specially trained DDS SIS assessor, and should include least two people (respondents) who know a great deal about the individual's daily support needs. The individual being assessed is encouraged to attend, and may serve as a respondent if he or she is able. It is best if respondents are from diverse areas of the individual's life, such as one family member and one professional.

The SIS assessment takes place at a location that provides privacy and is mutually agreed upon by those involved. The assessment can take up to three hours to complete.

What kinds of questions will be asked?

Topics relate to quality of life, and include medical and behavioral supports, home and community living, social activities, lifelong learning, employment, health, safety, and protection and advocacy.

The focus of the assessment is to identify what supports the individual would need to successfully take part in all activities, as compared to a typical person of the same age in his or her community.

The SIS assessor will identify answers to these questions:

- » What types of support would be needed for the individual to be successful?
- » How frequently would the support be needed?
- » How much support time would be needed cumulatively over a twenty-four hour period?

How will the SIS be used?

The results of the SIS can be used to design a person-centered plan that aims to meet the individual's unique needs.

Results will be processed electronically. The individual/family/guardian and DDS service coordinator will receive hard copies of the report for individualized service planning.

The SIS report can be shared with providers as part of the Individual Support Plan (ISP) process. It can help the team to plan what supports would be needed for an individual's success.

For additional information:

- » <http://tinyurl.com/ma-dds-sis>
- » <http://aaidd.org/sis>

The Supports Intensity Scale (SIS) is a registered trademark of the American Association of Intellectual and Developmental Disabilities (AAIDD).

ADULT SERVICES

The Department of Developmental Services (DDS) provides an array of service options for adults. Each DDS area office contracts with a variety of qualified adult provider agencies to provide these services and not all area offices contract with the same agencies.

Referral Process

When an individual has been prioritized for DDS-funded day and/or residential services, and a particular option is identified in consultation with the person's family/guardian, a referral is made by DDS to that provider agency. The referral is sent to the agency that provides the service that can meet the individual's needs. The agency that receives the referral will then complete an intake to determine whether or not they can safely and effectively serve the individual. Agencies must have the capacity to serve a person. Once a person has been accepted by an adult provider agency, a team meeting is held with the family, school, etc. and the transition planning process is identified. The time frame varies, by area office, provider agency, and availability.

DDS-Funded Models of Employment/Day Services

DDS is committed to promoting and assisting individuals who are motivated to work to become employed in integrated jobs in the community. This is consistent with DDS's Employment First policy and mission to support individuals to "fully and meaningfully participate in their communities as valued members." DDS has a network of providers that offer an array of employment-related supports to individuals. Providers are encouraged to individualize supports and create maximum flexibility to assist each person to achieve his or her employment goals. Some individuals may choose to participate in a combination of models of day services. Below is a summary of day service options:

INDIVIDUAL SUPPORTED EMPLOYMENT

Individual Supported Employment includes an array of services designed to assist individuals to obtain and maintain a job. The plan is for an individual to have a job, based on identified needs and interests, located in a community business; or to be self-employed and own his or her own business.

Supported Employment services may include assessment, career planning, skills training, job development and placement, job coaching at the job site, and ongoing supportive services to assist the person to successfully maintain employment. Regular or periodic assistance, training, and support are provided for the purpose of developing, maintaining, and/or improving job skills, fostering career advancement opportunities, and helping to ensure job retention.

Natural supports are developed by the provider to help increase inclusion and independence of the person within the community setting. When hired at a job, individuals are expected to have regular contact with co-workers, customers, supervisors, and people without disabilities, and to have the same opportunities as their co-workers without disabilities.

GROUP SUPPORTED EMPLOYMENT

Group Supported Employment is the provision of skills training, job coaching, and supervision to a small group of people (on average 4 to 6), working in the community under the supervision of a provider agency. Group Supported Employment may include small groups in industry (enclave); provider businesses/small business model; and mobile work crews which allow for integration, such as a cleaning or landscaping crew. This service can provide individuals the chance to explore career interests and different types of work and work settings, and assist in the development of work skills, work habits, endurance, and/or independence.

While the goal is to help people move into individual, integrated jobs at businesses through Individual Supported Employment, it is recognized that this employment model may be an appropriate alternative for some people on a long-term basis, based on their high level of need for consistent support, structure, and supervision in order to be successful on a job.

COMMUNITY-BASED DAY SUPPORTS (CBDS)

This array of supports is designed to enable a person to enrich his or her life and enjoy a full range of

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community activities by providing opportunities for developing, enhancing, and maintaining competency in personal, social, and community activities.

Services include, but are not limited to, the following options:

- » Career exploration, including assessing of interests through volunteer experiences or situational assessments.
- » Community integration experiences to support fuller participation in community life.
- » Skill development and training.
- » Development of activities of daily living and independent living skills.
- » Socialization experiences and support to enhance interpersonal skills.
- » Pursuit of personal interests and hobbies.

This service is intended for:

- » Individuals of working age who may be on a pathway to employment.
- » A supplemental service for individuals who are employed part-time and need a structured and supervised program of services during the day when they are not working, which may include opportunities for socialization and peer support.
- » Individuals who are of retirement age, who need and want to participate in a structured and supervised program of services in a group setting.

DDS-Funded Models of Residential Services

The goal of all residential support services is to ensure the health and safety of each person and provide all supports needed, while at the same time working to foster personal growth and maximum independence.

RESIDENTIAL

These homes offer 24-hour residential supports in a group setting. Oversight, training, and supervision are provided by staff employed by a provider agency. This model of DDS-funded residential services is provided to those who have significant health and/or safety needs and require the most intensive level of support.

SHARED LIVING

Shared living is a residential support in which a person resides with a non-family member (host family) in their home. Provider agencies who offer shared living services recruit host families and work to match a person with an optimal living situation that offers an appropriate level of support and supervision. These agencies are responsible for providing oversight, training, and assistance to the host families.

INDIVIDUAL SUPPORTS

Individual Supports are provided outside of the family home, assisting people to live in and maintain a household. Individuals who receive these services do not require 24-hour residential support, but typically need intermittent assistance and training in order to maintain their own apartment or independent living situation. The number of hours of support a person receives per week is based on the assessed needs and focuses on Independent Living Skills. Services may include the acquisition, retention, or improvement of skills related to personal finance, health, shopping and menu planning, community and personal safety, and use of generic community resources to live in the community.

SELF-DIRECTION

Some people choose to self-direct their supports in order to create unique, flexible options. The individual must be prioritized for supports and assigned an allocation before self-direction planning can begin. Self-directed services require the development of a vision, plan and budget.

There are two models of self-direction that are available: the Participant-Directed Supports Program, and the Agency With Choice Program. In order to self-direct supports, the person or family/legal representative must be interested to plan for, hire, and supervise staff with the help of a support broker, or to share responsibilities with an Agency With Choice provider.

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Masshealth/Medicaid-Funded Supports

DAY HABILITATION PROGRAMS

Day Habilitation Programs (Day Habs) are funded and licensed by MassHealth and typically serve people who require more clinical and therapeutic assistance, are not able to work full time, and who might desire a day structured around social, recreational, and therapeutic activities.

- » A day habilitation program provides the following services:
- » Nursing Services and Health Care Supervision
- » Developmental Skills Training
- » Therapy Services (Occupational Therapy, Physical Therapy, Speech and Language Therapy, and Behavior Management)
- » Assistance with Activities of Daily Living
- » Day Habilitation Service Management

ADULT FAMILY CARE (AFC)

Adult Family Care is a program for people ages 16 and older with disabilities who cannot live alone safely. Persons live with trained paid caregivers who provide daily care. Caregivers may be family members (except legally responsible relatives) or non-family members. Individuals must be Medicaid-eligible in order to participate in the AFC program.

PERSONAL CARE ATTENDANT SERVICES (PCA)

A PCA is hired by a person with a disability to assist with his or her personal care routine. Persons are eligible if they qualify for Medicaid, have a severe, chronic disability, and require physical assistance in personal care. The number of PCA hours a person qualifies for is assessed and determined by MassHealth.

Participant-Directed Supports Program

Some individuals wish to have choice and control over all aspects of their service delivery, including decisions about how their Department of Developmental Services (DDS) funds are used to support them. This involves finding and hiring support staff, managing an individual DDS budget, and working with a financial management service to process invoices and payments.

For these people, participant direction may be an option to consider. Individuals may do this with the help of family, a guardian, friends, and their DDS service coordinator/support broker.

This self-directed support model is referred to as the Participant-Directed Program. There are guidelines that must be observed, although great efforts have been made to preserve the flexibility and creativity that this model affords. The individual determines what supports will be provided based on specific needs identified in the Individual Support Plan (ISP).

The participant-directed model offers the following key components:

DDS SUPPORT BROKER

- » Works in full partnership with the individual/guardian to customize a support arrangement that will meet the individual's needs, and to develop an individualized budget. This includes assistance with the hiring process: developing job descriptions, creating interview questions, supporting worker recruitment, and negotiating wages.
- » Assists with the online registration and credentialing process for new workers.
- » Takes full responsibility for drafting and revising the individual's budget.
- » Assists the individual in monitoring the budget/spending so the individual will know if spending of DDS funds is as planned. Helps make adjustments to stay within the budget as necessary/directed.
- » Supports the individual with making changes to the budget as often as necessary, in accordance with changing needs.

FINANCIAL MANAGEMENT SERVICE

DDS contracts with Public Partnerships (PPL) to provide this service:

- » Responsible for processing completed employee registration, credentialing, and paperwork to help the individual hire support staff.
- » Assists in the financial management and accountability of the individual's DDS resource allocation, and assumes employer fiscal responsibility (e.g., payroll, taxes, worker's compensation).
- » Processes payroll as well as payment for specialized services and goods.
- » Provides a monthly financial report, as well as real-time online access to review the individual's budget.

Agency With Choice Program: Co-Directed Supports

Some individuals wish to have shared responsibility in selecting their support people and directing the day-to-day activities of their staff. For these people, the Agency With Choice model of support may be an option to consider.

Individuals who choose this support model will have an individual budget allocation for the purchase of services to meet their needs. The individual/family/guardian is able to identify the people they wish to employ with the support of an agency to assist in the hiring process, payroll management, and other related tasks.

The Agency With Choice program offers the following:

- » A co-employment model in which the agency serves as the employer, partnering with the individual/family/guardian to help train and manage staff. This enables the individual/family/guardian to serve as the managing employer.
- » The agency agrees to interview, hire, and negotiate a pay rate for the person or people the individual/family/guardian identifies to provide support, subject to agency personnel policies.
- » The individual/family/guardian has responsibility for daily supervision of workers, as well as the decision to no longer use a particular worker.
- » If the individual/family/guardian chooses to discharge a particular worker, that person may continue to work for the agency in a different capacity if the agency chooses.
- » The agency assumes responsibility for paying workers identified and hired. This includes withholding, filing, and paying federal and state income and employment taxes, as well as providing a worker's compensation policy.
- » The agency provides the individual with a monthly financial report so the individual is aware that spending is occurring as planned and can make adjustments if necessary.
- » Service options within the co-directed Agency With Choice program model include:
 - Adult Companion Services
 - Individualized Home Supports
 - Respite
 - Individualized Day Supports
 - Family Training
 - Peer Support
 - Behavioral Support and Consultation
 - Family Service Navigation
 - Financial Assistance

Employment First Initiative

Over the past several years, the Department of Developmental Services (DDS) has been working on an Employment First initiative. This is a plan to expand integrated employment for people with intellectual and developmental disabilities, and to phase out center-based/sheltered workshop services.

DDS is working with day and employment providers to get more full-time and part-time jobs for the people we serve. One primary reason for this is the expressed preference of many individuals and their families for competitive employment opportunities.

As of January 1, 2014, no new referrals can be made to sheltered workshop programs. DDS's goal is that the sheltered workshop model will be phased out by June 30, 2016. Individuals currently served in sheltered workshop situations will transition to individual or group supported employment, or to community-based day services. DDS is committed to supporting individuals during non-work hours in needed day services in a manner that maintains stability for families.

The DDS transition coordinator will plan with the individual and family to identify the most appropriate employment and day options available when the individual graduates. Typically, this requires a team approach, with all team members contributing toward a successful outcome.

Some individuals and families may craft a unique employment option, or may combine several models to create a meaningful experience. The option at graduation is a first step, and may evolve as the individual has different experiences and continues to develop and grow.

Factors to consider when planning:

- » The student's employment experiences, skills, and training and supervision needs.
- » The student's travel and transportation skills and needs.
- » The opportunity to build upon any current employment skills or jobs.
- » The location of the employment or training situation.
- » Flexibility and creativity in hours, scheduling, and transportation options.

Service Definitions

INDIVIDUAL SUPPORTED EMPLOYMENT

An individual receives assistance from a provider agency to obtain an integrated, paid job based on identified needs and interests. A job coach provides regular or periodic assistance, training, and support so that the individual can develop, maintain, and/or improve job skills and achieve successful job retention. Natural supports are developed by the provider to help increase the individual's inclusion and independence in the community.

GROUP SUPPORTED EMPLOYMENT

A small group of individuals work at businesses in the community with the supervision of a provider agency. Individuals have contact with co-workers, customers, supervisors, and other individuals without disabilities. Individuals may work in industry/businesses, mobile work crews, and temporary services.

COMMUNITY-BASED DAY SERVICES

Individuals are supported to enrich their lives through a full range of community activities while developing and enhancing personal and social competency. Services can include career exploration, volunteer experiences, community integration activities, skill development, and training in activities of daily living, independent living, and social skills. This model may be a pathway toward employment for some individuals.

DAY HABILITATION

Day habilitation services are funded by MassHealth. Services are based on a service plan of goals and objectives and a program of integrated activities and therapies to help participants achieve optimal physical and cognitive capabilities. Employment and related activities are not included in the day habilitation model of services.

PARTICIPANT-DIRECTED EMPLOYMENT AND INDIVIDUALIZED DAY SUPPORTS

Supports provided to individuals tailored to their specific goals and outcomes. Individuals acquire, improve, and/or retain skills to prepare and support them for work and/or meaningful community participation. Individuals work closely with DDS staff on needs assessment, prioritization, planning, and budget development, and have primary responsibility for the hiring of support staff.

Transportation

Travel and transportation arrangements are an important aspect of a successful transition to adult life. Individuals leaving school use a variety of transportation options. Many travel independently by public transportation or specialized public transportation (e.g., THE RIDE paratransit service). Others arrange rides with family members, friends, co-workers, volunteers, or provider staff.

The Human Service Transportation (HST) Office, a part of the Executive Office of Health and Human Services, oversees transportation to day and employment programs, as well as to day habilitation programs, for individuals served by the Department of Developmental Services (DDS). The HST Office manages contracts with six Regional Transit Authorities (RTAs). In turn, the RTAs subcontract with local transportation companies that hire and train drivers for vans and sedans maintained by the company. Transportation is provided if there are routes and seats available.

Tips for Arranging Successful Transportation

- » If feasible, take advantage of travel training activities while still in school to maximize the rider's independence.
- » Consider whether public transportation or specialized public transportation is an option.
- » When considering employment or a day program, consider location. **CLOSER IS USUALLY BETTER FOR TRANSPORTATION.**
- » If HST Office transportation is beneficial, work with your 688 transition coordinator on a transportation request (TR). The service coordinator will submit the TR to the HST Office on behalf of the individual.
- » Make sure the DDS 688 transition coordinator is aware of important physical, medical, or behavioral needs of the individual.
- » Try to be flexible and realistic about the available transportation options.

A Few Points About HST Services

- » The HST Office provides curb-to-curb service. The driver can assist an individual in and out of the vehicle, but cannot help the individual in or out of the home.
- » As much as possible, transportation companies try to assign permanent drivers to each route so that individuals, families, and staff know each other.
- » Transportation companies are required to conduct a Criminal Offender Record Information (CORI) check on each driver before hire and annually thereafter.
- » Transportation routes have established pick-up and drop-off times in a particular order. Drivers are not able to change these times unless instructed to do so by the transportation company. There is a 15-minute window before or after the designated pick-up or drop-off time.
- » Routes are designed so that individuals are not on the route more than 90 minutes one way.
- » If the vehicle arrives at a residence and no one is home to greet the individual, the driver will work with the transportation company, the RTA, and DDS to resolve the situation. The individual will not be left unattended unless a "Home Alone" authorization has been completed and is on file at the HST Office.
- » There is a complaint resolution system in place to resolve situations in which individuals and families feel that transportation standards have not been met.
- » The HST Office does not provide transportation to individuals working independently.

Transportation to Locations Other than Day and Employment

- » Some individuals receiving MA health are eligible to receive individual transportation to appointments and activities approved as medically necessary through PT-1 requests.
- » Although DDS-sponsored transportation options for social and recreational activities are limited, some family support centers and other entities do provide or assist in arranging transportation to some activities and events.
- » The HST Office website (www.mass.gov/hst) provides information about other transportation and travel resources.

Family Support, Recreation, and Friendships

Family Support Centers

The Department of Developmental Services (DDS) has established and funded Family Support and Autism Support Centers throughout the state in order to support children and adults living at home with their families. In addition, some areas have established Cultural/Linguistic Specific Family Support Centers in order to best serve families in those areas. Each center is created to respond to the unique needs of the families they support.

Family Support Center staff work with families to identify assistance or information that will be useful to them. They work individually, providing support and ensuring follow through.

Centers are rooted in communities and act as a hub for offering a wide range of services based upon need, interest, and available resources, including but not limited to:

- » Information and referral
- » Service navigation
- » Knowledge of generic, state, and federal resources that will support the family
- » Family training
- » Networking opportunities
- » Administration of DDS-approved flexible funds
- » Respite
- » Opportunities for socialization
- » Peer mentoring
- » Recreation opportunities

A statewide listing of the Family Support, Cultural/Linguistic-Specific, and Autism Support Centers can be found at www.mass.gov/dds.

Social & Recreational Opportunities

Staff at the Centers gather information from cities and towns they serve as well as other interesting events and activities throughout the state. With input from families, Family Support Centers create opportunities for social/recreational activities by either sponsoring an activity or supporting other agencies in their efforts.

Collaboration with community groups is important for individuals to become an active part of their community and begin to understand what local resources and opportunities exist. This can be done through calendars, Internet sites, and newsletters. Centers may also coordinate activities throughout the area so families do not have to travel from their own communities to gain access to recreational/ social activities.

Friendships

Relationships that blossom into friendships can be especially challenging to engage in for people of all ages who happen to have disabilities. Relationships for people with disabilities are often limited to family members, paid staff and other people with disabilities. These relationships may be the most critical and meaningful to the individual, but all people benefit greatly by a diversity of relationships.

There are many ways to bring people with and without disabilities together to grow and nurture friendships. Here are a few ideas to build from:

- » Religious activities
- » Volunteer in the community
- » Clubs
- » Join a gym or your local YMCA
- » Political involvement
- » Adult education classes
- » Special interest groups
- » Special Olympics
- » Best Buddies
- » Sports-related events and activities
- » Travel
- » Routinely visit local establishments in your community
- » Community theatre

Everyone needs friends!

People with friends are happier.
People with friends are healthier.
People with friends are safer.

*****"Widening the Circle" –
 expanding opportunities for friendships between
 people with and without disabilities**

State Agency Resources

Department of Mental Health (DMH)

State agency providing services to individuals with long-term or serious mental illnesses. DMH offers inpatient and outpatient services, case management, skill development, and employment, residential, individual, and family support.

25 Staniford Street
Boston, MA 02114
617-626-8000
Website: www.mass.gov/dmh

Department of Public Health (DPH)

State agency serving all citizens of the Commonwealth. Provides supports related to care, education, prevention, quality assurance, disease control, and research to promote healthy individuals, families, and communities.

250 Washington Street, 6th floor
Boston, MA 02108
617-624-6000
Website: www.mass.gov/dph

Department of Transitional Assistance (DTA)

State agency that administers a range of public assistance programs across the Commonwealth. Areas of focus include emergency and transitional assistance, food stamps, and Supplemental Security Income (SSI).

600 Washington Street
Boston, MA 02111
1-877-382-2363
Website: www.mass.gov/dta

Disabled Persons Protection Commission (DPPC)

State agency protecting adults with disabilities from abuse, neglect, and omission of care by investigation, oversight, public awareness, and prevention. Suspected abuse can be reported by calling the hotline number below.

300 Granite Street, Suite 404
Braintree, MA 02184
1-888-822-0350 (Voice/TTY)
617-727-6465
Website: www.mass.gov/dppc

Massachusetts Commission for the Blind (MCB)

State agency supporting optimal community participation and independence by providing vocational and social services as well as financial and medical assistance to Massachusetts residents who are legally blind.

600 Washington Street
Boston, MA 02111
617-727-5550
Website: www.mass.gov/mcb

Massachusetts Commission for the Deaf & Hard of Hearing (MCDHH)

State agency offering training, technology, case management, social services, interpreter support, and independent living support for deaf and hard-of-hearing individuals.

600 Washington Street
Boston, MA 02111
617-740-1600 (Voice)
617-740-1700 (TTY)
617-326-7546 (Videophone)
Website: www.mass.gov/mcdhh

Massachusetts Office on Disability (MOD)

State agency providing advocacy, information, and referral. Focuses on legal rights, accommodations, and accessibility to promote dignity, opportunity, and self-determination.

1 Ashburton Place #1305
Boston, MA 02108
617-727-7440
Website: www.mass.gov/mod

Massachusetts Rehabilitation Commission (MRC)

State agency promoting dignity for individuals with disabilities through employment, education, training, advocacy, assistive technology, and independent community living.

600 Washington Street
Boston, MA 02111
617-204-3600
Website: www.mass.gov/mrc

Residential Alternatives

Adult Family Care/Adult Foster Care (AFC)

- » Adult Family Care (sometimes called Adult Foster Care) is a Medicaid-funded residential program for individuals who require assistance with one or more activities of daily living (such as bathing or eating) to be able to live safely in their home. Each participant receives the assistance they need with personal care and activities of daily living. AFC members may only stay alone for up to three hours at a time.
- » The program is administered by an AFC provider agency, and provides case management, nursing consultation, and a MassHealth tax-free stipend to the caregiver. AFC has two levels of stipend payment related to the assessed needs of the individual. Each caregiver is thoroughly prescreened and undergoes a Criminal Offender Record Information (CORI) check.
- » To qualify for AFC, individuals must be 16 years of age or older, eligible for MassHealth, and willing to participate in the program. Caregivers must be at least 18 years of age and cannot be legal guardians.
- » Caregivers of Adult Family Care may be a parent, sibling, or an extended family member who resides in the biological family home. Caregivers of Adult Foster Care (not family members) provide support in their own residence.

Section 8 Housing Vouchers

- » Section 8 housing is a federal assistance program run through the U.S. Department of Housing and Urban Development (HUD). The program helps low-income Massachusetts residents pay for their housing.
- » Section 8 rental vouchers help Massachusetts tenants pay their rent. Two types of vouchers assist with rent:
 - 1) Section 8 Tenant-based Vouchers: A qualified individual chooses his/her own apartment. The apartment must be safe and clean, and the rent a fair market value. The landlord must agree to accept the requirements from HUD. Individuals usually pay 30% of their income for rent, and the Section 8 program pays the rest. If the individual moves, the Section 8 rental assistance goes with them.
 - 2) Section 8 Project-based Affordable Housing Vouchers: An individual must live in a specific Section 8 subsidized housing unit. Individuals usually pay 30% of their rent, and Section 8 pays the rest. The voucher does not go with the individual when they move.

HOW TO APPLY:

- » You can apply at public housing agencies or approved regional nonprofit housing agencies at the age of 18. Your name will be placed on a waiting list, which varies from community to community and can be very long (eight to ten years). Therefore, you should apply long before you will need the voucher.
- » Apply in several communities. Apply at the housing authority in your town, and also to the HUD centralized housing list at section8listmass.org. Once you've submitted an application, it is important to notify the housing authority of any address changes and to respond to housing communication in order to stay on the housing list.

Other Residential Options

- » Using self-directed supports and a combination of resources, creative living arrangements can be achieved. Some examples:
 - 1) Renting or leasing: Most communities have market rent or subsidized apartments available. Information can be obtained from state agencies, housing organizations, human service agencies, friends, relatives, landlords, and realtors.
 - 2) Home sharing: Two or more unrelated persons sharing housing and expenses.
 - 3) Home, condo, or apartment ownership: Can be financed with family savings, investments, first-time home ownership programs, or special needs trusts. In-home supports may be provided through a health care agency, the Department of Developmental Services (DDS), a roommate, or community and family supports.
 - 4) Collaboration with the local housing authority and provider agency.
 - 5) In-law apartment with separate entrance/exit and cooking/bath facilities.

Consider continuing dialogue with DDS around creative partnership ideas and options, keeping in mind the cost of long-term staffing needs.

DDS Home & Community-Based Waiver Overview

WHAT are the Home and Community-Based Services Adult Waivers?

The Department of Developmental Services (DDS) Home and Community-Based Services (HCBS) Waivers are a way for individuals to receive services in their home community instead of an institution. These waivers are a federal and state partnership. They are run by DDS on behalf of the Commonwealth of Massachusetts through MassHealth (Medicaid). Federal reimbursement to the Commonwealth of Massachusetts for waiver services helps support the availability and expansion of DDS supports. The waivers may provide participants some level of protection of their services.

WHO is eligible for HCBS Waivers?

To be eligible for the waiver program, you must meet these federal requirements:

- » Apply to become a waiver participant;
- » Be a person with an intellectual disability as determined by DDS;
- » Be eligible for and enrolled in the correct MassHealth category;
- » Be at least 22 years of age;
- » Be eligible for admission to an Intermediate Care Facility for Individuals with an Intellectual Disability (ICF/ID);
- » Agree to receive services in the community rather than an institution; and
- » Be assessed by DDS to need one or more waiver services.

HOW can I apply?

In order to apply, you need to fill out a waiver application. Your DDS Area Office can help you and can discuss the timing of your application. DDS will conduct an assessment of your needs, assign you a priority for services, and send you a letter to let you know if you are eligible for one of the waiver programs.

WHEN enrolled in one of the DDS Adult Waivers, can I still receive other Medicaid services?

Yes, you can be enrolled in the waiver program and still receive other Medicaid program services such as medical care, nursing care, home health aide services, personal care attendant services, and any other medically necessary service that is available through the Medicaid Program State Plan.

WHAT happens if I do not enroll or cannot enroll?

DDS will work with you and your family to determine if you need to enroll in the waiver program to obtain or keep services from DDS and help you resolve waiver eligibility issues.

WHAT if my needs change?

If your needs change, you will be referred for an assessment to determine if you need additional or different services. This may result in eligibility for and enrollment in a different waiver.

WHAT services can I receive in the DDS Adult Waiver Programs?

INTENSIVE SUPPORTS WAIVER PROGRAM

The **Intensive Supports Waiver Program** provides services for individuals with intellectual disability age 22 and older with an intensive level of support needs, requiring supervision or support for 24 hours a day, seven days per week, due to significant behavioral, medical, and/or physical support needs and the absence of available, natural, generic, and Medicaid services.

TRANSITION INFORMATION EVERY FAMILY SHOULD KNOW

Waiver services offered include:

Adult Companion, Assistive Technology, Behavioral Supports and Consultation, Center-Based Day Supports, Chore, Community-Based Day Supports, Day Habilitation Supplement, Family Training, Group Supported Employment, Home Modification and Adaptations, Individual Goods and Services, Individualized Day Supports, Individualized Home Supports, Individual Supported Employment, Live-In Caregiver, Occupational Therapy, Peer Supports, Physical Therapy, Residential Habilitation, Respite, Specialized Medical Equipment and Supplies, Speech Therapy, Stabilization, Transitional Assistance Services, Transportation, Vehicle Modification and 24-Hour Self-Directed Home Sharing.

COMMUNITY LIVING WAIVER PROGRAM

The **Community Living Waiver Program** is for individuals who can live in their family home, in the home of someone else, or their own home, and do not need supervision 24 hours a day, seven days a week due to the combination of natural, generic, and Medicaid services.

Waiver services offered include:

Adult Companion, Assistive Technology, Behavioral Supports and Consultation, Center-Based Day Supports, Chore, Community-Based Day Supports, Day Habilitation Supplement, Family Training, Group Supported Employment, Home Modification and Adaptations, Individual Goods and Services, Individualized Day Supports, Individualized Home Supports, Individual Supported Employment, Live-In Caregiver, Occupational Therapy, Peer Supports, Physical Therapy, Respite, Specialized Medical Equipment and Supplies, Speech Therapy, Stabilization, Transportation and Vehicle Modification

ADULT SUPPORTS WAIVER PROGRAM

The **Adult Supports Waiver Program** is for individuals who can live in their own home or apartment or family home due to the combination of strong natural/informal generic and Medicaid services.

Waiver services offered include:

Adult Companion, Assistive Technology, Behavioral Supports and Consultation, Center-Based Day Supports, Chore, Community-Based Day Supports, Day Habilitation Supplement, Family Training, Group Supported Employment, Home Modification and Adaptations, Individual Goods and Services, Individualized Day Supports, Individualized Home Supports, Individual Supported Employment, Occupational Therapy, Peer Supports, Physical Therapy, Respite, Specialized Medical Equipment and Supplies, Speech Therapy, Stabilization, Transportation and Vehicle Modification

HOW can I find out more about the DDS waiver program?

Your DDS Area Office can provide you with additional information about the services offered through the waiver program. You can also email the Waiver Management Unit at DDS-DL-WaiverManagementUnit@MassMail.State.MA.US or visit the DDS website at www.mass.gov/dds.

Age of Majority, Guardianship, and Alternatives

Every young person turning 18 has reached the age of majority and is considered an adult with the rights and responsibilities that come with it. For young people with disabilities approaching this milestone, it is a time to consider how best to support them in their decision-making.

Every person with disabilities does not need a guardian. Guardianship should not be used to protect the person from normal daily risks we all face in working, having a home, moving about, being consumers, and relating with other people. A guardian should not be appointed simply because the person has made (or is about to make) decisions that may be incorrect or show poor judgment, or because the person relies heavily on others for advice.

Alternatives to Guardianship

ADVICE

Some individuals can benefit from family members or other trusted advisors helping them make decisions. Questions to consider are whether an individual has people available to assist him/her; whether the people from whom he/she is likely to seek advice are likely to give sound advice; and whether the individual is likely to listen to, consider, and follow the advice.

EDUCATION

It is important to educate the individual not only on the areas in which he/she needs assistance, but also on how to make good decisions once he/she has the relevant information. Education can be specifically directed at a troublesome area, or can be used in a limited fashion in assisting with one particular decision.

INFORMED CONSENT

Informed consent is the agreement given voluntarily by an individual who understands and weighs the risks and benefits involved in a particular decision. An adult over the age of 18 is presumed legally competent to provide consent. According to Department of Developmental Services regulations, whenever informed consent is required (prior to admission to a facility, prior to medical treatment, prior to being involved in research activities, prior to release of personal information, or before moving to an alternative program option), the information must be provided in simple ways. This ensures that the individual has time to ask questions and consider options. There must be agreement that the individual understood the situation and made a clear decision.

LEGAL ADVOCACY

For many decisions, the advice and advocacy of an attorney may assist the individual in reaching a good conclusion if the individual will listen to the advice and act accordingly.

DURABLE POWER OF ATTORNEY

If the individual is capable of executing this document, then he/she can grant legal authority to another person to handle certain specified affairs. A Durable Power of Attorney is usually limited to financial issues, but does not have to be.

HEALTH CARE PROXY

An individual who is capable of making health care decisions may appoint a person, called a proxy, to make health care decisions for him/her in the event that he/she becomes incapacitated. The document to be executed may be as detailed as desired regarding guidance to the proxy. The involved physician must activate the health care proxy based on the individual's decision-making capacity.

TRANSITION INFORMATION EVERY FAMILY SHOULD KNOW

REPRESENTATIVE PAYEE

In the event that an individual receives Social Security benefits (SSI or SSDI), these benefits may be managed by a person appointed by the Social Security Administration. This “representative payee” is required to make annual accountings to ensure that the funds are received and are being properly expended for the benefit of the individual.

Types of Guardianship

GUARDIANSHIP

Guardianship is an option for a person who is deemed by the court to be incapable of making decisions about personal and financial affairs. The clinical team evaluation is presented to the judge, who makes the decision to appoint a guardian. The judge has the ability to limit the guardianship, having the individual retain certain rights and abilities. Examples may include the right to vote, to obtain a driver’s license, to choose people for friendships and visitation, and to use a telephone or computer.

CONSERVATORSHIP

If the individual is not competent to handle financial affairs, and there is income from sources other than benefit checks, or if there are assets that are not adequately protected, and there is some risk of loss if the individual continues to handle his/her finances, then a judge may appoint a conservator. The judge may decide that the individual is capable of handling a small amount of money, and can exempt that amount from the conservatorship (Massachusetts General Laws Chapter 201, Section 16B).

ROGER’S COURT MONITOR

This type of single-purpose guardianship applies to an individual who is not capable of understanding the reason an antipsychotic medication is needed, and is not capable of grasping the personal risks and benefits. If the person can apply reason and make informed choices, he/she has the legal right to either accept or reject antipsychotic medication (even if that choice is unwise).

SUBSTITUTED JUDGEMENT

Substituted judgment is used in cases when extraordinary treatment is proposed for a person under guardianship or a person who is in need of guardianship. “Extraordinary” treatments generally are medical treatments that are particularly intrusive, risky, or restrictive. The probate court renders a “substituted judgment” for the individual, and approves the treatment plan.

MassHealth Benefits

What is MassHealth?

MassHealth is state-administered Medicaid-funded health insurance. It provides comprehensive health insurance--or help in paying for private health insurance--to Massachusetts children, families, seniors, and people with disabilities.

To be considered "disabled" for MassHealth eligibility, you must have one of the following:

- » a certification of legal blindness from the Massachusetts Commission for the Blind
- » a disability determination by the Social Security Administration
- » a disability determination by the Division of Medical Assistance Disability Determination Unit

Types of Coverage:

MASSHEALTH STANDARD health insurance coverage is automatically provided to SSI recipients. This coverage type offers a full range of health care benefits. Young people who are not on SSI may apply separately for MassHealth Standard.

MASSHEALTH COMMONHEALTH is for adults, young adults, and children with disabilities who are not eligible for MassHealth Standard. There is no income limit for MassHealth CommonHealth. If your monthly income before taxes and deductions is above 100% of the federal poverty level, you may have to pay a premium,* or meet a one-time-only deductible.

MASSHEALTH COMMONHEALTH FOR WORKING ADULTS covers adults ages 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.

MASSHEALTH/KAILEIGH MULLIGAN allows certain children with significant disabilities under age 18 to live at home with their parents and have MassHealth eligibility determined without counting the income and assets of their parents. This program ENDS at age 18. Other MassHealth programs must be applied for at age 18 to maintain coverage as a young adult.

How to Apply:

The application for MassHealth (formerly the Member Benefit Request or "MBR") is now called the "Application for Health Coverage and Help Paying Costs." Applications can be obtained:

- » **BY PHONE** through the MassHealth Enrollment Center at 1-888-665-9993 (TTY: 1-888-665-9997). They will send you a MassHealth information booklet, application form, and any supplements. They will also answer any questions you have about applying for MassHealth.
- » **ONLINE** at <http://www.mass.gov/eohhs/docs/masshealth/membappforms/aca-2-english.pdf>.
- » **IN PERSON** at a local community health center, hospital, or other MassHealth-approved community organization. A MassHealth benefits advisor will answer your questions, fill out an online application with you, and submit your application via computer. To find a community health center near you, call the Massachusetts League of Community Health Centers Patient Referral Line at 1-800-475-8455.

To apply and be considered for MassHealth due to a disability, rather than income, either a **CHILD DISABILITY SUPPLEMENT** or **ADULT DISABILITY SUPPLEMENT** form must be included with the application.

An **AUTHORIZED REPRESENTATIVE DESIGNATION FORM** must be submitted to MassHealth when submitting an application or to check on eligibility, status of claims, supplies, etc. on behalf of an adult child (over 18 regardless of ability/disability). This form will allow information to be shared about the adult child. The authorization may need to be renewed periodically.

TRANSITION INFORMATION EVERY FAMILY SHOULD KNOW

What other benefits may be available?

In addition to a full range of health care needs, MassHealth offers services to eligible members for home health aides, personal care attendants, behavioral health (mental health and substance abuse) services, incontinence supplies (diapers/pull-up briefs), transportation services to medical appointments, adult family/foster care, adult day habilitation services, and pharmacy services, including coverage for prescription and over-the-counter drugs. For more information, go to www.mass.gov/masshealth/disability, or call 1-800-841-2900 or the Community Support Line at 1-800-882-1435.

Other benefits to consider:

*The **MASSHEALTH STANDARD/CommonHealth Premium Assistance (MSCPA)** program may pay some or all of you/your family's private health insurance premium or COBRA payment. The private insurance must meet the Basic Benefit Level of coverage as determined by MassHealth and MSCPA. MSCPA (premium assistance) will continue for as long as private health insurance is retained for the member with a disability, and as long as the member is eligible for MassHealth. Premium assistance is a separate application process and must be applied for by calling the MSCPA program at 1-800-862-4840.

As a young adult with private health insurance approaches the age of 26, an "Adult Dependent with a Disability" request should be considered and formally requested through the private health insurance. This request, if approved, will ensure that private insurance coverage continues past the current legally mandated age of 26.

As long as the private health insurance is maintained as primary insurance and MassHealth is secondary, eligibility for premium assistance (MSCPA) should be retained, regardless of age. Contact MSCPA to request an application at 1-800-862-4840.

For further information regarding MassHealth benefits, visit the Division of Medical Assistance website at www.mass.gov/dma, or call 1-800-841-2900.

SSI Benefits

There are different types of benefits provided by the Social Security Administration (SSA). These federal programs provide assistance to adults and children with disabilities, and to people who have reached retirement age.

- » **SUPPLEMENTAL SECURITY INCOME (SSI)** pays benefits to adults and children with disabilities who have limited income and resources and meet medical disability criteria.
- » **SOCIAL SECURITY DISABILITY INCOME (SSDI)** is for people who have been in the workforce and have accrued Social Security credits and have a disability; or a child with disabilities whose eligible parent is retired, deceased, or has disabilities.
- » **SOCIAL SECURITY** is for people who have reached retirement age.

Who is eligible for SSI?

A young adult may qualify for SSI benefits if he or she 1) has disabilities, 2) has low income, 3) has resources or assets **LESS THAN \$2000**, AND 4) earns less than \$1,000 per month (this earning requirement does not apply to those who are blind).

At age 18, an individual can apply for SSI independent of the parents' income and resources. Many individuals with disabilities who were ineligible for SSI due to their parents' income and/or resources prior to age 18 may be eligible upon their 18th birthday. However, SSI eligibility does not happen automatically even if the individual was eligible as a child.

How do I apply for SSI?

An application for benefits can be obtained at the local Social Security office. SSI does not have an online application, but most individuals over 18 can start the process online by reviewing the **ADULT DISABILITY CHECKLIST** and the **ONLINE DISABILITY BENEFIT APPLICATION** To assist in gathering the information and documents needed to apply.

Schedule an appointment with your local Social Security office or call 1-800-772-1213 (TTY 1-800-325-0778) to make a telephone or local office appointment. Original documents, not photocopies, are required for birth certificates and other documents. Bring and share original documents during your visit, but only leave copies, and ask for a receipt for all documents provided to SSA. This helps to maintain progress in the application process.

How much will I receive?

The amount you receive depends upon your living arrangement and employment status. Although SSA does not count the income and assets of parents to determine the financial eligibility of individuals ages 18 and over, living with parents or others may affect the amount of the SSI benefit.

The **STATE SUPPLEMENT PROGRAM (SSP)** in Massachusetts provides an additional supplement to the federal SSI cash assistance program through a separate payment. If you are blind and have another disability, you will receive a higher benefit through the SSP.

What other benefits will I get?

- » **HEALTH INSURANCE:** If you are determined eligible for SSI, you will automatically be eligible for MassHealth Standard health care coverage. You do not need to file a separate application.
- » **SNAP FOOD STAMPS:** SSI recipients usually qualify for SNAP food stamps. If you live in a household where everyone is applying for or receiving SSI, you may apply for SNAP food stamps at the Social Security office. Otherwise, you must apply at the Division of Transitional Assistance.
- » **FUEL ASSISTANCE:** SSI recipients may apply for fuel assistance during the heating season.
- » **SSP SPECIAL BENEFITS:** SSP Special Benefits may pay for moving expenses if you move within

TRANSITION INFORMATION EVERY FAMILY SHOULD KNOW

the state, or pay for replacement items if things you own are destroyed in a natural disaster or fire. To apply, contact the Department of Transitional Assistance.

- » **BURIAL EXPENSES:** You may receive up to \$1,100 for burial expenses for SSI recipients who do not have resources to pay toward these expenses. The total cost of the burial cannot be greater than \$1,500. No additional services or payments can be obtained or provided above the \$1,500 maximum burial expense, regardless of payor.

Working and SSI

In certain cases, SSA does not count some of your income or resources. Certain incentive programs allow you to continue to collect SSI cash benefits, or let you continue to receive Medicaid coverage even though you are not receiving SSI cash benefits.

THE PLAN TO ACHIEVE SELF SUPPORT (PASS) is an SSI work incentive program that allows a recipient to set aside income and resources to pay for education or training for the purpose of obtaining employment. The SSA will not count the income that you set aside under your PASS when they figure out your SSI benefit payment amount. In order to be eligible for PASS, the SSI recipient must prepare the plan in writing. A form is available at the Social Security office.

THE IMPAIRMENT-RELATED WORK EXPENSES (IRWE) program allows people with disabilities who are out of school and seeking employment to exclude certain costs from their gross income. Expenses such as the cost of job coaching may also be applied to reduce income in order to maximize the SSI benefit payment amount.

THE STUDENT EARNED INCOME EXCLUSION is a work incentive that allows qualified young people who are still in school to keep some or all of their earnings without losing money from their SSI checks.

BENEPLAN and **PROJECT IMPACT** can provide additional information about how working and earning or increasing wages impacts SSDI and/or SSI benefits. Which program you can access depends on where you live.

BenePLAN assists consumers and staff of state agencies, employment provider organizations, and school systems in these Massachusetts counties: Essex, Norfolk, Middlesex, Worcester, Hampden, Hampshire, Franklin, and Berkshire. BenePLAN can be reached at 1-877-YES WORK (1-877-937-9675) or online at www.BenePLAN.org.

Project IMPACT provides individualized benefits counseling to Massachusetts Rehabilitation Commission consumers, and to their family members, employment provider organizations, school systems, and state agencies in Suffolk, Plymouth, Bristol, Barnstable, Nantucket, and Dukes counties. Project IMPACT can be reached at 1-800-734-7475 or 617-204-3854, or at 617-204-3834 (TTY).

For more information, visit www.socialsecurity.gov/work or your local Social Security office.

Special Needs Trusts

What is a Special Needs Trust?

A Special Needs Trust is a fund set up to provide additional funds for an individual with a disability. When drafted and administered properly, a Special Needs Trust will allow the beneficiary to benefit from the trust while retaining eligibility for public benefits and maintaining the current amount of benefits being received. A Special Needs Trust may be created using assets of the beneficiary (the person with the disability) or funds from a family member. One does not have to be wealthy to create or have a Special Needs Trust.

Special Needs Trusts are designed to set aside funds for personal needs, and do not affect government benefits that are critical to individuals with disabilities, such as:

- » Supplemental Security Income (SSI)
- » Medicaid
- » Section 8 Housing
- » Food Stamps

Why Create a Special Needs Trust?

A person must have very few assets to be eligible to receive government benefits. For example, the 2008 SSI eligibility maximum is \$2000 for a single person and \$3000 for a married person, subject to certain exclusions for some personal assets. The creation of a Special Needs Trust allows additional funds for an individual to meet personal expenses. The trust needs to be irrevocable, and the beneficiary must not have the power to direct the use of trust assets for his or her own support.

What Is a Special Needs Trust Used For?

Trust assets should be used to provide goods and services beyond those provided by public benefits programs, such as entertainment, bus passes, household goods, education, medical costs not covered by other benefits, and medical equipment.

Other Suggestions

Speak with an attorney who specializes in estate planning for individuals with disabilities or elder law if you have questions about whether you or a loved one may benefit from a Special Needs Trust.

Special Needs Trusts are complex and must be drafted and administered very carefully. Make sure that the Special Needs Trust is drafted by an attorney skilled in this specialty.

Communicate your plans with siblings and future caregivers of the individual with disabilities.

Accept monetary gifts from grandparents and other relatives, but make certain that gifts are directed to the Special Needs Trust.