SPECIAL NEEDS ADVOCACY FORUM

Friday, October 28, 2016, 8:00-2:00

Marriott Boston Newton, 2345 Commonwealth Avenue, Auburndale

Sponsored by Special Needs Law Group of Massachusetts;
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Course Materials:
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Special Needs Advocacy Forum
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Special Needs Advocacy Forum
About the Program Faculty

Attorney Annette M. Hines, Chair, is the founding partner of The Special Needs Law Group of Massachusetts, P.C. located in Framingham, MA. Her law practice includes Estate Planning, Trust administration and Elder Law with Special Needs Planning and Healthcare Law being an especially personal focus. She serves as Trustee of over a dozen Special Needs Trusts. Attorney Hines knows first-hand the challenges of parenting and the necessities of a child with special needs. She is a member of the Massachusetts Bar Association, the National Academy of Elder Law Attorneys (NAELA) and the National Academy of Special Needs Planners (ASNP). Recently she was awarded 2016 "Top Women of law" (MA Lawyers Weekly Newspaper). She has been designated a Massachusetts Super Lawyer in 2014, 2015 and 2016. She has been recognized as a Distinguished Citizen by ARC Massachusetts and cited for public service by both the Massachusetts State Senate and House of Representatives.

Haven Andrews is originally from Greensboro, NC and has a Business Degree from ECU. Haven has been in the medically complex home care industry for 11 years starting as a scheduling coordinator in 2005. In 2008 he moved to Massachusetts and currently serves as Area Vice President of Operations for Maxim Healthcare and oversees 9 locations; 6 in MA, 1 in ME, 1 in NH, and in 1 in RI that serves 600+ patients on a daily basis. Haven has a passion for helping families keep their loved ones at home, resource connection, and adding value to the overall healthcare system.

Michael Caballero is an administrator and clinical director at Specialized Housing, Inc. Michael oversees management of homes for adults with developmental disabilities and the intake and assessment process of new families, which includes the marketing of units and finalizing resales. Michael has experience as a clinician in the community, school, and hospital settings and has remained involved with individuals with special needs for 20 years.

Emily Colonna, LICSW is a licensed independent clinical social worker with over 15 years of direct care experience working in a variety of acute and community based settings for individuals with serious mental illness. She obtained her Masters of Social Work from NYU Silver School of Social Work with a concentration in clinical social work and program evaluation. A New Jersey transplant, Emily is presently the Site Director for The Department of Mental Health's Canton Site Office overseeing the service delivery system of mental health services to constituents within a 16 town radius. Emily has a strong

interest in trauma informed care and maintains a private practice that incorporates trauma focused therapy with individuals, couples and families.

Hillary J. Dunn, Esq. is a Staff Attorney at the Disability Law Center. Her practice focuses on special education matters, abuse and neglect, and advocating for appropriate community supports and services for adults with intellectual and developmental disabilities. Ms. Dunn is regularly involved in legislative and regulatory advocacy regarding disability issues and has trained individuals with disabilities, families, and professionals in various areas of disability law. In addition to her work at the Disability Law Center, Ms. Dunn previously worked in the Special Needs and Elder Law Practice Group of a Mass. firm where she practiced in the areas of special education, guardianship issues, and advocacy with adult human service agencies. Following law school, she served as a law clerk to the Honorable Debra C. Freeman of the U. S. District Court for the Southern District of New York. Ms. Dunn is a graduate of Northeastern University School of Law and Tufts University.

Daryl Cameron Every, Esq. is a sole practitioner in Milton, where she concentrates in special needs and elder law, disability advocacy, public benefits. Ms. Every acts both as a trustee to family and special needs trusts, as well as trust counsel. She advises families, guardians, trustees, and non-profit organizations, who are committed to maximizing public benefits with private resources for individuals with intellectual and/or physical disabilities. Ms. Every is a Board Member of The League School and immediate past President of the Norfolk-Plymouth Estate Planning Council. Also, Attorney Every is a member of the Massachusetts Chapter of NAELA, Academy of Special Needs Planners, Boston Bar Association and Women's Bar Association. She is a graduate of Northeastern University School of Law and the University of Massachusetts at Amherst. Attorney Every may be contacted at: daryl@daryleveryesq.com

Jessica Kee is an Independent Living Coordinator at the Metrowest Center for Independent Living. My background is mainly working with individuals with developmental disabilities in the residential home setting, as well as homeless in shelters. Currently, I provide skills training, counseling, advocacy and other supportive services to consumers. I find services for individuals with many types of both physical and mental disabilities who are living in the community to ensure they stay out of institutions. I work with a large case load of individuals who need assistance with a range of services from SSDI, to DTA benefits, to housing and employment.

Elise S. Kopley is Assistant General Counsel at the Massachusetts Department of Developmental Services (DDS). She previously was an Officer with the firm of Fletcher Tilton PC, practicing in the area of Elder Law, Special Needs and

Probate Litigation.   She is a graduate, cum laude, from Boston University School of Law, holds a certificate of international and comparative human rights from the National University of Ireland and a B.B.A. in Finance, cum laude, from the University of Massachusetts, Amherst.

Linda L. Landry is a senior attorney who has worked at the Disability Law Center since 1990. Her focus is on Social Security benefit issues and work incentives, as well as the related health benefits, MassHealth and Medicare. She has over 30 years of experience in legal advocacy in these areas, which has included individual representation, training, impact and policy work, class action litigation, and backup, support, and technical assistance to a statewide project of attorneys and advocates who represent individual Social Security and SSI disability benefits claimants. She writes and presents on a variety topics for local and national audiences. She is a graduate of Northeastern University School of Law and worked at Neighborhood Legal Services in the 1980s before coming to DLC. She received the NOSSCR Distinguished Service Award in 2006, the Massachusetts Bar Association Equal Access to Justice Award in 2011, and a Massachusetts Top Women of the Law Award in 2013.

J. Michelle Lund, LICSW, is currently an Assistant Area Director for the Department of Developmental Services, in the Charles River West (CRW) Area Office. The CRW office services Belmont, Cambridge, Somerville, Waltham, and Watertown areas. She has an MSW in Psychology from Brandeis university and an MSW from Simmons College. J. Michelle has 20 years of experience working with children and adults with intellectual, developmental, and/or physical disabilities. She is committed to empowering self-advocates and families with varied abilities to reach their personal goals. J. Michelle currently resides in Framingham, MA with her husband, son, and father. She can be reached via email at michelle.lund@state.ma.us

Kristin M. Palace graduated from Cornell University with a B.S. in Education. She received her J. D. degree with distinction from Hofstra University School of Law where she was an Associate Editor of the Hofstra Law Review. She is admitted to practice in Mass. and New York. Over her 30 year plus career, she has served multiple state agencies as an administrative law judge, hearing appeals in the areas of mental health eligibility, public employee retirement benefits, and environmental law. In addition to her hearing officer work, Attorney Palace maintains a private practice as a parent special education attorney. She advocates on behalf of clients to attain eligibility for special education services, to receive better services in inclusion settings, and to obtain funding for placements in out-of-district special education schools. Attorney Palace began her career as a litigator for the firm of Davis & Gilbert in New York City and later moved to Massachusetts where she pursued public policy

interests as a lobbyist and as a government attorney before starting her private practice. Her offices are in Topsfield.

Susan Senator is an author, blogger, journalist, and educator living in Brookline, MA with her husband Ned Batchelder. She has three sons, the oldest of whom is 26 and has fairly severe autism. Ms. Senator is the author of Making Peace With Autism as well as The Autism Mom's Survival Guide and now, Autism Adulthood: Strategies and Insights for a Fulfilling Life. A journalist since 1997, she has published pieces on disability, parenting, and living happily, in places like the New York Times, the Washington Post, the Boston Globe, Exceptional Parent Magazine, NPR, Family Fun, and Education Week. Senator has appeared as a guest on the Today Show, MSNBC, ABC News, PBS, NPR and CNN. Her writings on Special Olympics took her to the White House in 2006, to a state dinner for Eunice Kennedy Shriver. Ms. Senator's blog, publications, and events can be found on www.susansenator.com

Tim Sindelar is a solo practitioner in Newton, where his practice focuses chiefly on special education and other litigation concerning the rights of children to essential services such as education and health care. Prior to entering private practice attorney in early 2003, Tim was a Senior Staff Attorney at the Disability Law Center for more than eight years, where he divided his time between work in the special education and health law fields. Before coming to the Disability Law Center, Tim had worked for more than 15 years in legal services programs in Massachusetts, Nebraska and West Virginia. Tim has represented hundreds of families in matters before the Bureau of Special Education Appeals and the state and federal courts on special education issues. He has also worked with parents' groups on legislative and regulatory issues pertaining to special education and health issues. He has served on a number of advisory groups for the Massachusetts Departments of Education and Mental Retardation and the Disabled Persons Protection Commission. Tim has presented testimony to committees of the United States Senate and the Massachusetts General Court on education and health matters. Tim is a frequent speaker at trainings and conferences on special education and children's health.

Ashley Starr, MPH, MetroWest Center for Independent Living. She is a Transition Coordinator at MWCIL, specializing in Nursing Home Transition. I do a lot of work with the Money Follows the Person Waivers and Acquired Brain Injury Waivers. MFP is a federal program for getting people out of nursing homes and for keeping them in the community.

Elizabeth White is a lawyer who specializes in Guardianships and Conservatorships, and serves as Trustee on Special Needs Trusts. She is the mother of two boys, one of whom has autism.

Alan White, Director of Residential Alternatives, TILL, Inc. Alan White has been working at TILL, Inc. for 32 years in the area of Residential Services. Have been working with families, individuals with both public and private funding resources to create individualized residential situations that provide opportunities for living independently in a variety of communities and settings. Oversees all development of residential options including TILL's Creative Living Options (CLO), Shared Living/ AFC services and Individual Residential and Community/ Home Supports to people with varied abilities including ASD. TILL,Inc. is a multi-service agency that provides services in the areas of residential, day habilitation, vocational/work supports, mental health/ clinical supports, PCA, ASD, CBHI and social/ recreational/ community connections.

Mark W. Worthington BU Law LL.M. (Tax) is a Senior Counsel with Special Needs Law Group of Massachusetts, P.C. in Framingham, MA. Mark received his J.D. from Northeastern University Law School and his LL.M. in Taxation from Boston University Law School. He is a Certified Elder Law Attorney (as certified by the National Elder Law Foundation (MA does not recognize legal specialties for certification) and is past President (2007) of the Massachusetts Chapter of the National Academy of Elder Law Attorneys. In 2016 he was appointed full-time Professor of Law and Director of the Graduate (LL.M.) Program in Elder Law and Estate Planning at Western New England University School of Law in Springfield, MA. He has taught as an Adjunct Professor at Western New England University School of Law in the LL.M. Program for eleven years, and at Northeastern in the J.D. Program for five years. Mark is admitted to practice in Massachusetts and before the United States Supreme Court.

Carlos Zimmerman-Diaz is an Assistant General Counsel at the Massachusetts Department of Mental Health (DMH). He is a 1992 graduate of Boston College and 1995 graduate Boston College Law School. Carlos has over over 17 years of experience as a practicing attorney in the greater Boston area, both in the private and public sectors. Prior to working for DMH, Carlos spent 6 years in private practice, with a focus on civil litigation. He has been Assistant General Counsel at DMH for over 11 years. His primary focus at DMH is on public policy, guardianship law and mental health law practice and procedure. Carlos has extensive courtroom experience in cases involving Guardianship and Substituted Judgment issues, in both Probate and District Courts. He is a frequent lecturer on Mental Health Law for both the Massachusetts Guardianship Association and for universities in the Greater Boston Area. Carlos also serves as a Board Member of the Massachusetts Guardianship Association (MGA), and works closely as a special liaison to the Trial Court on the development and implementation court procedure surrounding Guardianship cases, as well as special court sessions for Guardianship and Substituted Judgment cases throughout MA.

Transition Planning and Services

For Students Age 14-22

Hillary J. Dunn, Esq.

Disability Law Center

Our Mission:
To provide legal advocacy on disability issues that promote the fundamental rights of all people with disabilities to participate fully and equally in the social and economic life of Massachusetts.

www.dlc-ma.org

Transition Manual:
http://www.dlc-ma.org/manual/index.htm

Agenda

- Transition Legal Requirements
- Transition Planning Process & Assessments
- Graduation Issues
- Chapter 688 & Moving to Adult Services
- Questions & Answers

Free Appropriate Public Education (FAPE)

Board of Education of the Hendrick Hudson Central School District, Westchester County, et al., Petitioners v. Amy Rowley, by her parents, Rowley, et al.

The FAPE "Floor"

- IDEA does *not* require a particular outcome.
- An IEP need *not* maximize a student's potential.
- It need only be "reasonably calculated to enable [her] to receive educational benefits."

Who is Eligible for Transition Services?

- Student is on an IEP

- Student is at least 14 in MA
  (16 under IDEA)

- Student has *not* received a high school diploma

- Student is *under* age 22

IDEA's Transition Language – a Definition and a Mandate

20 USC § 1402 Definition

(34) Transition services.--The term `transition services' means a coordinated set of activities for a child with a disability that--
(A) is 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 post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;
(B) is based on the individual child's needs, taking into account the child's strengths, preferences, and interests; and
(C) includes 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.

20 USC § 1414(d)(1) Mandate

- **Individualized Education Program. ___**

(i) In General. --- The term '[IEP'] means a written statement for each child with a disability that is developed, reviewed, and revised in accordance with this section and that includes . . .

(VIII) beginning not later than the 1st IEP to be in effect when the child is 16, and updated annually thereafter—

(aa)appropriate measurable postsecondary goals based upon age appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills;

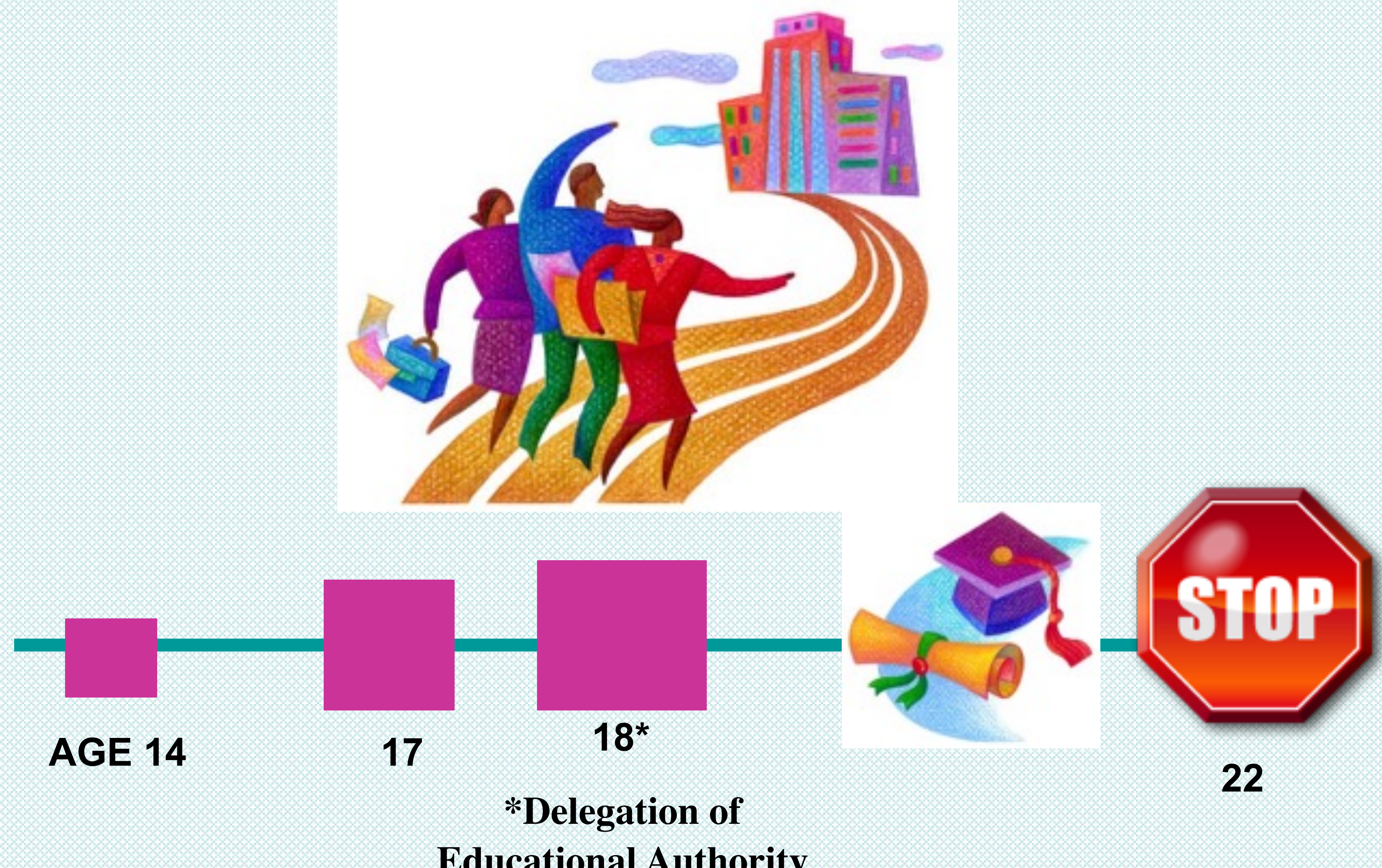
(bb)the transition services (including courses of study) needed to assist the child in reaching those goals; and

(cc)beginning not later than 1 year before the child reaches the [State law age of majority], a statement that the child has been informed of the child's rights under this chapter, if any, that will transfer to the child on reaching the age of majority under section 1415(m) of this title.

The Definition

- a coordinated set of activities
- designed within a **results-oriented** process
- focused on improving academic *and* **functional** achievement
- to facilitate movement from high school to life after high school

A Transition Timeline



The Basic Transition Planning Steps

1. Transition Planning Form (TPF) at home

2. Meeting # 1: TPF & Request Assessments

3. Meeting # 2: Review Assessments; Develop Goals; Plan Services

4. Miscellaneous: Graduation Dates; Turning 18

5. Adding Services or Enforcing Existing Ones

Transition Planning Form

Massachusetts Department of Elementary and Secondary Education, Transition Planning Form

TRANSITION PLANNING FORM (TPF)

Massachusetts requires that beginning when the eligible student is 14 for the IEP developed that year, the school district must plan for the student's need for transition services and the school district must document this discussion annually. This form is to be maintained with the IEP and revisited each year.

Student: **SASID:** **Age:**
Date form completed:
Anticipated date of graduation: **Current IEP dates from:** _______ **to:** _______
Anticipated date of 688 referral, if applicable:

POST-SECONDARY VISION

Write the student's **POST-SECONDARY VISION** in the box below. In collaboration with the family, consider the student's preferences and interests, and the desired outcomes for post-secondary education/ training, employment, and adult living. This section should correspond with the vision statement on IEP 1.

DISABILITY RELATED NEEDS

Write the skills (disability related) that require IEP goals and/or related services in the box below. Consider all skills (disability related) necessary for the student to achieve his/her post-secondary vision.

Meeting # 1:
Requesting Assessments

1. The Team must invite the student

2. Bring the TPF!

3. Request Transition Assessments
4.
5. The Evaluation Consent Form

Transition Age Assessments

The IEP must include "appropriate, measurable, post-secondary goals based upon age-appropriate transition assessments related to training, education, employment, and where appropriate, independent living skills."

Transition Assessments

Formal Assessments

- Interest & Preference Inventories
- Functional Vocational Evaluations
- Assistive Technology Evaluations
- Functional Behavioral Assessment
- Independent Living Assessment
- Educational Assessments
- Neuropsychological Evaluations
- Adaptive Behavior/Daily Living Skills
- Intelligence / Aptitude tests
- Transition Planning Inventory

Informal Assessments

- Interviews
- Questionnaires
- Learning styles assessments
- Interest & Preference Inventories
- Direct observation
- Self assessments
- Social support assessments
- Environmental analysis

Meeting # 2

- Discuss the Assessments
- Develop Goals
- Plan Services
- Don't Forget Community Placements!

When does Special Education end?

When the student:

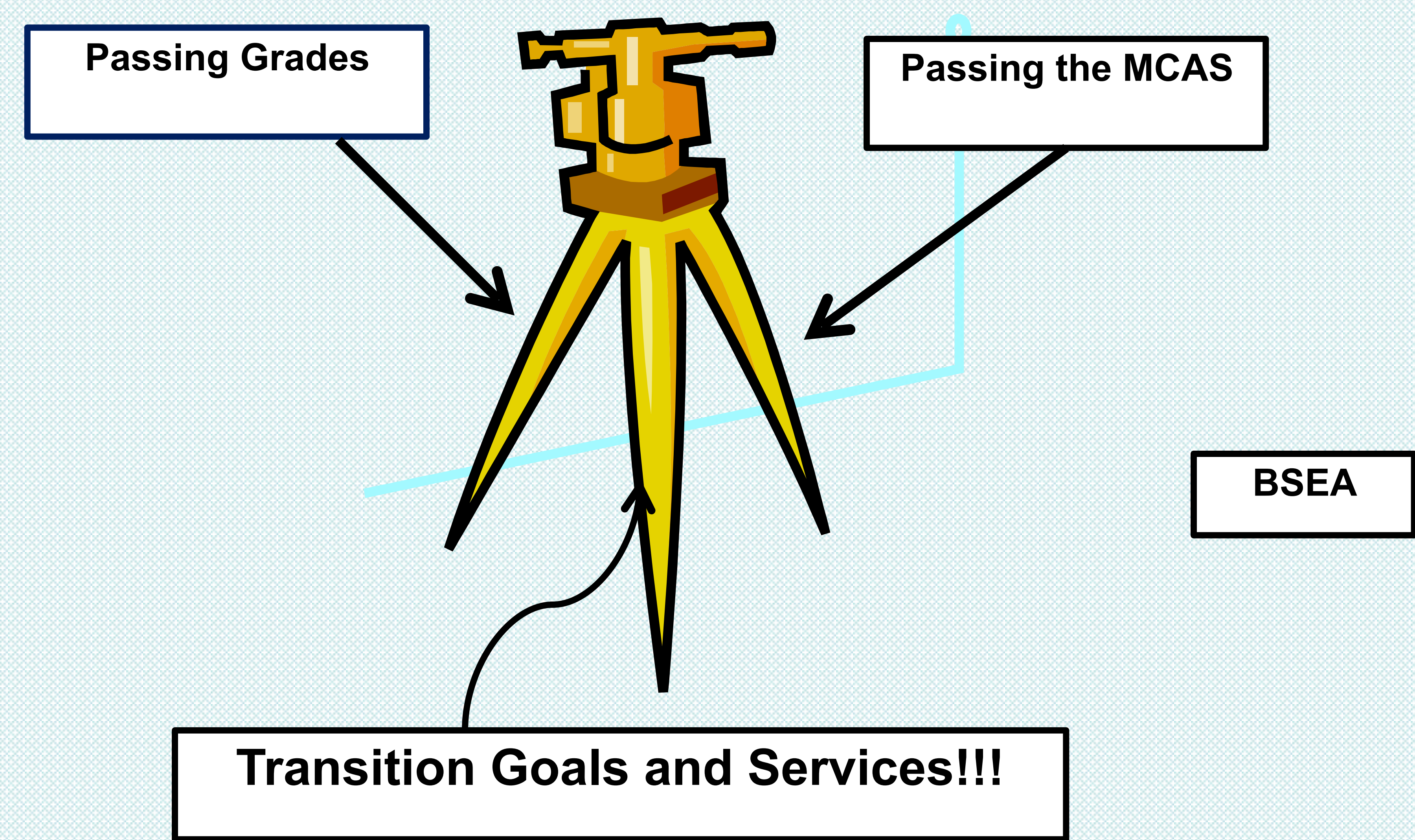
- receives HS diploma

  or

- turns 22

The Graduation "Tripod"

Always Consider FAPE



Chapter 688

M.G.L. c. 71B, § 12A-C

- Massachusetts "Turning 22 law"
- 2-year planning process
- School refers Student to the adult agency
- Develop Individualized Transition Plan (ITP)

MRC
DDS
DMH
MCDHH
MCB
BTP

688 Does *Not*

Continue Special Education

Determine Eligibility for adult services

Entitle someone to adult services

Additional Information about BTP & DDS

- Role of the Bureau of Transitional Planning (BTP)
- Role of the Transitional Advisory Committee (TAC)
- Update: Department of Developmental Services (DDS) eligibility criteria

Resources

- DLC's online Transition Manual: http://www.dlc-ma.org/_manual/LASE_manual.htm

- Transition Planning Form (TPF): www.doe.mass.edu/sped/28MR/28m9.pdf

- 688 Referral Form: http://www.doe.mass.edu/sped/28mr/28m11.pdf

- Federation for Children with Special Needs: http://fcsn.org/pti/topics/transition/

- Bureau of Special Education Appeals (BSEA): http://www.mass.gov/anf/hearings-and-appeals/bureau-of-special-education-appeals-bsea/

- The Road Forward: A DDS Guide for Transition Planning: http://www.mass.gov/eohhs/docs/dmr/transition-planning-road-forward.rtf

Resources

- A Family Guide to Transition Services in Massachusetts http://fcsn.org/transition_guide/english.pdf
- A Guide to Chapter 688: Massachusetts' Transitional Planning Program: http://www.doe.mass.edu/sped/iep/688/brochure.pdf
- Think College and ICE: http://www.thinkcollege.net/inclusive-video
- Technical Assistance Advisory SPED 2013-1: Postsecondary Goals & Annual IEP Goals in the Transition Planning Process http://www.doe.mass.edu/sped/advisories/13_1ta.html
- DESE Technical Assistance Advisory SPED 2014-4: Transition Assessment in the Secondary Transition Planning Process http://www.doe.mass.edu/sped/advisories/2014-4ta.html

Questions?

Hillary J. Dunn, Esq.
Disability Law Center
www.dlc-ma.org

- Special Education Home
- Technical Assistance
  - Educator Evaluation
  - Training
  - Documents
  - Grants
  - IDEA 2004
- LEAP
- Early Childhood
- Secondary Transition
- MA Tiered System of Supports
- IEP Process, Forms & Notices
  - IEP Improvement Project
- Policy and Guidance
  - MA SPP and APR
- Parent Information
- Complaints & Compliance
- Special Education Appeals
- MCAS
- MCAS Alternate Assessment
- Laws and Related Documents
- General Information
- Links and Resources
- Contact Us

Special Education

Technical Assistance Advisory SPED 2014-4:
Transition Assessment in the Secondary Transition Planning Process

To: Middle and High School Principals, Administrators of Special Education, General and Special Educators, and Other Interested Parties

From: Marcia Mittnacht, State Director of Special Education

Date: April 9, 2014

The purpose of this advisory is to:

a. Clarify the purpose of transition assessment in the secondary transition planning process.
b. Provide guidance to school districts concerning the selection and use of transition assessments.

This advisory is released in the context of previous Department of Elementary and Secondary Education (ESE) secondary transition advisories and other ESE secondary transition resources, both existing and forthcoming.[1] The reader is invited to study these materials as an integrated whole.

Background

Through secondary transition planning, which occurs in Massachusetts for students with IEPs aged 14-22,[2] IEP Teams facilitate an individualized process that moves a student ever-closer to the successful realization of his or her personal vision for the future. That vision, documented on the Transition Planning Form (TPF) and in the IEP,[3] is the beacon which guides the development of the IEP during the transition years.[4] Year by year, a student's IEPs detail a sequential and developmental process whereby the student's disability-related needs are addressed in order to build skills necessary to achieve the student's postsecondary goals/vision

Purpose of Transition Assessment

Individualized, age-appropriate transition assessment is integral to the development of the IEP for students aged 14-22 and is required by the Individuals with Disabilities Education Act (IDEA),[5] very much as assessments are integral to the special education process for students who are younger. Through ongoing transition assessment, the IEP Team (1) discerns the student's postsecondary goals in the areas of education/training, employment, and - where appropriate - independent living,[6] (2) gains an understanding of the student's needs, strengths, preferences, and interests,[7] and (3) measures the student's current performance and progress towards the development of skills. The results of transition assessment inform the development of measurable annual skill-based IEP goals and the delivery of transition services. Any reader of an IEP for a student aged 14-22 should be able to see a clear linkage between the student's postsecondary goals and transition assessments, and the student's annual IEP goals and transition services.[8] The IEP should contain annual goals and transition services that flow from the student's vision, needs, strengths, preferences, interests, and assessment results.

Rather than adopting a restrictive approach which might seem to imply the required use of highly specialized formal assessments for each student, we encourage IEP Teams to think broadly about assessing students when they are aged 14-22. Age-appropriate assessment (i.e., assessment that is chronologically appropriate for students) is often part of typical school routine. Transition assessment can be conducted through special education, but key transition-related assessment data can also be garnered through routine whole-school programming such as social-emotional learning curricula, work-and-learning experiences, guidance department courses and opportunities, or the standard academic course of study.

Any assessment that is conducted when a student on an IEP is aged 14-22 can be viewed as a transition assessment, in that it affords information which can be used to discern the student's vision; understand the student's needs, strengths, preference, and interests; and measure progress towards the acquisition of skills. ESE has created a sample - but not exhaustive - **list of possible transition assessments** that can be found on our website as a link from *Technical Assistance Advisory SPED 2013-1: Postsecondary Goals and Annual IEP Goals in the Transition Planning Process*.

The results of individualized transition assessment in the IDEA-defined domains of further education/training, employment, and independent living - as needed for each unique student - will inform the IEP Team's decisions regarding the student's course of study and the student's need for specially designed instruction, modifications, accommodations, supports, related services, and/or assistive technology, so as to gain skills and make progress towards realizing his/her vision.

Scope and Sufficiency of Transition Assessment

When considering an array of possible transition assessments, it may be helpful for IEP Teams to think in terms of an All-Some-Few model. For *all* students on IEPs, the Team may already possess certain types of information (e.g., data from the MCAS, report cards, achievement tests, work-based learning, preference surveys, student or family interviews, etc.). For *some* students on IEPs, Teams may have or need additional types of information (e.g., personality surveys, environmental or situational analyses, adaptive skills assessments, etc.). For a *few* students on IEPs, the Team may have or need more in-depth information (e.g., adaptive behavior assessments, functional vocational evaluation, life skills inventory).

The question often arises: "How do we know we have conducted enough transition assessments?" Transition assessment is an individualized, question-driven process, in that the number and type of assessments which are appropriate to conduct for each student is determined by the number and type of questions about the student for which answers are needed.

Experience demonstrates that a Team is likely to have many questions about a younger student for whom the transition process is beginning; indeed, it is developmentally appropriate for all students who are 14 or 15, with or without disabilities, to have many questions about themselves. Students nearing graduation who have had appropriate transition planning since age 14 are likely to have a clear vision and well-understood skills; therefore there will be fewer questions to address.

The IEP Team's questions to guide transition assessment fall into three general categories:

1. Who is the student (i.e., what are the student's needs and strengths)?
2. Who does the student want to be, or what does the student want to do (i.e., what are the student's preferences and interests)?
3. What is the fit between the student and the requirements of the educational, employment, and living environments into which the student plans to move when he or she exits high school?

The purpose of transition service delivery is to close the gap between the student's current skills and the demands of the student's intended future environment. Transition assessment enables the IEP Team to understand those gaps, and to plan how best to lessen or eliminate them. Depending on the individual needs of each student, examples of questions that can be addressed in post-secondary domains might include:

- If the student would like to attend college, does the student have necessary academic, social, and functional skills?
- Given the student's vision for employment, what experiences and educational opportunities does the student require now in order to be successful in that future occupation?
- If the student currently lacks skills necessary to fulfill a postsecondary goal of independent living, and the Team determines this is an area of need, how will those skills be acquired?
- If the student does not require an independent living postsecondary goal on his/her IEP, does the student nonetheless require functional IEP goals, perhaps involving the use of assistive technology, that will support the development of skills in areas such as financial literacy, healthcare, and/or self-help?[9]

As teens develop, it is expected that their postsecondary goals will change over time, as transition assessments and educational experiences in and beyond the classroom help them to clarify, refine, and communicate their vision and skills, and to better understand themselves and the demands of the future towards which they are working.

Types of Transition Assessments

Transition assessments can be formative or summative, and either informal or formal.

Formative assessments, such as quizzes, observations, running records, or short-term projects, are already used routinely on a regular (i.e., hourly, daily, weekly) basis to monitor student learning. They enable school professionals to see whether students are making progress and to create ongoing learning opportunities that are responsive to student needs. This type of "student progress monitoring" generally is summarized for the parent and student in progress reports during the course of the year. While these assessments are rarely specifically included in the IEP, unless there are notable patterns or findings associated with the progress monitoring activity, they provide important information to consider within the transition process and may help to inform annual skill-based IEP goals. Since general education professionals use formative assessments on a routine basis, these assessments can provide one avenue for the active and meaningful participation of general education teachers on the IEP team.

Summative assessments, such as a final exam, thesis, capstone project, or senior recital, are generally administered at the end of a term to provide a cumulative evaluation of a students' progress. This type of assessment is also often communicated to the parent and student in progress reports rather than in the IEP, again, unless there are notable patterns or findings associated with the completion of an activity. These too may provide important information to consider within the transition process and may help to inform annual skill-based IEP goals. Since general education professionals use summative assessments on a routine basis, these assessments, as well, can provide an avenue for the active and meaningful participation of general education teachers on the IEP team.

Informal assessments use non-standardized methods (e.g., interviews, inventories, curriculum-based assessments, criterion-referenced assessment), can be used in many settings and with many stakeholders in the student's life, and are useful in designing and evaluating the effect of instructional interventions. Unlike formal assessments, they may not allow comparisons with other students but can be used to establish a baseline and monitor progress. Informal assessment results may be reported to the parent and student through progress reports or in the IEP, depending on how they are used.

Formal assessments are standardized instruments that have guidelines for administering, scoring, and interpreting, and have been tested for reliability and validity. Scores can be compared across student populations. Formal assessments are almost always reported in the student's IEP unless they are not germane to the student's disability, or academic or non-academic functioning.

If the Team lacks understanding of how the student is likely to perform in varied environments such as the workplace, community, or college, or if a student has irregular and inconsistent performance, transition assessment information may be more helpful if it is collected across multiple settings at school (e.g., in an academic context and during "life of the school" and extracurricular activities), as well as in other settings such as home, community, and the workplace, and over time, and from a variety of people who know the student well (e.g., the student, family, teachers, agency personnel, friends, employers, coaches).[10] Informal assessments can be developed to be flexible and well-suited to use in many contexts, with many stakeholders in the student's life.

It is important to remember that the student him/herself should be involved - as much as possible - in planning, implementing, and evaluating the assessment process. Students can be supported over time to assume increasing responsibility for driving their own assessment process. Guiding questions for students may be helpful, such as "What do I enjoy or dislike? What can I do well? What are my challenges? What would I like to do in the future? What skills do I have now? What skills do I need in order to overcome barriers and achieve my vision? How can I track my own progress towards acquiring these skills?" Families, who know the student in multiple contexts outside the school walls, are also essential partners in the transition assessment process.

Consent

The question often arises: "Is written consent required in order to conduct transition assessments?" The answer is, "It depends." Several factors determine the need for parental consent, or for the consent of students 18 years or older who have decision-making authority. Parental or student consent for transition assessment is **not needed** when:

- the assessment is administered to all students in a class, at a grade level, in a school district building, or district-wide, unless consent is required for all students participating in the assessment.[11]
- the assessment is conducted as a routine activity or assignment within the curriculum.

In addition, according to IDEA, consent is not needed for "screening for instructional purposes, because such screening is not an evaluation."[12] Consent is not needed, also, to review existing data.[13] Good practice dictates that educators conduct regular progress monitoring and discuss results and next steps frequently with students and parents, at least annually and certainly on a routine basis. Consent for progress monitoring is not required.

Therefore, schools are required to obtain consent for only those individual transition assessments that are:

- not administered to all students,
- not part of a routine or informal classroom activity, and
- not part of ongoing progress monitoring.

- In this way, consent requirements for transition assessment are the same as those for any special education assessment and are generally required only for formal assessments given specifically to that one student and not to all students in the class or instructional group, in order to determine the student's needs, strengths, preferences, and interests related to further education/training, employment, and, where appropriate, independent living skills.
- For any transition assessment that does require consent, the school district is required to provide or arrange for the provision of the transition assessment of the student within 30 school days upon receipt of consent from the parent, or from the student 18 years or older who has decision-making authority.

Documenting Transition Assessment in the IEP

A student's IEP Team may choose to record transition assessments and their results in several places on the IEP. However, so that all IEP readers can easily obtain a comprehensive overview of each student's assessments, the ESE recommends that all transition assessments be listed on IEP 1, under *Student Strengths and Key Evaluation Results Summary*, recording the student's educational and functional performance, strengths, and needs; progress towards goals; personal attributes and accomplishments; preferences and interests.

As is the case with any IEP, information from assessments should also flow through the document as a whole. Since each section of the IEP has a different function, results of transition assessments should serve various purposes.[14] For example, the PLEP section facilitates instructional planning by providing a bridge from the *Key Evaluation Results Summary* to instructional intervention. Thus, in the PLEP section a discussion of results from transition assessment(s) can give information on how the identified disability(ies) impact the student's overall participation in the Massachusetts Curriculum Frameworks and the life of the school. Under *Current Performance Level* for each annual goal focus, transition assessment results may shed light on the student's current skill level in that particular focus area. Each focus area, whether academic (e.g., writing, reading, or math skills) or functional (e.g., organization, personal care, career awareness, self advocacy, or self regulation skills), builds skills that will make the biggest difference to the student during one school year. Each year's annual IEP goals build skills, year over year, which will promote the eventual realization of the student's vision/postsecondary goals.

Conclusion

According to IDEA, IEPs for students of transition age must include "appropriate measurable postsecondary goals based upon age appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills; and the transition services (including courses of study) needed to assist the [student] in reaching those goals."[15] Our state's goal is that all students will have "the opportunity to reach their full potential and to lead lives as participants in the political and social life of the commonwealth and as contributors to its economy."[16] In the rich context of Massachusetts' rigorous general education program, a carefully planned process of individualized, appropriate assessment and corresponding services for students on IEPs aged 14-22 helps prepare our youth to move confidently toward the future they have envisioned.

[1] See, for example, Technical Assistance Advisory SPED 2009-1: Transition Planning to Begin at Age 14, Administrative Advisory SPED 2011-1: Age of Majority, Technical Assistance Advisory SPED 2013-1: Postsecondary Goals and Annual IEP Goals in the Transition Planning Process, April 2013 Secondary Transition Capacity-Building Conference presentations and materials.

[2] Technical Assistance Advisory SPED 2009-1: Transition Planning to Begin at Age 14.

[3] Technical Assistance Advisory SPED 2013-1: Postsecondary Goals and Annual IEP Goals in the Transition Planning Process.

[4] See **Massachusetts Student-Driven Secondary Transition Visual Model**.

[5] 34 CFR §300.320(b)(1).

[6] 34 CFR §300.320(b)(1).

[7] 34 CFR §300.43(a)(2).

[8] For further discussion of the clear cause-and-effect relationship between the student's transition assessments and postsecondary goals, and the student's annual IEP goals and transition services, please see Technical Assistance Advisory SPED 2013-1: Postsecondary Goals and Annual IEP Goals in the Transition Planning Process.

[9] For information on which postsecondary goals are required by IDEA 2004 for students of transition age, please see Technical Assistance Advisory SPED 2013-1: Postsecondary Goals and Annual IEP Goals in the Transition Planning Process.

[10] See **Age Appropriate Transition Assessment** from the Division on Career Development and Transition (DCDT), in collaboration with the National Secondary Transition Technical Assistance Center (NSTTAC).

[11] 34 CFR §300.300(d)(1)(ii).

[12] 34 CFR § 300.302.

[13] 34 CFR §300.300(d)(1)(i).

[14] see **IEP Process Guide**

[15] 34 CFR §300.320(b)(1)(2).

[16] Massachusetts G.L. c. 69, §1

Last Updated: April 9, 2014

Special Education

Technical Assistance Advisory SPED 2013-1:
Postsecondary Goals and Annual IEP Goals in the Transition Planning Process

To: Middle and High School Principals, Administrators of Special Education, General and Special Educators, and Other Interested Parties

From: Marcia Mittnacht, State Director of Special Education

Date: September 14, 2012

The purpose of this advisory is to:

a. highlight the central role of appropriate measurable postsecondary goals and annual IEP goals in the transition planning process for students with IEPs, ages 14-22.
b. provide guidance to school districts concerning the inclusion of postsecondary goals in the Transition Planning Form (TPF) (28M/9) and the inclusion of postsecondary goals and annual goals in the IEP.

Background

According to Massachusetts G.L. c. 69, §1,

> It is hereby declared to be a paramount goal of the commonwealth to provide a public education system of sufficient quality to extend to all children... including a school age child with a disability... *the opportunity to reach their full potential and to lead lives as participants in the political and social life of the commonwealth and as contributors to its economy*[emphasis added].

The Individuals with Disabilities Education Act (IDEA) states

> Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society. *Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities* [emphasis added].[1]

Furthermore, one of the purposes of IDEA is

> to ensure that all children with disabilities have available to them a free and appropriate public education that emphasizes special education and related services designed to meet their unique needs and *prepare them for further education, employment, and independent living* [emphasis added].[2]

Therefore, the ultimate goal of all professional endeavors in special education is to prepare students with disabilities for adult life.

As expressed in a 2012 report from the Massachusetts Board of Elementary and Secondary Education's Task Force on Integrating College and Career Readiness,

> Every child deserves an education that nurtures their dreams and lays out a navigable pathway to accomplish them.[3]

Commissioner Mitchell Chester has identified "preparing students for college and careers" as one of five top Department of Elementary and Secondary Education's priorities. The Department's overarching goal is to "prepare all students to succeed in the world that awaits them after high school." All students deserve a world-class education that prepares them for postsecondary opportunities, career training options, economically viable careers, and healthy, productive lives.

A growing body of research indicates that teaching students with disabilities to be self-determined increases their chances of achieving positive adult outcomes.[4] This research aligns with findings in the areas of college and career readiness,[5] student motivation,[6] and student learning plans.[7] Self determination can be understood as "a combination of skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behavior. As such, self-determination includes an understanding of one's strengths and limitations, together with a belief of oneself as capable and effective."[8] Students who are self-determined are "causal agents in their own lives."[9]

Therefore, the more students are engaged in planning their own futures, the more promising those futures are likely to be.

In Massachusetts, transition planning for students with disabilities begins at age 14 (or earlier if deemed appropriate by the IEP team).[10] From the age of 14, students should be active participants in their own transition planning, to the maximum extent possible. Planning is driven by the student's needs, taking into account his/her "strengths, preferences, and interests."[11] If a student who is 14 or older does not attend his/her IEP meeting, steps must be taken to ensure that the student's preferences and interests are considered.[12] Since parents are experts regarding their own children, working in close partnership with the families of all students will enable school professionals to more fully understand each student's personal assets, challenges, inclinations, and hopes for the future.

As much as possible, efforts in transition planning should be conducted in concert with whole-school initiatives. For example, whole-school adoption of social and emotional learning (SEL) curricula[13] could increase students' self determination by helping them to recognize and manage their emotions, make responsible decisions, and demonstrate caring and concern for others. Using the Massachusetts Model for Comprehensive School Counseling Programs,[14] guidance counselors can collaborate with general and special education teachers to promote students' individualized college and career planning. Through Connecting Activities,[15] schools and businesses can connect to provide students with structured work-based learning experiences that support both academic and employability skill attainment.

Postsecondary Goals

A key way to capture students with disabilities' preferences and interests is to include postsecondary goals on the TPF and IEP. Postsecondary goals are those goals that a student hopes to achieve after leaving secondary school (i.e., high school).[16] All transition

planning is informed by and flows from these postsecondary goals; a truly individualized process uses postsecondary goals - which are an expression of each student's desired future outcomes - as the foundation for the development of the IEP.

Students' postsecondary goals should be recorded on page one of the TPF in the "Post-Secondary Vision" box. The TPF is intended to be a flexible, brainstorming document used by the IEP team to record the transition discussion. Once the TPF is complete, the IEP team documents the transition plan in a more formal manner on the IEP and should transfer the postsecondary goals to the Vision Statement on IEP 1.

IDEA requires that postsecondary goals:
(1) be appropriate,
(2) be measurable (i.e. countable),
(3) be annually updated,
(4) be based upon age-appropriate transition assessment, and
(5) express the student's future intentions in each of the areas of education/training, employment, and - if appropriate - independent living.[17]

Therefore, each student's TPF and IEP should detail at least two and possibly three postsecondary goals in this general format:

- Following high school, [STUDENT NAME] intends to pursue a bachelor's degree at a four-year college.
- [STUDENT NAME] plans to work at [NAME/TYPE OF BUSINESS] after graduating from high school.
- After exiting high school, I plan to live with my friend and use the public bus to get to my job, the supermarket, and the gym.

Additional examples of possible postsecondary goals are available at **Goals Example Sheet**. IEP teams are by no means limited to using these examples but should create individualized postsecondary goals for each student, always remembering that postsecondary goals are those that a student hopes to achieve after leaving secondary school and are appropriate, measurable, annually updated, and based upon age-appropriate transition assessment.

Annual IEP Goals

Separate and distinct, yet closely related to postsecondary goals in the transition planning process, are "annual IEP goals related to the student's transition services needs," also required by IDEA.[18]

Annual IEP goals for students 14 or older are developed from two streams of information: (a) the student's postsecondary goals and (b) the student's disability-related needs. Both of these streams are founded upon age-appropriate transition assessment, which is an "ongoing process of collecting data on the individual's needs, preferences, and interests as they relate to the demands of current and future working, educational, living, and personal and social environments."[19] Transition assessment, both formative and summative, is an essential part of understanding who the student is, where the student wants to go, what strengths the student can capitalize on, and what challenges the student needs to overcome. As with every part of the transition planning process, the student should be involved - as much as possible - in the assessment process and in the development of annual IEP goals. Families, also, are key partners in the creation of these goals.

When developing annual IEP goals for Transition, the team should discuss and complete the TPF before completing the IEP form. The team refers to the student's postsecondary goals and asks:

a. What skills, strengths, interests, personal attributes, and accomplishments does the student currently have that will contribute to his/her postsecondary success?
b. What skills and strengths will the student need to acquire in order to achieve his/her desired postsecondary outcomes?
c. Given the student's disabilities, what supports and services will be necessary for the student to make progress towards achieving his/her postsecondary goals?

To answer these questions, the team may rely on formal and informal transition assessments such as input from the student, his/her family, and others who know the student well; student transcripts; MCAS results; teacher notes; previous IEPs; achievement tests; functional behavioral assessments; life skills and/or interest inventories, etc. Additional examples of possible transition assessments are available at **Transition Assessments Example Sheet**.

Discussing and mapping out the Action Plan on page two of the TPF can also help the team to fully understand and articulate the intersection between the student's postsecondary goals, the student's skills and disability-related needs, and the supports and services that the student requires in order to achieve his/her desired postsecondary outcomes.

On page one of the TPF, the team documents the student's disability-related skills that require IEP goals and/or related services.

Next, the team should turn to the IEP form to complete Present Levels of Educational Performance A & B and to write annual IEP goals that are skill-based and are related to the student's transition services needs. In other words, *a clear and direct link should exist between the student's annual IEP goals and his/her postsecondary goals as delineated in the Vision section of the TPF and IEP.*

For example:

- A student who wishes to work in a bank and has language-based learning disabilities and social skills deficits may require annual IEP goals that will enable her to improve her reading comprehension and math skills, and to develop customer service skills.
- A student who wishes to attend a four-year college and who has Asperger's Syndrome may require annual IEP goals that will help him to develop his self-advocacy skills and avail himself of college disability support services.
- A student who wishes to have a job and a busy social life, and who has multiple disabilities, may require annual IEP goals that will help her to use her cell phone, access public transportation, and improve her personal care skills.
- A student with a health impairment who wishes to become a pastry chef may require annual IEP goals that will help him to research culinary schools, take charge of his own healthcare needs, and improve his organizational skills.

Additional examples of possible annual IEP goals are available at **Goals Example Sheet**. IEP teams are by no means limited to using these examples but should create individualized annual IEP goals for each student, keeping in mind that annual IEP goals should be directly linked to the student's postsecondary goals.

In the final step, the team completes the IEP form, enumerating any required transition services and supports which flow from the postsecondary goals and the annual IEP goals, as well as any other necessary information.

Conclusion

According to IDEA, transition services are a "coordinated set of activities... within a results-oriented process," so as to facilitate a student's "movement from school to post-school activities."[20] Through the active inclusion of students in their own transition planning, and through the use of student-centered postsecondary goals and annual IEP goals founded upon age-appropriate transition assessment, IEP teams can actualize a dynamic, coordinated, and student-driven transition process, affording students with disabilities "the opportunity to reach their full potential and to lead lives as participants in the political and social life of the commonwealth and as contributors to its economy."[21]

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[1] 20 USC §1400(c)(1).

[2]20 USC §1400(d)(1)(A).

[3]Massachusetts Board of Elementary and Secondary Education's Task Force on Integrating College and Career Readiness (2012, June). From *Cradle to Career: Educating our Students for Lifelong Success*. Massachusetts Department of Elementary and Secondary Education., p. 25.

[4]Landmark, L. J., Ju, S., & Zhang, D. (2010). Substantiated best practices in transition: Fifteen plus years later. *Career Development for Exceptional Individuals*, 33(3), 165-176.

[5]Conley, D. T. (2010). The Four Key Dimensions of College and Career Readiness. *In College and Career Ready: Helping All Students Succeed Beyond High School*. (1st ed.). (pp. 19-52). San Francisco, CA: Jossey-Bass.

[6]Usher, A. & Kober, N. (2012). *Student motivation: An overlooked piece of school reform*. Washington, D.C.: Center on Education Policy, Graduate School of Education and Human Development, The George Washington University.

[7]Rennie Center for Education Research & Policy. (2011). *Student Learning Plans: Supporting Every Student's Transition to College and Career*. Cambridge, MA: Rennie Center for Education Research & Policy.

[8]Field, Martin, Miller, Ward, & Wehmeyer, 1998, p. 2, as cited in Wehmeyer, M. L., & Webb, K. W. (Eds.). (2012). Providing Transition Education to a Diverse Student Population. In *Handbook of Adolescent Transition Education for Youth with Disabilities*. (1st ed.). (p. 278-294). New York, NY: Routledge, p.287.

[9]Wehmeyer, M. L. (2007). Overview of Self-Determination and Self-Determined Learning. In *Promoting Self-Determination in Students with Developmental Disabilities*. (1st ed.). (pp. 3 - 16). New York, NY: The Guilford Press, p. 7.

[10]G.L. c. 71B, §2; *Technical Assistance Advisory SPED 2009-1: Transition Planning to Begin at Age 14*.

[11]34 CFR §300.43(a)(2).

[12]34 CFR §300.321(b)(2).

[13]*Guidelines on Implementing: Social and Emotional Learning (SEL) Curricula*

[14]Massachusetts Model for Comprehensive School Counseling

[15]Connecting Activities

[16]71 Fed. Reg. 46668 (Aug. 14, 2008).

[17]34 CFR 300.320 (b)(1).

[18]34 CFR 300.320(a)(2)(i) and What is Indicator 13?.

[19]Sitlington, P. L., Neubert, D. A., & Leconte, P. J. (1997). Transition Assessment: The Position of the Division on Career Development and Transition. *Career Development for Exceptional Individuals*, 20(1), 69-79.

[20]34 CFR 300.43(a)(1).

[21]G.L. c.69 §1.

Last Updated: September 17, 2012

DDS Transition

AN OVERVIEW OF SERVICES FOR INDIVIDUALS 18-22

*Adapted from "The Road Forward," DDS; December 2013.

Chapter 688: “Turning 22 Law”

- The “Turning 22 Law” is not a continuation of special education, nor does it guarantee services after 22.
- Creates a single point of entry.

Who is Eligible?

Individuals who are:

- Receiving special education services paid for by the Commonwealth
- Need continuing habilitative services at the time of turning 22 or graduating from special education
- Unable to work competitively (without specialized supports) for more than 20 hours per week at the time of leaving school

688 Referrals

- Must be made while individual is still in school (IEP Team Meeting!)
- As early as 18, ideally no later than 20
- Request copies of these forms

- Around age 18:
  - Apply for SSI
  - Apply for MassHealth if you do not already have it
  - Apply for guardianship if applicable

Application Process

- Should start at 17 (688 or Adult Application)
- Complete application and submit to local DDS Eligibility Team
- Eligibility Specialist contacts applicant, guardian, referral source (school) for intake interview
- Relevant information gathered (education and clinical assessments)

Widening Eligibility

- Historically, DDS has served individuals with Intellectual and Developmental Disabilities whose IQ was significantly below average
- New eligibility for individuals with Autism Spectrum Disorder, Prader-Willi Syndrome, and Smith-Magenis Syndrome

Transition Timeline

Age 14-15: Planning a vision of what the student wants and is in best interest. Statement of Needed Transition Services listed in IEP.

Age 16-18: Refinement of vision. Identification of transition needs in Transition Planning Form at IEP. Assessment of needs, aptitudes and abilities, community based learning opportunities, work, and home based learning opportunities. This form should be filled out from the student's perspective. Gather information about SSI and MassHealth.

Transition Timeline (cont.)

- **Age 18: Age of Majority** – students become responsible for making their own medical and educational decisions unless a court appointed guardian is in place.
- If appropriate, apply for SSI, pursue guardianship.
- DDS eligibility application should be made.
- **Age 18-20:** Continue to refine the vision. School system makes 688 referral.

Transition Timeline (cont.)

- **Age 20-21:** DDS as Transitional Agency completes CCA and individual is prioritized
- Transition Coordinator completes ITP.
- Transition Coordinator continues as primary contact for individual, family, and school system.
- **Age 22:** Beginning of Adult DDS Services that may include employment, work training activities, day habilitation, transportation, individual or family support, and in some cases, residential supports.

You're Eligible!
Your Child is Eligible!
Your Student is Eligible!

Now What?

Transition Coordinator

- Works with individuals 18-22
- Facilitates navigation through the transition phase:
  - Provides resource information
  - Assists with prioritization process
  - Writes the ITP
  - Advises on service level and potential providers
  - Supports family at their level of need

Prioritization Process: MASSCAP
(Massachusetts Comprehensive Assessment Process)

- Inventory for Client and Agency Planning (ICAP) usually completed during application process
- Resource availability
- Individual characteristics
- Caregiver and Consumer Assessment (CCA) completed 18-6 months prior to 22nd birthday
- Individuals are prioritized for services: P1, P2, No Priority – for Day Services and/or Residential Services.

Individual Transition Plan (ITP)

- Held 12-3 months before student is ready to leave school
- "Blueprint" of student's requested support needs
- Includes interests, skills, and needs of the individual
- Not a guarantee of services
- Subject to prioritization, appropriation, and availability

DDS Funded Supports

- Community Based Day Supports
- Employment Support
- Family Support
- Crisis Intervention Services
- 24/7 Residential
- *Shared Living
- Individual Supports
- Facility-Based Respite

*See "The Road Forward," pages 18-20.

Massachusetts State Plan Services

- Day Habilitation Programs
- Adult Family/Foster Care
- Personal Care Attendant (PCA)

* See "The Road Forward," page 21.

Day Supports

- Day Habilitation
  - Individuals benefit from ongoing OT, PT, SLP consultation
  - Nursing on-site
  - Programming may be active in the community or in-program
- Community Based Day Supports
  - Active in community
  - Recreation, social, volunteer opportunities
- Group/Supported Employment
  - Job readiness skills
  - Job coach
- Combination of types

Residential Supports

- 24/7 Residential
  - 4-5 individuals, private bedrooms
  - Staffing based on need of individuals
- Less than 24/7 residential
  - Staffing based on need of individuals
- Shared Living
  - With typically developing householders
- Adult Family/Foster Care
  - Non-guardian family member or non-family member
- Independent Living Supports

Methods of Service Delivery

- Traditional *with Agency*
- Agency with Choice
- Self-Direction

**See the brochure entitled, “Choosing the Best Service Method for You”

Additional Resources

Please see "The Road Forward *A DDS Guide for Transition Planning*," pages 25-41, for additional resources and helpful information.

Contacts for Neighboring States

State	Department	Address	Phone
Connecticut	*Department of Developmental Services*	460 Capitol Ave. Hartford, CT 06106	860-418-6000 Toll Free 866-737-0330 TD 860-418-6079
Maine	Office of Aging and Disability Services	SHS 11 Augusta, ME 04333	207-287-9200 TTY- Maine Relay 711
New Hampshire	*Bureau of Developmental Services*	105 Pleasant St. Concord, NH 03301	603-271-5034 Toll Free 800-852-3345 ext 5034 Fax 603-271-5166 TDD 800-735-2964
New York	Office for People with Developmental Disabilities	44 Holland Ave. Albany, NY 12229	518-473-9689
Rhode Island	*Division of Developmental Disabilities*	6 Harrington Rd. Cranston, RI 02920	401-462-3421 Fax 401-462-2558
Vermont	*Division of Disability and Aging Services*	Mail: 103 S. Main St. Weeks Building Waterbury, VT 05671-1601	802-871-3064 Fax 802-871-3052

Services and reciprocity vary from state to state.

Please contact your local representative for more information.

The Road Forward

A DDS Guide for Transition Planning

Presented By:

Massachusetts Department of Developmental Services
500 Harrison Avenue
Boston, MA 02118
Tel. (617) 727-5608
www.Mass.Gov/DDS
To locate a DDS Area Office go to www.mass.gov/dds "Find an area office."

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INTRODUCTION

Transition is a word that has a unique meaning to families with a son or daughter aging out of the entitlement of education and into the world as happy, contributing adults. Fear, anxiety and dread are just a few words that come to mind around this anticipated change. As parents, after we were fairly competent with the educational terminology, we must now learn a new lingo: 688, ISP, MASSCAP. Also, transportation takes on a whole new meaning when the bus doesn't stop at your house any more.

When do we start? Who is involved? What are our options? Where do we go for help?
We don't even know all of the questions we need to ask! We do know that we need to begin with the vision and dream our young adults have for themselves, and we also have for them. We need to begin early, by encouraging self advocacy, seeking meaningful vocational experiences and providing opportunities for their strengths, desires, and interests to shine in a multitude of ways. We must plan, network, partner, ask questions, attend trainings and conferences that will connect you with other parents, guardians, professionals and agencies

This booklet is a tool, full of helpful resources and information you ***need*** to know. It outlines critical timelines, eligibility criteria, important linkages, pages of acronyms and much more. This guide helps take the mystery out of the process. It is an excellent reference guide to be kept handy and referred to often.

Transition is a journey, it doesn't happen overnight or in isolation, but it will happen. Be prepared! Our children have taught us so much and the learning doesn't stop when they leave school. We need to continue to listen and support our sons and daughters to follow their dreams for active, full, adult lives in their communities. Be creative, be innovative and reach for the stars!

Susan Nadworny
Chairperson
Massachusetts Families Organizing for Change

TRANSITION

What is Transition?

"This transition is not just about services; it is about creating a life for my son."

Transition is often described as the life changes, adjustments, and cumulative experiences that occur in the lives of young adults as they move from school environments to more independent living and work environments (Wehman, 2006). In 1994, the Council for Exceptional Children, Division on Career Development and Transition developed a definition that is still considered to be relevant today. *"Transition refers to a change in status from behaving primarily as a student to assuming emergent adult roles in the community. These roles include employment, participating in post secondary education, maintaining a home, becoming appropriately involved in the community and experiencing satisfactory personal and social relationships. The process of enhancing transition involves the participation and coordination of school programs, adult agency services and natural supports within the community."*

- from the MA Governor's Commission on Developmental Services 2007

In Massachusetts, there are two laws that provide very different types of transition requirements for students with disabilities: Individuals with Disabilities Education Act (IDEA) and Ch. 688. These two laws can be quite confusing to the student and family. Even though they both deal with "transition" and they both involve parents, the student, the school and an adult human service agency representative; the transition focus of the two are very different.

IDEA (The Individuals with Disabilities Education Act)

The Individuals with Disabilities Education Act (IDEA) is the Federal law for special education services (Public Law 108-446) which focuses on the school district's obligation to provide transition services before a young adult graduates or turns 22 and leaves special education. The purpose of this law is to "ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their needs and prepare them for employment and independent living."

IDEA mandates that transition planning be part of each student's Individual Education Plan that is in effect when the student turns 16 **(this is interpreted to mean that this planning should be included in the IEP that is developed when the student is 15 years of age)**. Transition related discussion and planning should be the beginning vision for adult life, and corresponding goals should be developed to address areas of need and related school services. These school services will help the student to live, work, or receive a post-secondary education as independently as possible when they leave special education services. The plan is reviewed annually by the educational team which includes student and family, and should change to reflect the student's more focused vision each year.

CHAPTER 688

WHAT IS CHAPTER 688?

Chapter 688 (commonly referred to as the"Turning 22 Law") is a law enacted in 1983 developed in partnership with parents, advocates and educators to address the needs of young adults. It provides 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.

This "Turning 22 Law" is NOT a continuation of the Massachusetts Special Education Statute, nor is it an entitlement guaranteeing services after the age of 22. The law creates a single point of entry into the adult human service system and establishes a planning process which identifies services or supports which may be needed through the adult service system once the student has graduated or turns 22 and special education entitlements have terminated.

WHO IS ELIGIBLE FOR CHAPTER 688?

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

1) Be receiving special education paid for by the Commonwealth of Massachusetts
2) Need continuing habilitative services at the time of turning 22 or graduating from special education, and
30 Be unable to work competitively (without specialized supports) for more than 20 hours per week at the time of leaving school

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

If an individual is not initially eligible for Chapter 688, DDS will refer the case to the MA 688 Eligibility Unit, a separate unit that will determine the Chapter 688 eligibility.

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 if the student will need additional services after leaving special education. *The referral must be made while the student is still in school.* The local school system typically decides which human service agency might best meet the student's needs as an adult and sends the referral directly to that agency. The LEA must ask the parent, young adult, or guardian to sign the 688 referral in order to send school records to the appropriate local human services agency e.g. DDS.

If an individual is being referred to DDS, the referral typically is sent directly to one of the DDS Area Offices. If a student or parent feels that a 688 referral has not been made, but should have been, they should contact the Special Education Department at their school.

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 even 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 2 years before graduation do not always 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 intellectual disabilities receive DDS services as children, a referral should still be made. The 688 referral starts the DDS planning process for the individual student and identifies the SPED date. The 688 referral also assists in identifying the number of individuals

requiring services. DDS uses this information to request appropriate funding from the Executive Branch and Legislature.

WHAT IS THE SPECIAL EDUCATION DATE (or "SPED DATE") AND WHY IS IT IMPORTANT?

This 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 their 22nd birthday. The sped date is used in the 688 referral process as the reference date for planning. If the sped date changes, inform the DDS or the Transitional Agency (TA). Students 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 Ch. 688 referral being made, the student is not eligible for planning or possible through 688. Families should complete all 688 processes with their LEA. The student can still apply to DDS or other state agencies serving adults at any time as any citizen could.

What is the parent/student role?

As part of the ongoing transition planning process:

1) A Ch. 688 referral should be discussed at the IEP Team meeting *at least two years before the student is expected to graduate or turn 22*.
2) Parents should ask the school to submit a 688 referral for their child.
3) It must be signed by the parent, legal guardian, or by the young adult who is 18 or older.
4) Request a copy of the form that is submitted.
5) The parent/student may want to consider applying for Supplemental Security Income (SSI) for any individual who may meet the 688 eligibility criteria.

TRANSITION AGENCY

WHAT IS THE TRANSITIONAL AGENCY?

The Transitional Agency (TA), sometimes referred to as the Lead Agency, is the state agency that receives the 688 referral. It is the agency that the local school system feels will best meet the student's future needs as an adult.

The TA is responsible to assist the individual in planning to move from special education services into adult life. DDS is one such agency. Other Transitional Agencies include the Department of Mental Health and the Massachusetts Rehabilitation Commission.

For students who receive a 688 referral to DDS, the role of the TA is delegated to the DDS Area Office that covers the town of the responsible local school system. Often this coincides with where the student lives, unless the student is placed in a residential school. If an individual is followed by the Dept. of Children and Families, we often look at which school system (LEA) is responsible for the individual and use that as a guideline to determine which DDS Area Office is responsible.
If a student or their family moves after a 688 referral is made, the Area Office receiving the 688 referral is responsible for that individual until a transfer referral is made and accepted within the DDS system.
To locate a DDS Area Office go to www.mass.gov/dds "Find an area office."*

DDS CHAPTER 688 TRANSITION COORDINATOR

What is a DDS Transition Coordinator?

A Transition Coordinator, sometimes called the "688 Coordinator", is a case manager who works at the local DDS Area Office. The Transition Coordinator's caseload typically consists of individuals ages 18-22 who have been found eligible for adult supports through DDS. The Transition Coordinator is the primary link to information and assistance from DDS during the transition from special education to adult life. The Transition Coordinator will help the individual and family understand what DDS can

offer and assist with identifying and securing requested supports, subject to **MASSCAP** (Massachusetts Comprehensive Assessment Process) prioritization for those supports. Soon after graduation or when an individual leaves school and transition into adult supports, an individual's case will be transferred to an adult Service Coordinator within the Area Office.

INDIVIDUAL TRANSITION PLAN

What is an ITP?

The Individual Transition Plan (ITP) is the document that specifies what kinds of support the student/family is requesting upon leaving special education. The Transitional Agency (usually, but not always DDS) arranges and chairs a meeting or meetings in order to develop the ITP. The ITP meeting is normally held about one year before the student is ready to leave school, and typically involves the student, family members, school personnel, and other individuals who know the student well. The Transitional Agency representative is responsible for inviting other agency staff, if that agency could assist a student e.g. MRC. Students and their families may also invite others whom they feel might be helpful.

The purpose of an ITP meeting is to develop a plan that includes the interests, skills and needs of the person. The ITP does not contain specific goals and objectives, or identify specific provider agencies. The ITP functions as more of a "blueprint" of the student's requested support needs. **Supports identified in the ITP are not guaranteed or create an entitlement; they are subject to prioritization, appropriation and availability.** ☆

The DDS Transition Coordinator conducts the meeting and writes the ITP. DDS's Central Office reviews the plan and sends it to the individual or guardian for approval.

DDS ELIGIBILITY PROCESS

The Department of Developmental Services is dedicated to creating, in cooperation with others, genuine opportunities for individuals with intellectual disabilities to participate fully and meaningfully as valued members of their communities.

WHO IS ELIGIBLE FOR ADULT SUPPORTS FROM DDS?

A person, 18 or older meets the criteria for eligibility for services and supports provided, purchased or arranged by the Department if the individual:

1) Is domiciled in the Commonwealth of Massachusetts
2) Meets the eligibility criteria as defined in 115 CMR 2.01

WHAT IS THE APPLICATION PROCESS?

Application Process:
The Application process should start when the person is 17 and initiated when the 688 referral form is sent by the LEA or by sending an application form (Application for DDS Eligibility) to the DDS Eligibility Team. This information can be found through the "Related Links" section at www.mass.gov/DDS

This form contains basic information about the applicant that enables the Regional Eligibility Specialist to make contact with the applicant to arrange an interview. The Regional Eligibility Team may receive telephone requests for eligibility determination and may complete the application form via telephone conversation.

Intake Process:
When the information is received, an eligibility specialist from the Regional Eligibility Team will contact the applicant, guardian or referral source within 10 days of receipt of a complete application form to arrange for an intake interview. This interview can take place at the DDS Regional Office, the Area Office, or other location. The intake process generally consists of the initial

interview, the gathering of relevant information which may include requests for additional assessments or testing and a clinical assessment that assists the DDS to identify needed resources.

Eligibility Determination:
The applicant or guardian is responsible for obtaining all relevant information needed to determine eligibility and must make every reasonable effort to ensure that the information is received by the Department in a timely manner. When all information is gathered and assessments completed, the Regional Eligibility Team Psychologist conducts a review and makes the determination decision after conferring with members of the Eligibility Team. The Regional Eligibility Team is asked to make a determination within 60 days. If no final determination can be reached after 60 days due to incomplete information the DDS may extend the process for an additional 60 days. After 120 days, the Regional Eligibility Manager will send a formal decision letter based on the information that has been made available to DDS. This decision is communicated to the applicant or his/her guardian and to the appropriate DDS Area Office.

Determination of needed supports for eligible individuals:
The Department of Developmental Services Area Office will work with the newly eligible individual and/or family/guardian to determine the supports needed and desired by the individual and the individual's priority for services.

RIGHTS AND RESPONSIBILITIES

There are many steps in the process of applying for services from the Department of Developmental Services. All applicants have the right not to be discriminated against on the basis of gender, race, ethnic background, disability, religion or sexual orientation. Individuals have the right to appeal any findings contained in the eligibility letter within **30 days** of receiving the letter. Information about how to make an appeal will be sent to you with the eligibility determination letter. We will assist you to complete these steps.

(MASSACHUSETTS COMPREHENSIVE ASSESSMENT PROCESS)

MASSCAP stands for the Massachusetts Comprehensive Assessment Process. The **MASSCAP** process consists of two major components: the Inventory of Client and Agency Planning (ICAP), and the Client and Caregiver Assessment profile.

What is the Purpose of MASSCAP?

The Department of Developmental Services (DDS) has created the **MASSCAP** for adults in order to determine what types of services the person needs. In particular, it addresses the question of "Who needs DDS funded residential supports, defined as 24/7 out-of-home, 24 hour, 7 days a week?" Individuals with the greatest functional and cognitive limitations will be offered, when requested, residential support options ranging from an array of supports in the family or individual's home to out of home placement. DDS staff will consider this continuum of least restrictive potential options when considering appropriate supports for all individuals, using a rule-out strategy before offering a more intensive support. By definition, **MASSCAP** also addresses the question that if an individual does not need 24/7, out-of-home residential supports, what other types of supports would meet the person's need. The **MASSCAP** is designed to explicitly clarify the difference between the individual/family preference and the need for supports.

What are the elements of MASSCAP process?

There are four major elements to **MASSCAP**: ICAP, resource availability, individual characteristics, and caregiver capacity. The first is the ICAP, which is a nationally recognized proprietary instrument that assesses the functional limitations of an individual. The instrument generates a score which indicates the level of supervision that an individual may require. The ICAP has both good reliability and validity. The second element examines what resources are currently available to support the individual, and what might be available to support the individual in the future. The third element examines specific characteristics of the individual, such as unique medical, mental health or

forensic issues, which might affect the need for 24/7 residential support services. The fourth element examines caregiver capacity to provide care, since an individual's need for 24/7 out-of-home residential support is an interaction between the person's needs and the ability of the caregiver(s) to provide care. The caregiver's capacity may be impacted by such factors as age, health, including both physical and mental health, the number of available caregivers in the home, the number of other dependents the caregiver is responsible to care for, and the capacity of the caregiver to provide a safe, supervised environment for their family member. The **MASSCAP** examines these factors and generates a **MASSCAP** Summary Profile.

What is the role of the caregiver in MASSCAP?
In order to complete the **MASSCAP** the active participation of the caregiver is desirable and an integral part of the process.

How is MASSCAP being implemented?
DDS applies **MASSCAP** as part of the Intake and Eligibility process for all new adults applying for eligibility at the DDS Regional Eligibility Teams. **MASSCAP is** used to address changing needs of either the individual or the caregiver when the area office is contemplating changing the service package to a more intensive array of supports.

What is the MASSCAP Summary Profile?
The **MASSCAP** Summary Profile assists the Area Office in making prioritization decisions. It ensures that those individuals with the greatest functional limitations are offered, when requested, residential support options ranging from an array of supports in the family or individual's home, Community Living Supports, to DDS funded 24/7 residential support services. In developing appropriate residential support options for individuals who need this service, DDS staff will use a rule-out strategy by first considering this continuum of least restrictive residential support options before offering more intensive out-of-home supports. Families and guardians will be actively engaged in discussion with DDS about the variety of options available to support their family members based on their **MASSCAP** profile.

SSI/SSDI

Supplemental Security Income (SSI) is a federal benefits program of the Social Security Administration. SSI disability benefits are payable to adults or children who are disabled or blind, have limited income and resources, meet the living arrangement requirements, and are otherwise eligible. The monthly payment varies up to the maximum federal benefit rate, which may be supplemented by the state or decreased by countable income and resources. Even though the Social Security Administration runs the program, SSI is not the same as Social Security. SSI provides monthly cash benefits and makes one eligible for Medicaid, which covers payment of medical bills.

Social Security Disability Income (SSDI) is financed with Social Security taxes paid by workers, employers, and self-employed persons. To be eligible for a Social Security benefit, the worker must earn sufficient credits based on taxable work to be 'insured' for Social Security purposes. Disability benefits are paid to blind or disabled workers, widow(er)s, or adults disabled since childhood, who are otherwise eligible. A son or daughter that is disabled is eligible for SSDI benefits under the parent's work history if either parents have retired and are collecting social security. The amount of the monthly disability benefit is based on the Social Security earnings record of the insured worker.
For further information on these programs, visit the Social Security Administration website at www.ssa.gov or call 1-800-772-1213.

MASS HEALTH/MEDICAID

The Division of Medical Assistance (DMA) runs the Mass Health program, formerly known as Medicaid. The DMA offer various types of insurance coverage, including primary or supplementary policies, available on a sliding fee scale, for families who do not meet income guidelines for the free or lower cost plans. Mass Health offers coverage intended to provide primary or supplementary health insurance to families without insurance, to families who have insurance but need help paying the premiums or paying the

deductibles and co-payments, to women who are pregnant, to families who have children under the age of 18, and to people with disabilities.

Medicaid covers most necessary medical services, such as those provided by physicians, hospitals, clinics, long term care facilities, medical equipment suppliers, and therapists. This also includes x-rays, prescription drugs, and eyeglasses. You must complete a Medicaid application and submit proof of the information DMA requests. For further information, you can access the DMA website at www.mass.gov/dma or call 1-800-841-2900.

MEDICARE

Medicare is a health insurance program for:

1. People 65 years of age and older.
2. Some people with disabilities under age 65.
3. People with End-Stage Renal Disease (permanent kidney failure requiring dialysis or a transplant.

Medicare has three parts, **Part A, Part B and Part D**. **Part A** helps pay for care in hospitals as an outpatient, critical access hospitals (small facilities that give limited outpatient and inpatient services to people in rural area, skilled nursing facilities (not custodial or long-term care), hospice care, and some home health care. **Part B** helps pay for doctor's services, outpatient care, and other medical services that Part A doesn't. Part B helps pay for these covered medical services and items when they are medically necessary. Part B also covers some preventive services. **Part D** covers the prescription drug plans.

Medicare Eligibility: Generally, you are eligible for Medicare if you or your spouse worked for at least 10 years in Medicare-covered employment and you are 65 years old or older and a citizen or permanent resident of the United States. If you aren't yet 65 you might also qualify for coverage if you have a disability or have End-Stage Renal disease. For further information regarding eligibility, application details and other questions, visit the Medicare website at www.medicare.gov or call 1-800-Medicare.

Massachusetts provides home and community-based services through the federal Medicaid Home and Community-Based Services (HBCS) waiver program. Massachusetts has had a HCBS waiver since 1985.

What is a home and community-based services (HCBS) waiver?
In 1981, a change was made to federal regulations allowing states to ask the federal Medicaid agency for permission to waive -or disregard certain regulations that only allowed the state to use Medicaid funds for institutional or hospital programs. This new program, authorized under section 1915(c) of the Social Security Act as the Home and Community-Based Services (HCBS) Waiver allowed Massachusetts to use funds that would have been used to pay for institutional care, for a wide variety of home and community-based services for individuals who lived in institutions or were at risk of entering institutions. Medicaid is a partnership between the Massachusetts (MassHealth) and the federal government. Massachusetts and the federal government share the costs of providing services under the Medicaid program. Massachusetts pays a portion of the costs of Medicaid and the federal government then "matches" the state payments at a rate determined through a formula for each state.

Each state has flexibility around Medicaid eligibility. While Massachusetts has some flexibility about who is eligible for a Medicaid card, the state generally include low income families and individuals and people with disabilities, typically those who qualify for federal disability payment such as Supplemental Security Income (SSI). Individuals who are eligible get a Medicaid card that gives them access to medically necessary services. Massachusetts has had an approved HCBS waiver since 1985 operated by the Department of Developmental Services. Today, thousands of adults with intellectual disabilities receive their services and funding for those services through the HCBS waiver.

States use the HCBS waiver because it helps fund services. As noted above, the Medicaid program is a state-federal partnership that provides

federal "match" money to states. Massachusetts can use the federal money to refinance services that were once paid for solely with state funds. This allows the state to collect federal money and potentially save state funds. These saved funds can be used for other services, programs or populations in the Massachusetts. In many states the refinancing has been a means to expand services or has helped hold the line against cuts in programs. The more federal funds a program brings into the Massachusetts, the better the case for getting new state funds to increase services.

Waiver mandate - Because the waiver program brings federal funds into the services system, Massachusetts has a "waiver mandate". **This means that the waiver is the first source of funding for services for anyone who is—or can become—eligible for the waiver.** Because the waiver covers the same types of services as would be covered by state funds, it makes sense to get federal money for those same services. And it makes financial sense for Massachusetts to get as much federal funding as possible for services, allowing the state to use their funds for individuals or services not allowable under the HCBS waiver, or to save those funds for other uses in the state.

Waiver Services

Waiver eligibility has four aspects:

- First the person must be eligible for a Medicaid card under the Massachusetts Medicaid plan. Not all individuals who are eligible for Medicaid can enroll in a HCBS waiver. Only individuals who are in certain Medicaid eligibility "categories" can potentially be eligible for the HCBS waiver for persons with intellectual disabilities.
- Second, eligibility for the HCBS waiver requires the person must meet what is termed the "level of care" for institutional services. In Massachusetts this refers to the six state developmental centers. This means that the individual would need, and qualify for institutional services that in a Medicaid funded setting if they didn't receive the home and community based services. (This does not mean that the person either has to request or want institution based services.)That is, without the supports and services the waiver provides, the person could be

eligible for services in an institution. This regulation allows Massachusetts to serve both individuals who are residing in institutions who wish to leave as well as divert individuals from entering institutions.

- Third, the individual must meet the Massachusetts Department of Developmental Service's eligibility standard for services. States can decide what populations—called target groups—the waiver (or waivers) will serve. For example, Massachusetts can decide to serve only individuals with intellectual disabilities or serve individuals only over a certain age. But all individuals with developmental disabilities or intellectual disabilities must meet the level of care rules for eligibility to an ICF-MR—an Intermediate Care Facility for the Mentally Retarded— the type of Medicaid funded institution that serves individuals with intellectual and/or developmental disabilities.
- And fourth, the person may also have to meet any state rules about who has priority for services. In Massachusetts our regulations set the rules for prioritizing the needs of the individual. Within those standards an individual can meet specific criteria for waiver programs. First priority to individuals in crisis such as people who are homeless or who have lost a caregiver. Other individuals may also be eligible, but may be a Priority 2 and have to wait longer for waiver funding.

The State Decides the Size of the Waiver - How many people a waiver serves is the at the state's discretion. In Massachusetts the size of the Waiver is determined by an analysis of the projected needs of the population of people with intellectual disabilities and the projected budget services. As the use of Waiver services is dependent on a match of federal and state dollars the analysis of Waiver use is critical in managing the size of the Massachusetts Waivers. Of course the number is also affected by whether individuals are Medicaid eligible and can meet the level of care and/or other target group requirements too.

For more information related to the Waiver, please go the DDS website, www.mass.gov/DDS .

DDS FUNDED SUPPORTS

RESIDENTIAL

The programs offer 24 hour residential supports, although some also provide supports that entail less than round the clock supervision. A typical 24 hour residential program would have a House Manager, who oversees and coordinates all of the home-based supports provided to the resident, as well as Direct Care Staff, who are responsible for much of the day to day assistance an individual might need.

Further oversight and supervision is provided through management processes within the individual provider agencies. The goal of all residential support services is to ensure the health and safety of each individual and provide all supports needed, while at the same time working to foster individual growth and maximum independence.

SHARED LIVING

Shared living is a residential support in which an individual resides with another, non-disabled person or host family. Efforts are made to match an individual with an optimal living situation that offers an appropriate level of support and supervision as well as oversight, training and assistance by the provider agency.

INDIVIDUAL SUPPORTS

This is a service provided to individuals who meet the criteria for individual supports through DDS and who are prioritized, based on need. Such individuals do not require 24 hour residential support, but typically need intermittent assistance and training in certain areas of maintaining their own apartment or generally independent living situation. Examples of supports provided might include assistance with cooking and meal preparation, bill paying, attending medical appointments and accessing community resources.

FACILITY-BASED RESPITE

These programs offer respite to individuals at their own home-style sites. Facility based respite can involve a day, overnight, weekend, or possibly a longer stay. This support offers individuals the opportunity to enjoy social and recreational opportunities with peers and also provides for families a sometimes much needed break from the work and stress of day to day provision of care.

EMPLOYMENT SUPPORT

DDS is committed to promoting and assisting individuals who become employed in integrated jobs in the community. This is consistent with DDS's mission to support individuals to "fully and meaningfully participate in their communities as valued members." DDS issued an Employment First Policy in 2010 that established integrated, individual employment as a preferred service option and optimal outcome for working age adults with ID. This policy raises expectations and expands opportunities by prioritizing assistance and supports for integrated employment in the development of service plans and delivery.

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 and creativity, in order that each person can achieve his or her employment goals. Supports offered vary, but a main focus is on the development of individual community employment opportunities in which a person is hired by a business directly and the provider offers job coaching and periodic check-ins based on the person's ongoing support needs. Some providers also offer group employment where a number of individuals work in a community business setting with a job coach on site. Community Based Day Support (CBDS) programs include a career exploration/planning component for individuals who are on a pathway to employment, and can also provide complementary support services for individuals who work part-time in individual or group supported employment.

FAMILY SUPPORT

These programs provide a wide range of services to individuals who live at home with their families. These services can include in-home training and support, respite, behavioral consultation and independent living skills assessments.

DDS provides funding for Family Support Centers across the state to provide a local presence and act as a hub for offering a wide range of general family support services and activities to families of children and adults who are eligible for DDS services. The Center's staff is expected to be experts in generic resources and services in their respective areas and to work with families to maximize natural supports. Services include: information and Referral, Service Navigation, Trainings and educational events on topics of interest, Parent Networking opportunities, and a variety of Social, Recreational and Community activities. Centers are expected to provide services to families from diverse cultural, ethnic and linguistic communities in the geographic areas they serve, which may involve creating partnerships with community organizations and other resources in order to provide culturally responsive services

Agencies work with families to identify and address needs by developing an individualized Family Support Plan. Individual flexible funding is allocated to address these needs must meet criteria as identified within the DDS Family Support Guidelines and Procedures manual.

CRISIS INTERVENTION SERVICES

DDS area offices contracts with local crisis intervention agencies to provide on-call response to individuals in crisis. The Crisis Team is available 24 hours a day, 7 days a week. Services include telephone, mobile outreach and on-site face to face evaluations, medication management, outreach and on-site short term clinical interventions, pre-screening for crisis stabilization programs, inpatient facilities and arranging for other diversionary services. Outreach consultation is provided by the Team to prevent an emergency situation from arising, to divert from hospitalization and to stabilize crisis situations. Outreach contact can be maintained for high-risk individuals until transition to other supports can be put in place.

DAY HABILITATION PROGRAMS

Day Habilitation Programs (Day Habs), funded and licensed by MassHealth, typically work with individuals who are not interested in work, and who might desire a day structured around social and recreational activities, or would benefit from the availability of ancillary supports such as Occupational Therapy, Physical Therapy, Speech and Language, and other assistance. Day Habs are reimbursed by Medicaid for the supports they provide, so individuals must be Medicaid eligible in order to attend these programs.

ADULT FAMILY CARE

Adult Family Care is a residential support available to individuals who are Medicaid eligible and meet criteria related to daily living needs. There are two ranges of support needs that would provide different levels of reimbursement to a host caregiver. Individuals meeting criteria for AFC Tier I support must have a need in at least one area of daily living. Activities of Daily Living (ADL's) include but are not limited to: bathing, grooming, dressing, toileting, mobility, range of motion, and taking medications. To qualify for AFC Tier II supports, a person must have at least 3 ADL needs and require physical assistance, or have 2 ADL needs and also present behavioral challenges. Family members can act as AFC providers unless they are spouses, parents, or guardians.

PERSONAL CARE ATTENDANT SERVICES (PCA)

'PCA' stands for Personal Care Attendant. A PCA is hired by a person with a disability to assist with his or her personal care routine. Examples of personal care activities would include bathing and grooming, dressing, taking medications, toileting, mobility, range of motion exercise, and eating. Individuals are eligible if they qualify for Medicaid, have a severe, chronic disability, and require physical assistance in personal care.

What if the local school system is unsure which agency would best serve a particular student?

The local school system can send the 688 referral to the Bureau of Transitional Planning (BTP) for assistance. The BTP will review the referral and decide which agency should take a lead role in planning for that student.

If the local school system feels that more than one agency might be able to assist a student, should more than one 688 referral be sent?

No. Each individual should only have one 688 referral. The school system should send the 688 referral to the agency that appears to be most likely to play the greatest role for that student. A 688 referral to a specific agency does not limit an individual from accessing services provided by other agencies. General referrals, meaning non-688 referrals, may be made to other agencies as appropriate at any time. More than one agency can have a role in an individual's supports when an individual leaves school.

Is eligibility for 688 and eligibility for DDS the same?

No. Eligibility for 688 is more general than eligibility for DDS. Individuals eligible for 688 have a variety of diagnoses or disabilities. Eligibility for DDS is more specific. An individual must be a person with intellectual disabilities and meet other eligibility criteria currently specified by DDS.

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 supports through the agency. If the person is eligible for 688 services but is not eligible for DDS, services, DDS transfers the case the appropriate state agency for 688 planning assistance. The Transition Coordinator in the local DDS Area Office must send a complete package of material for the ineligible person to Central Office in order to complete the transfer. Any student whom DDS finds ineligible for services also has the right to appeal that decision.

In addition to supporting material, a copy of the 688 referral and the DDS ineligibility letter is included in the transfer packet. The transfer will be completed by DDS Central Office working with the Central Office of the agency of the proposed transfer. 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 is the Bureau of Transitional Planning (BTP)?

The Bureau of Transitional Planning is a unit of the Executive Office of Health and Human Services (EOHHS) responsible for the administration of Chapter 688. The BTP can provide technical assistance to schools, state agencies, individuals and families regarding the policies and practices relevant to Chapter 688. The BTP works with a number of state agencies in order to ensure that polices and practices related to 688 are up to date and implemented effectively within the agencies.

What is the Transitional Advisory Committee?

The Transitional Advisory Committee (TAC) consists of: the Director of the Bureau of Transitional Planning and representatives from the Department of Mental Health (DMH), the Department of Developmental Services (DDS), the Department of Children and Families (DCF), the Department of Youth Services (DYS), the Massachusetts Commission for the Blind (MCB), the Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH), the Massachusetts Rehabilitation Commission (MRC), and the Department of Elementary and Secondary Education (DESE). The TAC assists the BTP in developing policies and practices related to Chapter 688. In addition, the TAC is a resource for problem solving for complex cases.

TRANSITION TIMELINE

WHAT IS THE TIMELINE OF THE 688 PROCESS?

Age 14-15	Planning at this point begins with a vision of what the student wants and what will be in his/her best

interest. There should be a Statement of Needed Transition Services listed in the IEP.

Age 16 – 18	Refinement of the vision and identification of transition needs in the Transition Planning Form at the IEP. Assessment of interests, aptitudes and abilities, community based learning opportunities, work, and home based learning opportunities. Gather information about Social Security (SSI) and MassHealth
Age 18	**Age of Majority** - under Massachusetts State law, students become responsible for making decisions about their own medical and education programs and services, unless a court appointed guardian is in place. If appropriate, students or guardians should apply for SSI. Eligibility for DDS adult services can be determined at age 18 and DDS eligibility application should be made at this time.
Age 18-20	Continued refinement of the vision for the future and more directed educational team planning towards that goal. School system makes the 688 referral. DDS Area Office assigns a Transition Coordinator.
Age 20 – 21	DDS as the Transitional Agency, completes an Individual Transitional Plan (ITP) outlining needed services and supports and also identifying the state agency responsible for them. Continuation of community and work based learning opportunities as identified in IEP and ITP. DDS Transition Coordinator continues as the primary DDS contact for the individual, family and school system.

Age 22	Beginning of Adult DDS Services that may include employment, work training activities, day habilitation, transportation, individual or family support, and in some cases, residential supports.

ADDITIONAL RESOURCES OF INTEREST

THE RIDE

The RIDE is a MBTA program which provides door to door transportation to eligible people who cannot use general public transportation all or some of the time, because of a physical, cognitive or mental disability. The RIDE is operated in compliance with the federal Americans with Disabilities Act (ADA) and is a shared-ride service, which means that you are traveling with other people. Lift equipped vans are used to serve persons with disabilities, including those who use wheelchairs and scooters. The RIDE operates 365 days a year from 6am to 1am in 62 cities and towns. Not all <Insert Area Name Here>cities and towns are served by the RIDE. Those that are include Arlington, Bedford, Burlington, Concord, Lexington, Lincoln, Wilmington, Winchester and
Woburn.

In order to use the RIDE, you must complete and submit an application. PER ADA regulations, 21 days is allowed to process applications upon receipt. Only completed signed original applications mailed to the address below will be considered for review. You will receive written notification of eligibility via U.S. mail. For further information and to access RIDE applications, please contact:

MBTA Office for Transportation Access
10 Park Plaza Room 5750
Boston, MA 02116
1-800-533-6282
Web Site: www.mbta.com/riding_the_t/accessible_services

Alternative Leisure Company & Trips Unlimited

Offers a range of programs and recreational opportunities, including day and weekend trips, and week-long vacations for adults with developmental disabilities.

165 Middlesex Turnpike, Suite 206
Bedford, MA 01730
781-275-0023
Web Site: www.alctrips.com

Camp Allen

Private, non-profit program located in Bedford, NH that offers residential and day camp experiences to individuals with physical and/or developmental disabilities.

56 Camp Allen Road
Bedford, NH 03110
603-622-8471
Web Site: www.campallennh.org

Challenge Unlimited at Ironstone Farm

Therapeutic horseback riding program for people with physical, emotional, and cognitive challenges. Opportunities to both ride and care for horses encourages increased self-confidence and physical condition.
450 Lowell Street
Andover, MA 01810
978-475-4056
Web Site: www.challengeunlimited.org

Friends for Tomorrow

Therapeutic horseback riding programs located in Lincoln and Sudbury. Offers customized programs tailored to individual needs that provide new sensory experiences and encourage increased self-esteem and motivation.
131 Weston Road
Lincoln, MA 01773
781-259-8909
Web Site: www.friendsfortomorrow.org

Grotonwood

Operates Christian camp programs in Groton, MA and Oceanwood, ME that offer activities including horseback riding, leadership development and fellowship.
167 Prescott Street
Groton, MA 01450
978-448-0025
Web Site: www.grotonwood.org

Outdoor Explorations

Program providing opportunity for shared activities between disabled and non-disabled people. 1 day and multi-day activities include backpacking, sailing, rafting, rock climbing, kayaking, and community service.
98 Winchester Street
Medford, MA 02155
781-395-4999 Web Site: www.outdoorexp.org

Special Olympics Massachusetts

Year round opportunities for sports training and athletic competition in a variety of Olympic-type sports for individuals with developmental disabilities.
450 Maple Street, Bldg. One
Danvers, MA 01923
978-774-1501
Web Site: www.specialolympicsma.org

Trips R Us

Offers variety of social programs, recreation and travel opportunities. Options range from social groups to day trips, weekend getaways and vacations.
42 Eden Street
Framingham, MA 01702
508-405-0999
Web Site: www.tripsrus.org

YMCA/YWCA

Services available throughout the state provide a wide range of health promoting courses and activities including but not limited to exercise and swimming lessons. To find a location near you, go to the YMCA website:
Web Site: www.ymca.net

One Stop Career Centers:

One stop career centers are designed to provide a full range of assistance to job seekers under one roof. Established under the Workforce Investment Act, the centers offer training referrals, career counseling, job listings, and similar employment-related services. Services are provided to both older youth and adults with and with out disabilities and often work in collaboration with DDS and MRC funded employment service providers.

Career Centers in Massachusetts

	City/Town	Career Center Name	Career Center Website
Boston Region	Boston	JobNet	www.jobnetboston.org
	Boston	Boston Career Link	www.bostoncareerlink.org
	Boston	The Work Place	www.theworkplace.org
Metro North	Cambridge	Career Source	www.yourcareersource.com
	Everett	Career Source	www.yourcareersource.com
	Woburn	The Career Place	www.careerplacejobs.com
Metro South	Marlboro	Employment and Training Resources	www.etrcc.com
	Newtonville	Employment and Training Resources	www.etrcc.com
	Norwood	Employment and Training Resources	www.etrcc.com
Northeastern Massachusetts	Gloucester	North Shore Career Center	www.nscareers.org
	Haverhill	ValleyWorks	www.valleyworks.cc
	Lawrence	ValleyWorks	www.valleyworks.cc
	Lowell	Career Center of Lowell	www.cclowell.org
	Lynn	North Shore Career Center	www.nscareers.org
	Salem	North Shore Career Center	www.nscareers.org
Southeastern Massachusetts	Attleboro	Attleboro Career Center	www.bristolwib.org
	Brockton	Career Works	www.careerworks.org
	Fall River	Fall River Career Center	www.bristolwib.org

	Falmouth	Career Opportunities	www.capejobs.com
	Hyannis	Career Opportunities	www.capejobs.com
	New Bedford	New Bedford Career Center	www.newbedford careercenter.org
	Orleans	Career Opportunities	www.capejobs.com
	Plymouth	Plymouth Career Center	www.plymouth careercenter.org
	Quincy	Quincy Career Center	www.quincycareer center.org
	Taunton	Taunton Career Center	www.bristolwib.org
	Wareham	Wareham Career Center	www.newbedford careercenter.org
Central Massachusetts	Gardner Leominster	North Central Career Centers North Central Career Centers	www.ccncm.com www.ccncm.com
	Milford	Workforce Central of Milford	www.workforce centralma.org
	Southbridge	Workforce Central of Southbridge	www.workforc ecentralma.org
	Worcester	Workforce Central of Worcester	www.workforce centralma.org
Western Massachusetts	Greenfield	Franklin/Hampshire Career Center	www.fhcc-onestop.com
	Holyoke	CareerPoint	www.careerpointma.org
	North Adams	BerkshireWorks, North Adams	www.berkshireworks.org
	Northampton	Franklin/Hampshire Career Center	www.fhcc-onestop.com
	Pittsfield	BerkshireWorks, Pittsfield	www.berkshireworks.org
	Springfield	FutureWorks	www.getajob.cc

American Association on Intellectual and Developmental Disabilities
(Formerly the American Association on Mental Retardation; AAMR)
National organization promoting effective policies and research to expand opportunity, equality, dignity, accommodation, self-determination and human rights for individuals with intellectual and developmental disabilities.
444 North Capitol Street, NW Suite 846 Washington, DC 20001
Web Site: www.aaidd.org

Autism Support Centers
Regional programs that provides services and resource information to families of individuals with Autism, Pervasive Developmental Disorder and Asperger's Syndrome. Can be found at mass.gov/dds

Department of Elementary and Secondary Education (DESE)
Special education services are provided to children ages 3-22 who are unable to process effectively in a regular school program. Services include evaluation, individual education plans (IEP's), and training.
350 Main Street
Malden, MA 02148
781-338-3000 Web Site: www.mass.gov/DESE

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
Web Site: 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
Boston, MA 02108
617-624-6000
Web Site: 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
1-800-249-2007/1-800-445-6604
Web Site: www.mass.gov/dta

Disabled Persons Protection Commission (DPPC)
State agency protecting disabled adults 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.
50 Ross Way
Quincy, MA 02169
1-800-426-9009
Web Site: 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
Web Site: www.mass.gov/mcb

Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH)
State agency offering training, technology, case management, social services, interpreter and independent living support for deaf and hard of hearing individuals.
600 Washington Street
Boston, MA 02111
617-740-1600
Web Site: www.mass.gov/mcdhh

Massachusetts Office on Disability (MOD)
State agency providing advocacy, information, and referral. Focuses on legal rights, accommodations, accessibility to promote dignity, opportunity and self-determination.
1 Ashburton Place #1305
Boston, MA 02108
617-727-7440
Web Site: 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
Web Site: www.mass.gov/mrc

United Cerebral Palsy
Offers information, advocacy, programs and referral services to individuals with cerebral palsy and their families. Also provides technology, and research information.
71 Arsenal Street
Watertown, MA 02472
617-926-5480
Web Site: www.ucpboston.org

The Arc of Massachusetts

Works to enhance the lives of people with cognitive and developmental disabilities and their families through education, advocacy, and work with policy issues and legislatures.
217 South Street
Waltham, MA 02453
781-891-6270
Web Site: www.arcmass.org

BenePlan and Project Impact:

These two programs provide comprehensive benefits assessment, planning and assistance to SSI and SSDI beneficiaries, their families and service providers in Massachusetts. The experienced Benefits Specialists can help a disabled consumer and their family make educated employment choices by evaluating the person's current benefits and explaining how working will affect them.

BenePlan operated by Resource Partnership:
The BenePlan covers the communities located in Berkshire, Franklin, Hampden, Hampshire, Middlesex, and Worcester Counties.
www.resourcepartnership.org or call 1 877-937-9675

Project Impact, operated by the Massachusetts Rehabilitation Commission:
Project Impact covers the communities located in Barnstable, Bristol, Dukes, Nantucket, Plymouth and Suffolk Counties.
www.mass.gov/mrc/ or call 617-204-3854

Federation for Children with Special Needs

The Federation is a center for parents and parent organizations to work together on behalf of children with special needs and their families.
1135 Tremont Street, Suite 420
Boston, MA 02120
Phone: (617) 236-7210, (800) 331-0688 (in MA)
Email: fcsninfo@fcsn.org

Institute for Community Inclusion (ICI)

ICI offers training, clinical, and employment services, conducts research, and provides assistance to organizations to promote inclusion of people with disabilities in school, work, and community activities.
Institute for Community Inclusion/UCEDD
UMass Boston
100 Morrissey Blvd.
Boston, Massachusetts 02125
Voice:(617) 287-4300
www.communityinclusion.org

Massachusetts Aging & Disability Information Locator (MADIL)

MADIL is an on-line tool designed to help find information on services and programs that support elders and people with disabilities in Massachusetts.
www.mass.gov/madil

Massachusetts Advocates for Children

Massachusetts Advocates for Children is a private non-profit organization dedicated to being an independent and effective voice for children who face significant barriers to equal educational and life opportunities.
25 Kingston Street, 2nd. Floor
Boston, MA 02111
Phone: 617-357-8431
www.massadvocates.org

Massachusetts Advocates Standing Strong (M.A.S.S.)
Statewide self-advocacy organization educating and empowering individuals with cognitive and developmental disabilities to make choices that will enrich their lives.
P.O. Box 6025
Plymouth, MA 02362
508-747-8111
Web Site: www.massadvocatesstandingstrong.org

Massachusetts Developmental Disabilities Council (MDDC)
State agency offering resources, housing and education to families. Provides information, advocacy and grants to agencies assisting people with disabilities.
1150 Hancock Street
Quincy, MA 02169
617-770-7676
Web Site: www.mass.gov/mddc

Massachusetts Down Syndrome Congress (MDSC)
The MDSC offers a broad array of programs to serve people with Down syndrome and their families throughout the state.
20 Burlington Mall Road
Suite 261
Burlington, MA 01803
781-221-0024
Web Site: www.mdsc.org

Mass. Families Organizing for Change
Agency that offers empowerment, advocacy and leadership for families to optimize planning, choice, and decision making about individual and family supports.
P.O. Box 61
Raynham, MA 02768
1-800-406-3632
Web Site: www.mfofc.org

New England INDEX
Online resource providing resource and referral information on a broad range of services for individuals with disabilities.
200 Trapelo Road
Waltham, MA 02452
1-800-642-0249
Web Site: www.disabilityinfo.org

PALS (Personal Advocacy and Lifetime Support)
A program designed to support parents and caregivers in establishing a support network of family and friends, which provides advocacy in the present and future, when primary caregivers are no longer able to do so.
130C Baker Ave. Extension
Concord, MA 01742
978-369-0025
Web Site: www.palsinc.org

MRC Home Modification Program:

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

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

MASS ACCESS: The Accessible Housing Registry:

The Mass Accessible Housing Registry is a free program that helps people with disabilities find rental housing in Massachusetts, primarily accessible and barrier-free housing. The database tracks accessible and affordable apartments throughout the state, maintaining information about their availability. The program is based at Citizens' Housing and Planning Association and can be accessed through the internet and offers many housing tips.

http://www.massaccesshousingregistry.org

Massachusetts Housing Consumer Education Centers:

Nine Housing Consumer Education Centers around the state offer answers to a wide range of questions about all types of housing problems. Tenants, landlords, prospective buyers, and homeowners can access information designed to maximize housing stability, strengthen investments, and minimize disputes. Consumer Education Centers can offer valuable assistance to disabled consumers.

http://www.masshousinginfo.org

Housing Consumner Education Centers in Massachusetts

Berkshire Housing Development Corporation
74 North St.
Pittsfield, MA 01201
(413) 499-1630
www.berkshirehousing.com

Community Teamwork, Inc.
167 Dutton St.
Lowell, MA 01852
(978) 459-0551
(800) 698-0551
www.comteam.org

Franklin County Housing & Redevelopment Authority
42 Canal Rd.
Turners Falls, MA 01376
(413) 863-9781
www.fchra.org

HAP, Inc.
322 Main St.
Springfield, MA 01105
(413) 233-1600
(800) 332-9667
www.masshousinginfo.org/hap

Housing Assistance Corporation
460 West Main St.
Hyannis, MA 02601
(508) 771-5400
www.haconcapecod.org

Metropolitan Boston Housing Partnership, Inc.
125 Lincoln Street
Boston, MA 02111-2503
(617) 425-6700 (800) 272-0990
www.mbhp.org

South Shore Housing Development Corporation
169 Summer St.
Kingston, MA 02364
(781) 422-4200 (800) 242-0957
www.southshorehousing.org

South Middlesex Opportunity Council, Inc.
300 Howard St.
Framingham, MA 01701
(508) 620-2675 (800) 286-6776
www.smoc.org

RCAP Solutions, Inc.
205 School Street, PO Box 159
Gardner, MA 01440-0159
(978) 630-6600
www.rcapsolutions.org

Independent Living Centers (ILC)

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

Independent Living Centers in Massachusetts

Berkshire County
Ad-Lib, Inc.
215 North Street
Pittsfield, MA 01201
(413) 442-7047
TTY (413) 442-7158
adlib@vgernet.net

North Shore and Cape Ann
Independent Living Center
of the North Shore and Cape Ann
27 Congress Street, Suite 107
Salem, MA 01970
(978) 741-0077 voice/TTY
http://www.ilcnsca.org/

Metropolitan Boston
Boston Center for Independent Living
60 Temple Place, 5th floor,
Boston, MA02111
(617) 338-6665 TTY (617) 338-6662
www.BostonCIL.org.

Metrowest Area
Metro West Independent Living Center
280 Irving Street, #401
Framingham, MA 01702
(508) 875-7853
www.mwcil.org

Worcester County
Center for Living and Working
484 Main Street, Suite 345
Worcester, MA 01608-1874
Phone (508) 798-0350
www.centerlw.org

Northeastern MA
Northeast Independent Living Program
20 Ballard Road
Lawrence, MA 01843
(978) 687-4288 voice/TTY
www.nilp.org

Cape and Islands
Cape Organization for the Rights of the Disabled
1019 Iyanough Road, #4
Hyannis, MA 02601
(508) 775-8300 voice/TTY
www.cordonline.org

Fall River and New Bedford
Southeast Center for Independent Living
Merrill Building
66 Troy Street
Fall River, MA 02721
(508) 679-9210 voice/TTY
www.secil.org

Southeastern MA
Independence Associates
141 Main Street, 1st Floor
Brockton, MA 02301
(508) 583-2166 voice/TTY
www.iacil.org

Hampshire, Hampden and
Franklin Counties
Stavros Center for
Independent Living, Inc.
210 Old Farm Road
Amherst, MA& 01002
(413) 256-0473 voice/TTY
staff@stavros.org

Roxbury, Dorchester, Hyde Park, Jamaica Plain, Roslindale, Mattapan, West Roxbury
Independent Living Project
Multicultural Independent Living Center
22 Beechwood Street
Dorchester, MA 02121
(617) 288-9431 **TDD:** 617-288-2707
www.milcb.org

This information is provided by
the Massachusetts Rehabilitation
Commission

LEGAL

Disability Law Center

Private, non-profit agency providing protection and advocacy for Massachusetts residents with disabilities. Offers information, referral, technical information and representation.
11 Beacon Street, Suite 925
Boston, MA 02108
617-723-8455
Web Site: www.dlc-ma.org

Massachusetts Office on Disability

One Ashburton Place, Room 1305
Boston, MA 02108
1-800-322-2020
Web Site: www.mass.gov/mod

FREQUENTLY USED ACRONYMS

AAMR......... American Association on Mental Retardation, www.aamr.org
ADA............ Americans with Disabilities Act
ADD............ Attention Deficit Disorder
ADDP...........The Association of Developmental Disabilities Providers, www.addp.org
ADHD......... Attention Deficit/Hyperactivity Disorder
ADL............ Activities of Daily Living
ALAB.......... Alleged Abuser
ALV .... Alleged Victim
ARC .... Association of Retarded Citizens, www.thearc.org, www.arcmass.org
ASC............ Autism Support Center
ASD............ Autism Spectrum Disorder
ASL............. American Sign Language

BTP .... Bureau of Transitional Planning

CAB .... Citizen Advisory Board
CMS............ Centers for Medicare and Medicaid Services
CORI .... Criminal Offender Record Information
CP................ Cerebral Palsy
CRT .... Complaint Resolution Team

DD .... Developmental Disability
DET .... Department of Employment and Training, www.detma.org
DMH .... Department of Mental Health, www.mass.gov/dmh
DDS .... Department of Developmental Services, www.mass.gov/DDS
DDSIS......... Department of Developmental Services Information System
DESE.......... Department of Elementary and Secondary Education, www.mass.gov/DESE
DOL............ Department of Labor, www.mass.gov/dlwd
DPH............ Department of Public Health, www.mass.gov/dph
DPPC .... Disabled Person's Protection Commission, www.mass.gov/dppc

DCF............. Department of Children and Families, www.mass.gov/DCF
DTA............ Department of Transitional Assistance, www.mass.gov/dta
DX.............. Diagnosis

EEP.............. Extended Employment Program
EI................ Early Intervention Services
EOEA.......... Executive Office of Elder Affairs, www.mass.gov/elders
EOHHS....... Executive Office of Health and Human Services, www.mass.gov/eohhs

FSP .... Family Support Plans
FC .... Facilitated Communication
FEDERATION – The Federation for Children with Special Needs, www.fcsn.org
FOC .... Families Organizing for Change, www.mfofc/.org

GAL .... Guardian Ad Litem

HCBW......... Home and Community Based Waiver
HCSIS .... Home and Community Services Information System
HIPAA......... Health Insurance Portability and Accountability Act of 1996
HMO........... Health Maintenance Organization
HOH........... Hard of Hearing
HRO............ Human Rights Officer
HUD .... Department of Housing and Urban Development, www.mass.gov/dhcd

ICAP .... Inventory for Client and Agency Planning
ICF.............. Intermediate Care Facility
ICF/MR....... Intermediate Care Facility for the Mentally Retarded
ICI .... Institute for Community Inclusion, www.communityinclusion.org
ID.............. Intellectual Disabilities
IDEA .... Individuals with Disabilities Education Act

IEP............... Individual Education Plan
IL .... Independent Living
ISP............... Individual Support Plan
ISS .... Individual Support Services
ITP............... Individual Transition Plan
LEA............. Local Education Authority
LHA............ Local Housing Authority

MAAPS........ Massachusetts Association of 766 – Approved Private Schools, www.spedschools.com
M.A.S.S. ..... Massachusetts Advocates Standing Strong, www.communitygateway.org
MASSCAP....Massachusetts Comprehensive Assessment Process
MassHealth..Office of Medicaid, MassHealth
MBTA.......... Massachusetts Bay Transportation Authority, www.mbta.com
MCB............ Massachusetts Commission for the Blind
MCCD......... Massachusetts Coalition for Citizens with Disabilities
MCDDH...... Massachusetts Commission for the Deaf and Hard of Hearing, www.state.ma.us/mcdhh
MDDC......... Massachusetts Developmental Disabilities Council, www.state.ma.us/mddc
MFOFC....... Massachusetts Families Organizing for Change, www.mfofc.org
MHFA.......... Massachusetts Housing Finance Agency, www.mhfa.com
MI............... Mental Illness
MOD........... Massachusetts Office of Disability, www.state.ma.us/mod
MRC........... Massachusetts Rehabilitation Commission, www.mass.gov/mrc
MS.............. Multiple Sclerosis
MSPCC....... Massachusetts Society for the Prevention of Cruelty to Children,
www.mspcc.org
OJT.............. On the Job Training
OT............... Occupational Therapy
PAC .... Parent Advisory Committee
PASARR...... Pre-Admission Screening and Annual Resident Review

PASS........... Plans to Achieve Self-Sufficiency
PCA............ Personal Care Attendant
PDD............ Pervasive Developmental Disorder
PDD, NOS.. Pervasive Developmental Disorder, Not Otherwise Specified
POC............ Plan of Care
PT............... Physical Therapy

RAC............ Regional Advisory Committee
RFP.............. Request for Proposal
RFR............, Request for Response
RTA............ Regional Transit Authority

SAC............ Statewide Advisory Council
SHIP............ Statewide Head Injury Program, www.mass.gov/mrc/ship
SIB.............. Self-Injurious Behavior
SNF............. Skilled Nursing Facility
SpEd........... Special Education
SSA............. Social Security Administration, www.ssa.gov
SSDI........... Supplemental Security Disability Income
SSI.............. Supplemental Security Income, www.ssa.gov

TAC............ Transitional Advisory Committee
TASH.......... The Association for Persons with Severe Handicaps, www.tash.org

UCPA.......... United Cerebral Palsy, www.ucpa.org

VG .... Virtual Gateway
VNA .... Visiting Nurses Association

NOTES

Important Transition Information Every Family Should Know

Transition Information Fact Sheets

April 2015

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.

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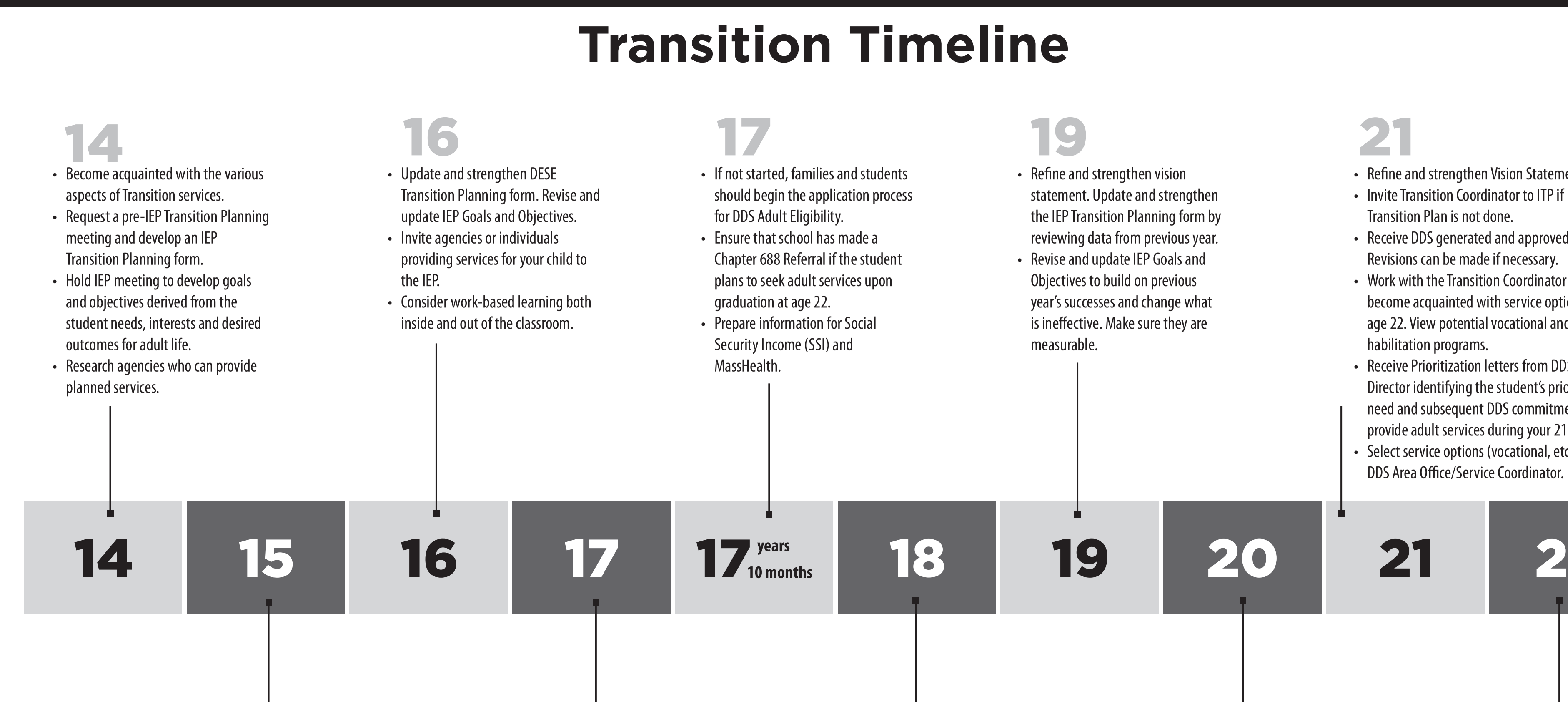
Transition Timeline



14
- Become acquainted with the various aspects of Transition services.
- Request a pre-IEP Transition Planning meeting and develop an IEP Transition Planning form.
- Hold IEP meeting to develop goals and objectives derived from the student needs, interests and desired outcomes for adult life.
- Research agencies who can provide planned services.

15
- Refine and strengthen Vision Statement. Update and strengthen the DESE Transition Planning form by reviewing data from previous year. Revise and update IEP Goals and Objectives to build on previous year's successes and change what was ineffective.

16
- Update and strengthen DESE Transition Planning form. Revise and update IEP Goals and Objectives.
- Invite agencies or individuals providing services for your child to the IEP.
- Consider work-based learning both inside and out of the classroom.

17
- Explore "Age of Majority" (age 18) issues. Review and consult with Children's Coordinator for direction.
- Prepare to apply for SSI and MassHealth.
- Ensure that the DDS Eligibility Application is sent to the DDS Eligibility Team.
- School district generates the 688 Referral to DDS or other adult human service agency.

17 (years 10 months)
- If not started, families and students should begin the application process for DDS Adult Eligibility.
- Ensure that school has made a Chapter 688 Referral if the student plans to seek adult services upon graduation at age 22.
- Prepare information for Social Security Income (SSI) and MassHealth.

18
- DDS Adult Eligibility process should be completed and eligibility determined.
- SSI Application should be submitted and determination complete.
- Transfer of parental rights occur, unless a formal Guardianship process has been complete.
- Pending adult eligibility, students and parents will be contacted by their assigned DDS Transition Service Coordinator.
- Review MCAS, MassCap prioritization materials sent by DDS.
- Discuss with DDS Transition Service Coordinator if you have any questions.
- Apply for Section 8 Housing.

19
- Refine and strengthen vision statement. Update and strengthen the IEP Transition Planning form by reviewing data from previous year.
- Revise and update IEP Goals and Objectives to build on previous year's successes and change what is ineffective. Make sure they are measurable.

20
- Refine and strengthen Vision Statement. Update and strengthen the IEP Transition Planning form by reviewing data from the previous year.
- Invite the DDS Transition Coordinator to the IEP this year. Work with the Transition Coordinator to learn about DDS service option at age 22.

21
- Refine and strengthen Vision Statement.
- Invite Transition Coordinator to ITP if DDS Transition Plan is not done.
- Receive DDS generated and approved ITP. Revisions can be made if necessary.
- Work with the Transition Coordinator to become acquainted with service options at age 22. View potential vocational and/or day habilitation programs.
- Receive Prioritization letters from DDS Area Director identifying the student's priority of need and subsequent DDS commitment to provide adult services during your 21st year.
- Select service options (vocational, etc.) with DDS Area Office/Service Coordinator.

22
- Eligibility for adult services begins.
- Meet Adult Service Coordinator and anticipate setting up an Individual Service Plan (ISP), if applicable. The ISP usually occurs after a 60-day period of the individual being in a new program.
- The Transition Coordinator assures that programming has begun and gives family and individual the name and contact of Adult Service Coordinator.

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 in 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 an address of such person, the record of the special education services being provided to such person, and the expected ate 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

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.

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

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.

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.

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**

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

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 quality 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.

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.

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 Assisance 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.

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 T**o 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

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.

<u>Eligibility Fact Sheet for Adult Autism Spectrum Disorders</u>

In order to be eligible for supports and services from the Department of Developmental Services a person must:

1. Be domiciled in the Commonwealth of Massachusetts.
2. Have a primary diagnosis of Autism Spectrum Disorder ("ASD"), based on the most recent addition of the Diagnostic and Statistical Manual (DSM V).
3. Provide the Department with an evaluation(s) for Autism Spectrum Disorder, completed by a qualified physician or psychologist, that includes standardized diagnostic instruments such as the Autism Diagnostic and Observation Schedule (ADOS), Autism Diagnostic Interview-Revised (ADI-R) the Childhood Autism Rating Scale, 2nd edition (CARS-2), Gilliam Autism Rating Scale 3rd edition (GARS-3), Gilliam Asperger's Disorder Scale (GADS). In cases that an evaluation from a standardized diagnostic instrument is not provided, a diagnostic assessment provided by a qualified physician or psychologist detailing the reasons for the ASD diagnosis must be provided.
4. Have substantial functional impairment in **three** or more areas of the seven areas of major life activities as determined by Adaptive Skill Testing administered by DDS. The seven areas are self-care, expressive communication, receptive communication, learning, mobility, capacity for self-direction, economic self-sufficiency. Adaptive Skill tests such as the Scales of Independent Behavior, Revised (SIB-R), Vineland Adaptive Behavior Scales, 2nd edition (Vineland II) and the Adaptive Behavior Assessment Scale (ABAS) assess the individual's capabilities with respect to daily activities. In some cases, the Department may need additional information to determine if an applicant has substantial functional impairment and may obtain this information by administering an alternative adaptive skill test, the Major Life Activities Questionnaire, and/or require the applicant to attend an in-person interview with the DDS Psychologist.
5. Provide documentation and information that demonstrates that ASD and substantial functional impairment manifested prior to 22 years of age.
6. Provide documentation and information that demonstrate that the developmental disability is likely to continue indefinitely (chronic) and which reflects a need for a combination and sequence of special, interdisciplinary or generic supports or assistance that is lifelong in nature.
7. Provide personal, clinical, psychological, medical/specialty, and educational records that indicate a diagnosis of ASD made through psychological and/or psychiatric evaluations that clearly outline the justification for the differential diagnosis.
8. Provide the reports from previous adaptive assessments.
9. Although <u>IQ is not a relevant determinative factor</u>, providing IQ information is recommended because it helps delineate both the strengths and weaknesses of the individual and assists in support planning.

Eligibility Fact Sheet for Prader-Willi Syndrome

1. Be domiciled in the Commonwealth of Massachusetts.
2. Have a primary diagnosis of Prader-Willi Syndrome, based on medical evidence which includes genetic testing results.
3. Provide personal, clinical, psychological, medical, and educational records that indicate a diagnosis of Prader-Willi Syndrome made through psychological and/or psychiatric evaluations that describe the impact of the disability on the individual.
4. Have substantial functional impairment in **three** or more areas of the seven areas of major life activities as determined by Adaptive Skill Testing administered by DDS. The seven areas are self-care, expressive communication, receptive communication, learning, mobility, capacity for self-direction, economic self-sufficiency. Adaptive Skill tests such as the Scales of Independent Behavior, Revised (SIB-R), Vineland Adaptive Behavior Scales , 2nd edition (Vineland II) and the Adaptive Behavior Assessment Scale (ABAS) assess the individual's capabilities with respect to daily activities. In some cases, the Department may need additional information to determine if an applicant has substantial functional impairment and may obtain this information by administering an alternative adaptive skill test, the Major Life Activities Questionnaire, and/or require the applicant to attend an in-person interview with the DDS Psychologist.
5. Provide documentation and information that demonstrates that Prader-Willi Syndrome and substantial functional impairment manifested prior to 22 years of age.
6. Provide documentation and information that demonstrates that a developmental disability is likely to continue indefinitely (chronic) and which reflects a need for a combination and sequence of special, interdisciplinary or generic supports or assistance that is lifelong in nature.
7. Provide the reports from previous adaptive assessments.
8. Although IQ is not a relevant determinative factor, providing IQ information is recommended because it helps delineate both the strengths and weaknesses of the individual and assists in support planning.

Eligibility Fact Sheet for Smith-Magenis Syndrome

1. Be Domiciled in the Commonwealth of Massachusetts.
2. Have a primary diagnosis of Smith-Magenis Syndrome, based on medical evidence which includes genetic testing results.
3. Provide personal, clinical, psychological, medical, and educational records that indicate a diagnosis of Smith-Magenis Syndrome made through psychological and/or psychiatric evaluations that explain the impact of the disability on the individual.
4. Have substantial functional impairment in **three** or more areas of the seven areas of major life activities as determined by Adaptive Skill Testing administered by DDS. The seven areas are self-care, expressive communication, receptive communication, learning, mobility, capacity for self-direction, economic self-sufficiency. Adaptive Skill tests such as the Scales of Independent Behavior, Revised (SIB-R), Vineland Adaptive Behavior Scales , 2nd edition (Vineland II) and the Adaptive Behavior Assessment Scale (ABAS) assess the individual's capabilities with respect to daily activities. In some cases, the Department may need additional information to determine if an applicant has substantial functional impairment and may obtain this information by administering an alternative adaptive skill test, the Major Life Activities Questionnaire, and/or require the applicant to attend an in-person interview with the DDS Psychologist.
5. Provide documentation and information that demonstrates that Smith- Magenis Syndrome and substantial functional impairment manifested prior to 22 years of age.
6. Provide documentation and information that describes a developmental disability is likely to continue indefinitely (chronic) and which reflects a need for a combination and sequence of special, interdisciplinary or generic supports or assistance that is lifelong in nature.
7. Provide reports from previous adaptive assessments.
8. Although IQ is not a relevant determinative factor, providing IQ information is recommended because it helps delineate both the strengths and weaknesses of the individual and assists in support planning.

The Commonwealth of Massachusetts
Executive Office of Health & Human Services
Department of Developmental Services

Application
Adult Eligibility Determination Ages 22 +

Applicant Information

Full Name: ____ Date: ____________________
Last First MI

Address: ____
Street Number Street Name Apartment/Unit #

____
City/Town State Zip Code

Primary Phone: ____________________ Second Phone: ____________________ Email: ________________________

DOB: ____________________ Gender: ____________________ SS #: ________-_______-_______

Primary Language: ____________________ ________________________ Interpreter services needed? ☐Yes ☐ No
Of Applicant Of Family

Reason for applying: ____

Diagnosis: ____

Authorized Contact
Parent/Guardian/Other

Full Name: ____ DOB: ____________________
Last First MI

Address: ____
Street Number Street Name Apartment/Unit #

____
City/Town State Zip Code

Primary Phone: ____________________ Second Phone: ____________________ Email: ________________________

Primary Language: ________________________ Interpreter services needed? ☐Yes ☐ No

Relationship to Applicant: ____

IMPORTANT – Please Read Carefully

Has Intellectual Disability been determined by evaluation by a licensed psychologist? ☐ YES ☐NO

If 'YES'ATTACH COPIES OF:

- All Available Intelligence/Cognitive Tests ie;
  - Wechsler
  - Stanford-Binet
- Diagnostic Report of any diagnosed developmental condition from a Physician or other medical professional ie;
  - Down Syndrome
  - Fragile X Syndrome
  - Williams Syndrome

Has Autism Spectrum Disorder been determined by evaluation by a qualified practitioner, ie; a licensed psychologist, developmental pediatrician, specialty developmental clinic, or a physician? ☐ YES ☐NO

If 'YES' ATTACH COPIES OF:

- Comprehensive DIAGNOSTIC REPORT from a Physician or Psychologist that details the closely related developmental condition
- For Autism Spectrum Disorder based on age of applicant include an AUTISM DIAGNOSTIC TEST i.e.;
  - Autism Diagnostic Observation Schedule (ADOS),
  - Autism Diagnostic Interview-Revised (ADI-R)
  - Childhood Autism Rating Scale (CARS)
  - Gilliam Autism Rating Scale (GARS),
  - Gilliam Asperger's Disorder Scale (GADS)
- The test(s) should indicate a diagnosis of and Autism Spectrum Disorder
- Reports need to reflect a demonstration of the core symptoms of an Autism Spectrum Disorder
- For genetic developmental disabilities provide the genetic testing and comprehensive medical records

NOTE: A positive M-Chat is not a diagnostic test

The test(s) should indicate a diagnosis of an Autism Spectrum Disorder. Reports need to reflect a demonstration of the core symptoms of an Autism Spectrum Disorder.

Has Prader-Willi Syndrome been determined by evaluation by a medical doctor, hospital, clinic/lab? ☐ YES ☐ NO

If 'YES' ATTACH COPIES OF:

- Genetic Testing Report providing confirmation of Prader-Willi Syndrome
- Attach medical history providing confirmation of Prader-Willi Syndrome

Has Smith-Magenis Syndrome been determined by evaluation by a medical doctor, hospital, clinic/lab? ☐ YES ☐NO

If 'YES' ATTACH COPIES OF:

- Genetic Testing Report providing confirmation of Smith-Magenis Syndrome
- Attach medical history providing confirmation of Smith-Magenis Syndrome

ALL APPLICANTS: Provide copies of documents noted below

REQUIRED DOCUMENTS:

- Proof of MA Domicile– (parents or guardian) ie; MA Driver's License, MA ID Card
- Utility Bill
- Birth Certificate
- Social Security Card
- Health Insurance Card(s) (MassHealth, Medicare, Private Insurance)

IF APPLICABLE PLEASE ALSO PROVIDE:

- Most Recent Early Intervention Plan
- Most Recent IEP and Related Assessments
- Adaptive Skills Reports (if available) –Scale of Independent Behavior- Revised (SIB-R), Adaptive Behavior Assessment System (ABAS), or Vineland II
- Psychological testing including all available IQ and Cognitive tests
- Individual Family Support Plan (IFSP) and developmental assessments
- 504 Accommodation Plan
- Medical and Specialty Assessments

Has a Probate Court appointed a legal guardian for the applicant? ☐ YES ☐NO

If 'YES' please attach a copy of the Guardianship Decree or Conservatorship:

IF SOMEONE ASSISTS YOU WITH THIS APPLICATION:

Please complete the information below if someone other than the applicant or guardian is helping with the application. The person you choose to assist you may be a family member, friend, teacher, counselor, social worker, family support center, etc.

Full Name: ____ Agency: ____________________
Last First MI

Address: ____
Street Number Street Name Apartment/Unit #

____
City/Town State Zip Code

Primary Phone: ______________________ Second Phone: ____________________ Email:_________________________

I give permission to DDS to discuss my application and records with the person named above for the purpose of completing the eligibility determination process.

____________________________________ ____________________________________
Signature of Applicant/Legal Guardian Date

____
Print name of Applicant/Legal Guardian

AUTHORIZATION FOR DDS ELIGIBILITY DETERMINATION

I request that the Department of Developmental Services (DDS) conduct a determination of eligibility for services. This permission is valid until my application is fully processed or unless I notify DDS in writing that I revoke it. This document is being signed by: ☐ Applicant ☐ Guardian

Print Name: ____ Date: ____________________

Signature: ____

If any addresses or phone numbers identified in this application change prior to the eligibility determination please contact your Regional Eligibility Team to inform them of the new information. Applications for eligibility do not go to a Privacy officer

The Commonwealth of Massachusetts

Executive Office of Health & Human Services
Department of Developmental Services

NOTICE OF PRIVACY PRACTICES

THIS NOTICE DESCRIBES HOW PROTECTED HEALTH INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW IT CAREFULLY.

Purpose:
This notice is to inform you about the Department of Developmental Services's privacy practices and legal duties related to protection of the privacy of your medical or health records that we create or receive. This notice also explains your rights regarding your health information and the Department's responsibilities. As explained below, we are required by law to ensure that medical or health information that identifies you is kept private.

If you have any questions about the content of this Notice of Privacy Practices, if you need to contact someone at the Department about any of the information contained in this Notice of Privacy Practices, or if you have a complaint about the Department's Privacy Practices, you may contact the Department's Privacy Office at:

Privacy Officer
Department of Developmental Services
500 Harrison Avenue
Boston, MA 02118
(888) 367-4435, ext. 7717

I. What is Protected Health Information?

Protected Health Information (**PHI**) is information which the Department gathers about your past, present or future health or condition, about the provision of health care to you, or about payment for health care. Whether based upon our confidentiality policies, or applicable law, the Department has a long-standing commitment to protect your privacy and any personal health information that we hold about you. Under federal law, we are required to give you this Notice about our privacy practices that explains how, when, and why we may use or disclose your PHI.

You may request a copy of the notice from any Department of Developmental Services Office. It is also posted on our website at www.dds.state.ma.us.

II. How May the Department Use and Disclose Your PHI?

In order to provide services to you, DDS must use and disclose Protected Health Information in a variety of ways. The following are examples of the types of uses and disclosures of PHI that are permitted *without your authorization*.

Generally, the Department may use or disclose your PHI as follows:

- **For Treatment**: DDS may use PHI about you to provide you with treatment or services. For example, your treatment team members may internally discuss your PHI in order to develop and carry out a plan for your services. DDS may also disclose PHI about you to people or service providers outside the Department who may be involved in your medical care, but only the minimum necessary amount of information will be used or disclosed to carry this out.

- **To Obtain Payment**: DDS may use or disclose your PHI in order to bill and collect payment for your health care services. For example, DDS may release portions of your PHI to the Medicaid program, Social Security Office, staff at the Department, or to a private insurer.
- **For Health Care Operations**: DDS may use or disclose your PHI in the course of operating the Department's facilities, offices, developmental centers and all other Department programs. These uses and disclosures are necessary to run our programs including ensuring that all of our consumers receive quality care. For example, we may use your PHI for quality improvement to review our treatment and services and to evaluate the performance of Department and/or provider staff in caring for you. We may also disclose information to doctors, nurses, technicians, medical students and other personnel as listed above for review and learning purposes. It may also be necessary to obtain or exchange your information with other Massachusetts state agencies.

The law provides that we may use or disclose your PHI *without consent or authorization* in the following circumstances:

- **When Required By Law and For Specific Governmental Functions**: DDS may disclose PHI when a law requires that we report information about suspected abuse, neglect or domestic violence, or relating to suspected criminal activity, or in response to a court order. We may also disclose PHI to authorities that monitor compliance with these privacy requirements. We may also disclose PHI to government benefit programs relating to eligibility and enrollment, such as Medicaid, for workers' compensation claims, and for national security reasons, such as protection of the President.
- **For Public Health and Safety Activities**: DDS may disclose PHI when we are required to collect information about disease or injury, or to report vital statistics to a public health authority, reporting adverse medication reactions, product recalls, or preventing disease.
- **For Health Oversight Activities**: DDS may disclose PHI within the Department or to other agencies responsible for monitoring the health care system for such purposes as reporting or investigation of unusual incidents, and monitoring of the Medicaid program.
- **Relating to Decedents**: DDS may disclose PHI related to a death to coroners, medical examiners, or funeral directors, and to organ procurement organizations relating to organ, eye, or tissue donations or transplants. Information may also be disclosed in relation to internal or external investigations.
- **For Research, Audit or Evaluation Purposes**: In certain circumstances, and under the oversight of a research review committee, DDS may disclose PHI to approved researchers and their designees in order to assist research.
- **To Respond to Lawsuits and Legal Actions**: DDS may share health information about you in response to a court or administrative order, or in response to a subpoena to the extent authorized by state law or federal law, including but not limited to G.L. c. 123B, § 17 (DDS Records Confidentiality); G.L. c. 66A, § 2 (Fair Information Practices Act); G.L. c. 111, § 70(f) (HIV testing); G.L. c. 111B, § 11 (alcohol treatment); and G.L. c. 111E, § 18 (drug treatment).
- **To Avert Threat(s) to Health or Safety**: In order to avoid a serious threat to health or safety, DDS may disclose PHI as necessary to law enforcement or other persons who can reasonably prevent or lessen the threat of harm.

III. Uses and Disclosures of PHI Requiring your Authorization.

For uses and disclosures other than treatment, payment and healthcare operations purposes we are required to have your written authorization, unless the use or disclosure falls within one of the exceptions described above. Authorizations may be revoked at any time to stop future uses/disclosures except to the extent that we have already undertaken an action in reliance upon your authorization.

IV. Limited Uses and Disclosures to Families, Friends, and Others Provided You Do Not Object

We may disclose a limited amount of your PHI to families, friends, or others involved in your care if we inform you about the disclosure in advance and you do not object, as long as the law does not otherwise prohibit the disclosure.

V. Your Preference(s) for How DDS Shares Your Protected Health Information

For certain health information you can inform DDS your preferences for how/what we may share. In these cases, you have both the right and choice to inform DDS to:

- Share information with your family, close friends, or others involved in your care;
- Share information in a disaster relief situation;
- Include your information in a hospital/facility directory;
- Contact you for fundraising efforts.

If you are not able to tell us your preferences, for example if you are unconscious, DDS may share your information if we believe it is in your best interest. We may also share your information when necessary to lessen a serious and imminent threat to health or safety.

VI. Prohibited Disclosures

The Department will never use or disclose your protected health information for marketing purposes, for sale of your information, or for most sharing of your psychotherapy notes unless you have provided your written permission authorizing such. In the case of fundraising, DDS may contact you for fundraising efforts – but you may advise DDS not to contact you again.

VII. Your Rights Regarding Your Protected Health Information

You have the following rights relating to your protected health information:

- **To Obtain a Copy of this Notice of Privacy Practices**: You may ask DDS for a paper copy of this notice at any time.
- **To Inspect and Request a Copy of Your PHI:** Unless access to your records is restricted for clear and documented treatment reasons, you have a right to inspect and obtain a copy of your paper and electronic protected health information upon your written request. A request should be made to the Privacy Officer through your service coordinator or Area Office. DDS will respond to your request within 30 days. If you want copies of your PHI, a charge may be assessed.
- **To Choose Someone to Act for You**: If you have given someone medical power of attorney or if someone is your legal guardian, that person may exercise your rights and make choices about your health information to the extent authorized by law. DDS will respect the requests/choices of your legally authorized representative to the extent authorized by law.
- **To Request Restrictions on Uses/Disclosures:** You have the right to ask that DDS limit how we use or disclose your PHI or request that DDS not use or share certain health information for treatment, payment, or health care operations. The Department will consider your request, but is not legally bound to agree to the restriction if it may affect your care or service provision. If you pay for service or health care item out-of-pocket in full, you can ask that DDS not share that information for the purposes of payment or our operations with your health insurer.

- **To Choose How We May Contact You**: You have the right to ask that DDS send you information at an alternative address or by an alternative means; including request(s) that we contact you by confidential communications.

- **To Request Amendment of your PHI**: If you believe there is a mistake or missing information in our record of your PHI, you may request, in writing, that DDS correct or add to the record. DDS will respond within 60 days of receiving your request. Any denial will state the reason for denial and explain your rights to have the request and denial, along with any statement in response that you provide, appended to your PHI.

- **To Request an Accounting of What Disclosures Have Been Made**: In certain circumstances, you have a right to get a list of when, to whom, for what purpose, and what content of your PHI has been released.

- **To File a Complaint**: If you think DDS may have violated your privacy rights, or you disagree with a decision the Department has made about access to your PHI, you may file a complaint with the DDS Privacy Officer. You may also file a complaint with the U.S. Department of Health and Human Services Office for Civil Rights by sending a letter to 200 Independence Avenue, S.W., Washington, D.C. 20201, calling 1-877-696-6775, or by visiting HHS's Website at: www.hhs.gov/ocr/privacy/hipaa/complaints/. The Department will take no retaliatory action against you if you make such a complaint.

VIII. DDS's Privacy and Security Responsibilities

The Department has the following responsibilities relating to your protected health information:

- **Protect the Privacy of Your Health Information**: DDS is required by law to maintain the privacy and security of your protected health information.

- **Notify You of Breaches**: DDS will contact you promptly if there is a breach of security that may have compromised the privacy or security of your unsecured health information.

- **Notice of Privacy Practices**: DDS must adhere to the duties and privacy practices described in this notice and make copies of such available to you.

- **Authorized Uses and Disclosures**: DDS will not use or share your information other than as described in this notice unless authorized by you in writing. You may also change your mind and revoke your authorization at any time by contacting the Department in-writing.

For additional information see: www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/noticepp.html.

Application and Effective Date:
This notice applies to the use or disclosure of protected health information at all Department Facilities, Offices, Developmental or Regional Centers, and all other Department programs; including the use or disclosure of PHI by individuals or entities engaged in an organized health care arrangement (OHCA) with the Department. Any individual or entity so engaged with DDS in an OHCA shall adhere to DDS's duties and privacy practices as described in this notice.

This notice is effective as of April 14, 2003 (as revised September 1, 2014). The Department reserves the right to make changes to its privacy practices and the terms of this Notice at any time. The new notice will be available upon request, in any DDS Office, and on the Department's website.

The Commonwealth of Massachusetts

Executive Office of Health & Human Services
Department of Developmental Services

Notice of Privacy Practices Acknowledgment Form

Name of Applicant:____

Facility/Region/Area/Program:____

I have received a copy of the DDS Notice of Privacy Practices

Signature: ____Date:_____________
Individual or Personal Representative with legal authority to make healthcare decisions

If signed by a Personal Representative:

Print Name:__________________________________

Role:_______________________________________(Parent or guardian etc.)

Witness:_____________________________________ Date:__________________

This form must be retained for a period of at least six years in the appropriate record in accordance with the DDS Privacy Handbook.

The Commonwealth of Massachusetts

Executive Office of Health & Human Services
Department of Developmental Services

HIPAA NOTICE OF PRIVACY PRACTICES TRACKING FORM

If the Individual has a Personal Representative with legal authority to make health care decisions on the Individual's behalf, the notice must be given to and acknowledgment obtained from the Personal Representative. ***If the Individual or Personal Representative did not return a signed acknowledgment form, staff must document when and how the notice was given to the Individual, why the acknowledgment could not be obtained, and the efforts that were made to obtain it***.

Notice of Privacy Practices given to the Individual on______________ by:
Date

- ❑ Face to face meeting
- ❑ Mailing
- ❑ Email
- ❑ Other___________________

Reason Individual or Personal Representative did not sign acknowledgment form:

- ❑ Individual or Personal Representative chose not to sign
- ❑ Individual or Personal Representative did not respond after more than **one** attempt
- ❑ Email receipt verification
- ❑ Other ____

Good Faith Efforts: The following good faith efforts were made to obtain the Individual or Personal Representative's, if applicable, signature. Please document with detail (e.g., date(s), time(s), individuals spoken to and outcome of attempts) the efforts that were made to obtain the signature.

- ❑ Face to face ____
- ❑ Telephone ____
- ❑ Mailing(s)____
- ❑ Email____
- ❑ Other____

DDS Staff Signature/Title:____

Date: ______________________________

This form must be retained for a period of at least six years in the appropriate record in accordance with the DDS Privacy Handbook.

The Commonwealth of Massachusetts

Executive Office of Health & Human Services
Department of Developmental Services

REQUEST/RELEASE OF INFORMATION FORM

Provider: ____________________________________ Individual: ________________________________
or
Agency: ____________________________________ Address: ___________________________________

Address: ___________________________________ Date of Birth: ______________________________

[ ] I hereby authorize the provider or agency named above to release the following information to the Department of Developmental Services.

[ ] I hereby authorize the Department of Developmental Services to disclose to the above provider or agency or other named entity the following information.

____ Psychological Testing	_____ Complete Record	____Other Service Plan
____ Medical History	_____ Medication History	____Guardianship Documents
____ Educational History	_____ ITP	____Other (Specify)
____ Hospital Reports	_____ ISP	_________________________

Purpose of use or disclosure of information (For example: Medical Care, Legal, Insurance, Personal, Individual's request, etc. must be specific)

____

Any other use of disclosure of this information is prohibited under Massachusetts statutes and Departmental regulations and policies.

I have been informed of the benefits and disadvantages of releasing the above information, and I voluntarily execute release.

____
Signature of Individual

or

____
Signature of Guardian

Date Signed:
____

I understand that I have a right to revoke the authorization at any time. If I revoke this authorization, I must do so in writing and present it to the person/facility/agency that was authorized to release the information. I understand that the revocation will not apply to information that has already been released in response to this authorization.

This authorization will expire ______________________ (date or event – must not exceed one year). I understand that once the above information is disclosed, the recipient may re-disclose it and the information may not be protected by federal or state privacy laws or regulations. I understand that authorizing the use or disclosure of the information identified above is voluntary. I understand that I do not need to sign this form to continue to receive health services from DDS.

____ ________________________

Signature of individual who is the subject of the Information or Guardian Date

____

Print Name

Specially Authorized Releases of Information (please initial all that apply)

_____ To the extent that my medical record contains information concerning HIV antibody and antigen testing that is protected by MGL c.111 S.70F, an HIV/AIDS diagnosis or HIV/AIDS treatment, I specifically authorize release or disclosure of such information.

_____ To the extent that my medical record contains information concerning alcohol or drug treatment that is protected by Federal Regulation, 42 CFR, Part 2, I specifically authorize release or disclosure of such information.

____ ________________________

Signature of individual who is the subject of the Information or Guardian Date

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INSTRUCTIONS:

1. This form must be completed in full (excluding Specially Authorized Releases) to be considered valid.
2. Ensure that the expiration date or event listed on page 2 is practical.
3. **Distribution of copies: Original to provider; copy to individual or personal representative; copy to person/facility/agency making request.**

COMMONWEALTH OF MASSACHUSETTS
DEPARTMENT OF DEVELOPMENTAL SERVICES
Regional Intake and Eligibility
Regional Cities/Towns

DDS Central/West Region
Regional Eligibility Coordinator
140 High Street
Springfield, MA 01105
Intake Line:(413)-205-0940
Fax: (413) 205-1605

CENTRAL/ WEST Cities and Towns:

Adams, Agawam, Alford, Amherst, Ashburnham, Ashby, Ashfield, Ashley Falls, Athol, Auburn, Ayer, Barre, Becket, Belchertown, Bellingham, Berlin, Bernardston, Blackstone, Blandford, Bolton, Boylston, Brimfield, Brookfield, Buckland, Charlemont, Charlton, Cheshire, Chester, Chesterfield, Chicopee, Clarksburg, Clinton, Colrain, Conway, Cummington, Dalton, Deerfield, Douglas, Dudley, East Brookfield, Easthampton, East Longmeadow, Egremont, Erving, Feeding Hills, Fitchburg, Florida, Franklin, Gardner, Gill, Goshen, Grafton, Granby, Granville, Groton, Great Barrington, Greenfield, Hadley, Hancock, Hampden, Hardwick, Harvard, Hatfield, Hawley, Heath, Hinsdale, Holden, Holland, Holyoke, Hopedale, Housatonic, Hubbardston, Huntington, Indian Orchard, Lancaster, Lanesboro, Lee, Leeds, Leicester, Lenox, Leverett, Leyden, Longmeadow, Ludlow, Lunenburg, Medway, Mendon, Middlefield, Miller's Falls, Milford, Millbury, Monroe, Monson, Montague, Monterey, Montgomery, Mt. Washington, New Ashford, New Braintree, New Marlboro, New Salem, North Adams, Northampton, Northbridge, Northfield, North Brookfield, Oakham, Orange, Otis, Oxford, Palmer, Paxton, Pelham, Pepperell, Petersham, Peru, Phillipston, Pittsfield, Plainfield, Princeton, Richmond, Rowe, Royalston, Russell, Rutland, Sandisfield, Savoy, Sheffield, Shelburne, Shirley, Shrewsbury, Shutesbury, Southbridge, South Deerfield, South Hadley, Southampton, Southwick, Springfield, Sterling, Sturbridge, Stockbridge, Sunderland, Sutton, Templeton, Tolland, Townsend, Turner's Falls, Tyringham, Upton, Uxbridge, Wales Ware, Warren, Warwick, Washington, Webster, Wendell, West Boylston, West Brookfield, Westfield, Westhampton, Westminster, West Springfield, West Stockbridge, Whately, Whitinsville, Wilbraham, Williamsburg, Williamstown, Winchendon, Windsor, Worthington, Worcester

<table>
<tr>
<td>DDS Metro Region
Regional Eligibility Coordinator
411 Waverly Oaks
Waltham, MA 02452
Intake Line (781) 314-7513
Fax Number: (781) 314-7539</td>
<td>→
New
Address
as of
1/1/15</td>
<td>DDS Metro Region
Regional Eligibility Coordinator
465 Waverley Oaks Road Suite 120
Waltham, MA 02452
Intake Line: (781) 314-7513
Fax Number: (781) 314-7539</td>
</tr>
</table>

Metro Region Cities and Towns:

Allston, Ashland, Beacon Hill, Belmont, Boston, Brighton, Brookline, Cambridge, Canton, Charlestown, Chelsea, Chestnut Hill, Chinatown, Dedham, Dorchester, Dover, Downtown Crossing, East Boston, Foxboro, Framingham, Holliston, Hopkinton, Hudson, Hyde Park, Jamaica Plain, Marlboro, Mattapan, Medfield, Millis, Natick, Needham, Newton, Norfolk, Northborough, North Dorchester, North End, Norwood, Plainville, Revere, Roslindale, Roxbury, Sharon, Sherborn, Somerville, Southborough, South Boston, South End, Sudbury, Walpole, Waltham, Watertown, Wayland, West Roxbury, Wellesley, Westboro, Weston, Westwood, Winthrop, Wrentham

DDS Northeast Region
Regional Eligibility Coordinator
Hogan Regional Center
PO Box A
Hathorne, MA 01937
Intake Line: (978) 774-5000 x850
Fax Number: (978)739-0420

Northeast Region Cities and Towns:

Acton, Amesbury, Andover, Arlington, Bedford, Beverly, Billerica, Boxborough, Boxford, Bradford, Burlington, Carlisle, Chelmsford, Concord, Danvers, Dracut, Dunstable, Essex, Everett, Georgetown, Gloucester, Groveland, Hamilton, Haverhill, Ipswich, Lawrence, Lexington, Lincoln, Littleton, Lowell, Lynn, Lynnfield, Malden, Manchester, Marblehead, Maynard, Medford, Melrose, Merrimac, Methuen, Middleton, Nahant, Newbury, Newburyport, North Andover, North Reading, Peabody, Reading, Rockport, Rowley, Saugus, Salem, Salisbury, Stoneham, Stow, Swampscott, Tewksbury, Topsfield, Tyngsboro, Wakefield, Wenham, West Newbury, Wilmington, Winchester, Woburn, Westford

DDS Southeast Region **Regional Eligibility Coordinator** **68 North Main Street** **Carver, MA 02330** **Intake Line 508-866-5000** **FAX number 617-727-7822**	→ New address as of 3/1/15	**DDS Southeast Region** **Regional Eligibility Coordinator** **151 Campanelli Drive** **Middleboro, MA 02346** **Intake Line 508-866-5000** **FAX Number 508-866-8859**

Southeast Region Cities and Towns

Abington, Acushnet, Assonet, Attleboro, Avon, Barnstable, Berkley, Bourne, Braintree, Brewster, Bridgewater, Brockton, Carver, Chatham, Chilmark, Cohasset, Dartmouth, Dennis, Dighton, Duxbury, East Bridgewater, Eastham, Easton, Edgartown, Fairhaven, Fall River, Falmouth, Freetown, Gay Head, Gosnold, Halifax, Hanover, Hanson, Harwich, Hingham, Holbrook, Hull, Hyannis, Kingston, Lakeville, Mansfield, Marion, Marshfield, Mashpee, Mattapoisett, Middleboro, Milton, Nantucket, New Bedford, North Attleboro, Norton, Norwell, Oak Bluffs, Orleans, Pembroke, Plymouth, Plympton, Provincetown, Quincy, Randolph, Raynham, Rehoboth, Rochester, Rockland, Sandwich, Scituate, Seekonk, Somerset, Stoughton, Swansea, Taunton, Tisbury, Truro, Wareham, Wellfleet, West Bridgewater, Westport, West Tisbury, Weymouth, Whitman, Yarmouth

Eligibility for DMH Services

KRISTIN M. PALACE, ATTORNEY-AT-LAW

LAW OFFICE OF KRISTIN M. PALACE, TOPSFIELD, MASSACHUSETTS

MAY 2016

What does DMH do?

- Provides mental health support services to clients
- Operates an inpatient hospital system
- Support some families and homeless persons who are not clients

What services does DMH offer?

- Residential and impatient programs
- Case management services
- Community Based Flexible Supports (CBFS)

Transition-age youth: qualifying for adult services

- May be an initial application
- May be a current client, but eligibility as a child does not equal eligibility as an adult

Who is eligible for DMH services?

- 104 CMR 29.00
- Interpretive Guidelines for 104 CMR 29.00: Determining Service Authorization for Children, Adolescents and Adults (December 2009, revised December 2011). Find them here: http://www.mass.gov/eohhs/consumer/behavioral-health/mental-health/applying-for-mental-health-services.html

What are the clinical criteria for adults?

- 18 years of age or older
- Serious mental illness
- Primary cause of a persistent and substantial impairment that interferes with one or more major life activities
- Is expected to continue to cause impairment in the succeeding year

Ref: 104 CMR 29.04(2)(a) and the Interpretive Guidelines

What is a serious mental illness?

- Determined with reference to the DSM IV (regulations have not been updated since the issuance of the DSM-5)
  - Qualifying disorders for adults include:
    - Schizophrenia and other psychotic disorders (but only if not due to a general medical condition and not substance-induced)
    - Mood disorders (but not including dysthymia and only if they are not due to a general medical condition)
    - Anxiety disorders (but only if not due to a general medical condition and not substance-induced)
    - Dissociative Disorders
    - Eating Disorders
    - Borderline Personality Disorder
    - *Note: ADHD is not a qualifying disorder for adults.*

What is a serious mental illness (continued)?

- An serious mental illness cannot be based on symptoms caused primarily by
  - A developmental disorder such as mental retardation, pervasive developmental disorders (such as autism), learning disorders, motor skills disorders, communication disorders, elimination disorders, feeding or eating disorders of infancy or early childhood, tic disorders
  - A cognitive disorder such as delirium, dementia or amnesia
  - A mental disorder due to a general medical condition (e.g., traumatic brain injury)
  - A primary diagnosis of substance-related disorder
- These are disqualifying diagnoses!

What is serious mental illness (continued)?

- Co-occurring disorders

Ref: 104 CMR 29.04(2)(a) and the Interpretive Guidelines

Clinical criteria met? But wait, there's more …

What else is required to receive services?

- Needs of the Applicant
- Are there medical entitlements or insurances?
- Can anybody else provide the services?
- Is there capacity?

Ref: 104 CMR 29.04(3),(4) and the Interpretive Guidelines

Can adverse decisions be appealed?

Some decisions are appealable, some are not…

What is the appeal process?

- Informal conferences
- Reconsideration
- Fair Hearings

Ref: 104 CMR 29.16

Pay attention to the filing deadlines!

They are short: 10, 20, or 30 days depending on the relief sought

Fair hearings

- Hearings are typically convened by independent contractors (all are lawyers)
- Burden of proof is on the applicant
- Applicant must prove that DMH did not have a reasonable basis for its decision
- Standard for proof is a preponderance of the evidence
- Applicants have the right to present evidence
- Need for expert witnesses
- Hearings are not open to the public

Decisions from Fair Hearings

- Written by the Hearing Officer
- Decisions are sent to Commissioner by the Hearing Officer
  - within 20 days
  - findings of fact binding
  - conclusions of law and final decision can be modified
- Decisions are no longer published

New developments…

- New regulations coming:
  - DMH is revising its service authorization regulations
  - Target date for public comment is late summer, early fall of 2016
- New coordination with DDS on cross-over cases

Linda Landry
Disability Law Center

MILCB
May 18, 2016

What is the Social Security Administration (SSA)?

- SSA is a federal agency that administers two cash benefit programs for elders and people with disabilities.
  - Social Security Insurance – Title II
  - Supplemental Security Income – Title XVI

Social Security Administration Benefits for Minor Children

- **Minor child = under age 18**
- **Supplemental Security Income** (SSI) – Title XVI -for disabled or blind children.
- **Social Security Insurance - Title II Minor Child Dependents/Survivors Benefits**–on the wage record of a parent receiving a Social Security benefit or who died insured for Social Security benefits.

Social Security Administration Disability Benefits for Adults

- **Adult = 18 and older**
- Supplemental Security Income (**SSI**) for disabled and blind adults
- Social Security Disability Insurance **(SSD**I) – on the individual's own wage record.
- Social Security Insurance **Dependents' or Survivors' Benefits** – as disabled adult child of parent receiving a Social Security benefit or of parent who died insured for Social Security Insurance benefit

What is Social Security Insurance?

- **Social Security Insurance programs** are those workers earn through FICA on wages.
- These are **not needs-based benefits**.
- People with insured status can get a **disability** or **retirement** benefit on their own wage records.
- Certain **dependents or survivors of insured wage earners** may be eligible for benefits on the wage earner's record.
- Immigration status rules are less strict than for SSI.

What is Social Security Disability Insurance (SSDI)?

- SSDI is a Social Security insurance program that pays a monthly cash benefit to people who are:
- Disabled = same definition of disability as with SSI (for adults), AND
- Insured = worked and earned Social Security credits by paying FICA taxes close to disability onset. For most adults, this means working for about 5 of the last 10 years before disability onset.

Earning Credits to Become Insured for SSDI

- Earn 1 credit for $1260 earned in 2016. $4880 earned = 4 credits.
- Maximum of 4 credits/year.
- Must pay FICA taxes. No credits for “under the table” work.
- Special Rule for Young Adults under age 31:
  - To be insured for SSDI, adults under 24 years old only need to earn 6 credits in the 3 years before disability onset. 20 CFR 404.130

What Are Child Disability Benefits?

20 CFR 404.350 - .368

- Title II Dependent or Survivors benefit.
- Paid on the wage record of a parent who receives Title II disability or survivors benefits, or, who has died.
- The adult child (18 or older) must have continuously met the adult disability standard
  - since prior to attaininga ge 22, and
  - be unmarried, unless spouse receives Title II disability benefits.

More About Social Security Insurance Benefits

- The amount of a Social Security Insurance benefit is personal to the wage earner. It generally depends on how long the wage earner worked and paid FICA – and how much s/he earned.
- Dependents'/survivors' benefits are based on the wage earner's amount.
- The average SSDI benefit is about $1000 per month, but the benefit could be much lower or higher. In 2016, the maximum is $2639.

Social Security Disability Insurance and Medicare

- Medicare comes with Social Security Insurance Disability benefits
- But, most must be eligible for benefits for 24 months. Exceptions are ALS and ERSD (End Stage Renal Disease).
- SSDI recipients may also qualify for MassHealth, but they must apply for it.

What is SSI?
(Supplemental Security Income)

- A Social Security program that pays a monthly cash benefit to:
  - Disabled children under 18
  - Disabled or blind adults ages 18-65
  - People 65 and older
- SSI is **needs-based** with **strict income and asset rules**:
  - Must have less than $2000 in countable assets to get SSI
  - Income of parents (for minors), and other sources counts
- No work history needed to get SSI.
- SSI has strict immigration status requirements.
- SSI comes with MassHealth (Medicaid).

SSI Overview

- The **maximum monthly payment** is set each year by SSA. States can choose to add a supplement. 2016 Federal Benefit Rate is $733. With the max. Mass. state supplement, $114.39, the maximum 2016 in is $847.39.
- Monthly cash SSI benefit amount depends on:
  - whether recipient is disabled, blind, or aged;
  - the recipient's living arrangement; and
  - whether the recipient has any other income.

State Supplement Program Payment (SSP)

- Massachusetts pays and administers an SSI state supplement.
- “SSI” means the SSI Federal Benefit Rate (FBR)
- “SSP” refers to the state supplement.
- The amount of SSP varies with eligibility category and living arrangement.
- SSA’s COLA does not apply to the SSP

SSP, continued

- SSP regulations are at 106 CMR 327.010 – 327.090 http://www.mass.gov/eohhs/docs/dta/g-reg-327.pdf
- SSP customer Service Center, 877-863-1128
- Website, www.mass.gov/hhs/ssp

How Much SSI Can You Get?

- It depends on:
  - Whether you are disabled, blind or aged.
  - What other income you have.
    - Wages?
    - Money from other sources?
  - What your living situation is.
    - Do you live alone & pay your own rent & food?
    - Do you share food & rent costs with roommates?
    - Do you live with your parents?
    - Are you married or single?
  - **All changes must be reported to SSA**

SSI Income Counting Rules Overview

- Income is counted in the month it is received.
- Not all income is counted to reduce SSI.
- Only about half of **earned** income is counted. All but $20 of **unearned** income is counted.
- Some unearned and in-kind income **exclusion**s:
  - Medical care and services
  - **Bills paid for the recipient – if paid directly to the vendor (for non-shelter/food items**)
  - Replacement of income that was lost, stolen or destroyed
  - Housing assistance such as public housing or a Section 8
  - Proceeds of a loan

SSI Resource Definition

- A resource is cash on hand, other personal property, or real property that an individual:
  - owns or has an ownership interest in;
  - has the legal right to dispose of and convert to cash; and
  - is not legally restricted from using for support
- **Income remaining after the month of receipt becomes a resource**. Think of income twice – in both month of receipt and in subsequent months.
- 20 C.F.R. 416.1201

SSI Asset Counting Rules Overview

- Not all assets are countable resources.
- Some examples of assets that are not counted:
  - The home that the individual lives in.
  - Household goods and personal effects.
  - One automobile of any value.
  - Life insurance (face value up to $1500).
  - Burial funds (up to $1500); burial spaces.

SSI Suspense v. Termination 20 CFR 416.1320 - .1336

- SSI ineligibility for a non-disability reason (e.g., income or resources) does not immediately result in eligibility termination; it results in suspense of benefits instead.
- Excess funds can be spent down on the SSI recipient.
- Suspense for 12 consecutive months results in termination. 20 CFR 416.1335
- The difference is that a termination requires a reapplication to regain eligibility.

Spending Down Excess Funds and Transfer Of Assets Penalty

- Any resource that is transferred for less than fair market value will result in a "transfer of assets penalty" causing ineligibility for a maximum of 36 months.
- POMS SI 01159.000 https://secure.ssa.gov/apps10/poms.nsf/lnx/0501150000

SSI Residence and Citizenship Overview

- Residence in U.S. for 30 days required.

- Citizen and/or alien status requirements for benefits payable after 12/1/96.

SSI Overview

- Earliest possible payment date is the first of the month <u>after</u> the month of application.

- In Massachusetts, SSI eligibility automatically confers Medicaid (MassHealth) eligibility.

They could not get SSI
Why?

What Is "Disabled" for SSI? Children Under 18

- The child must have a physical or mental condition, or a combination of conditions, that results in "marked and severe functional limitations." This means that the condition(s) must very seriously limit your child's activities.
- The child's condition(s) must have lasted, or be expected to last, at least 12 months; or must be expected to result in death.
- The child must not be earning more than $1130/month gross, or $1820 if blind, in 2016.

Disability Determination for Children under Age 18

- Does the child’s medical condition(s) meet the criteria in SSA’s medical listings

- If not, SSA does an individualized assessment of the child’s ability to function in age appropriate manner in several domains. SSA compares the child’s functioning to that of an average child of the same age without a disability.

Why Some Children with Severe Disabilities Do Not Get SSI

- For children under 18, SSI counts some of their parents' income and assets as theirs. This is called **deeming**. If the parents' income or assets are too high, the child will not qualify for SSI.

- When kids turn 18, SSI counts only the child's income and assets.

New SSI Eligibility Potential at Age 18

- When a young person turns age 18, SSA no longer counts his/her parent's income and assets against SSI eligibility.
- This means that some 18 yr olds who were not previously SSI eligible can be eligible and should consider applying.

Child Support and SSI

- If a parent gets child support for a child on SSI, the child support counts as the child's income.
- For kids under 18, SSI counts 2/3 of monthly child support. So, if parent gets $600 a month in child support for a minor child, $400 of it counts as the child's income and the child's SSI is reduced by $400.
- For kids 18 and older, SSI counts all the child support as the child's income except $20.

SSA Adult Disability Definition – It's the Same for SSI and SSDI

- The inability to engage in any substantial gainful activity (SGA) by reason of medically determinable physical and/or mental impairment(s) which can be expected to last for a continuous period of not less than 12 months or result in death.
- SGA = earning $1090/month gross, or, if blind, $1820 in 2015.

Overview of Adult Disability Analysis (1)

- Medical (MD) evidence of mental and/or physical conditions
- That have lasted or are expected to last at least one year or result in death, AND
- That result in functional limitations (physical and/or mental), AND

  - ➢prevent the individual from performing past work, AND
  - ➢prevent the individual from performing other work on a sustained basis in light of his age, education, and work history.

Residual Functional Capacity (RFC)

- A person’s maximum ability to do sustained work-related physical and mental activities in a work setting, on a **regular and continuing basis**, despite limitations caused by their impairment(s) and related symptoms.
- “Regular and continuing basis” means 8 hours/day 5 days/week or equivalent.
- Must consider total limiting effects of all impairments, even non-severe ones and all relevant evidence in the record.

Proving Disability

- MD evidence preferred, often necessary to establish diagnosis.
- Treating source evidence often due great weight.
- BUT other evidence, especially from professional sources is very important, especially as to nature & severity of functional limitations.

Social Security Administration Appeal Process

- Levels of appeal:
  - **Reconsideration** -to appeal application decision
  - **Administrative Law Judge (ALJ) Hearing** - to appeal Reconsideration
  - **Appeals Council Review** - to appeal ALJ decision
  - **Federal Court**
- 60-day deadline for filing appeals; SSA assumes notices received within 5 days of date on notice. Can file late for good cause.
- Forms at www.ssa.gov/online/forms.

SSI Benefits and Work

- For SSI recipients the issue is the amount of gross monthly earnings and how much is countable.
- **A good estimate**: about half of gross monthly earnings count against the SSI benefit.
- The formula is $65 plus half of the rest.
- The $20 general income deduction can also be used if not used on unearned income.

SSI and Work – Effect of Wages Example 1

- Carmen lives by herself in a section 8 apartment and receives $847.39 ($733 = $114.39) in SSI/SSP disability benefits in 2016. She has no other income.

- She takes a job paying $985 in gross wages per month.

- What is the effect on her SSI?

SSI and Work – Effect of Wages Example 1

- **$450** of Carmen's gross monthly wages is **countable** [$985 – 85 ($65 + $20) divided by 2 = $450].
- Carmen's SSI benefit will be **$283** ($733 - $450 = $283).
- She'll still be eligible for her $114.39 in SSP
- Her total gross monthly income will be **$1382.39** ($985 + $283 + $114.39).

SSI and Work- Effect of Wages Example 2

- Anne lives with housemates paying her pro rata share of the household's food & shelter-related expenses. She receives $763.40 ($733 = $30.40) in SSI/SSP disability benefits in 2016. She has no other income.
- She takes a job paying $885 in gross wages per month.
- What is the effect on her SSI?

SSI and Work – Effect of Wages Example 2

- $450 of Anne's gross monthly wages is countable [$985 – 85 ($65 + $20) divided by 2 = $450].
- Anne's SSI benefit will be $283 ($733 - $450 = $283).
- She'll stay eligible for her $30.40 SSP.
- Her total gross monthly income will be $1298.40 ($985 + $283 + $30.40).

SSI and Work – Effect of Wages Example 3

- Joe lives by himself in a rent subsidized apartment and receives $520 in SSDI, $233 in SSI disability benefits, and $114.39 in SSP per month in 2016.
- He also takes a job paying $985 per month in gross wages.
- These wages make him SSI and SSP ineligible.

SSI and Work – Effect of Wages Example 3

- $520 SSDI - $20 = $500 countable SSDI
- $985 gross wages - $65 = $920.

  $920 divided by 2 = $460 countable wages.
- $500 + $460 = $960, more than the $847.39 maximum SSI and SSP amounts ($733 + $114.39 =$847.39)for his living arrangement.
- But, Joe's total gross monthly income with the wages is $1505 ($520 + $985).

SSI Benefits and Work - IRWE Deductions

- **Impairment Related Work Expenses** - (IRWEs) can be deducted from gross monthly wages.
- IRWE deductions are **in addition** other permitted earned income deductions

SSI Benefits and Work
IRWE Deductions

- IRWEs are:
  - impairment related items and services
  - needed in order to work
  - out of pocket
  - paid in a month when working
- Examples: service animal expenses; uncovered medical expenses like co-pays or acupuncture; work transportation needs made necessary due to disability

Blind Work Expense Deductions

- Examples of BWEs
  - service animal expenses;
  - transportation to and from work;
  - taxes;
  - attendant care services;
  - visual aids;
  - translation of materials into Braille;
  - lunches;
  - professional association dues.

Student Earned Income Deduction

- The student earned income deduction is for SSI recipients who:
  - are under age 22, and
  - are regularly attending school.

Student Earned Income Deduction

- In 2016, the student earned income deduction is $1780 per month up to $7180 per calendar year.
- This deduction is **in addition** to other permitted earned income deductions.

Plan to Achieve Self-Support (PASS)

- A PASS allows SSI recipients to save $$ for a vocationally achievable goal.

- If PASS is approved by SSA and exactly followed, income and resources put in the PASS account don't count for SSI.

Plan to Achieve Self-Support (PASS)

- Set aside income and resources to use to achieve an occupational goal.
- Occupational goal must be feasible.
- PASS must be in writing and include budget (& business plan if self-employment).

How Does Work Affect SSDI ?

The rules for SSDI and work are completely different than for SSI. It's like being on another planet.

What Happens When SSDI Recipients Work?

- It's much more complicated than with SSI and completely different.
- 9 month trial work period
- 36 month extended period of eligibility
- Substantial Gainful Activity
- (These rules also apply to the Child Disability Dependent/Survivor benefit)

What You Need to Know About SSDI When Going to Work

- Have I completed my 9-month **Trial Work Period**? When?
- If yes, when does/did my 3-year **Extended Period of Eligibility** end?
- Are my countable earnings above the **Substantial Gainful Activity** level?

SSDI & Trial Work Period

- 9 service months
- Keep your benefits no matter how much you earn as long as you remain medically disabled
- 1 Trial Work Period per period of disability

Trial Work Period

- You only use a trial work month if you perform "services," meaning:
  - Earn $810 or more gross wages per month in 2016.
  - No deductions apply.

After the EPE – The Cliff

- If you have SGA level wages at end of the 36 months, SSDI terminates.
- Otherwise, SSDI terminates with the first month of SGA after the 36th month.
- In 2016, SGA is presumed with $1130 in gross monthly earnings, or, $1820 for those eligible on the basis of blindness.

Extended Period of Eligibility An All or Nothing Deal

- 36 months starting after the last (9th) month of the Trial Work Period.
- Get SSDI in months where no SGA.
- Get no SSDI in months with SGA level earnings.

Expedited Reinstatement

- A faster way to reapply for benefits if you have lost eligibility because of work.
- Apply within 60 months of losing SSI or SSDI due to work.
- Can receive up to 6 months of prospective benefits while SSA completes the formal eligiblity determination.

Duty to Report: SSI/SSDI Recipient & Rep. Payee

- Must report to SSA anything that might affect benefit eligibility and amount as soon as the change happens.
- Report by the 10th day of the month after the month of the change.
- Representative payees share reporting duties with benefit recipients.
- Be sure to be able to show that you reported.
- This can help avoid or reduce overpayments.

SSI and Medicaid – “MassHealth

- In Massachusetts, the Medicaid program is called MassHealth.
- Medicaid is a needs–based health coverage program.
- **In Massachusetts, all SSI recipient are automatically eligible for MassHealth.**

MassHealth: Home and Community Based Waivers

- Some MassHealth recipients may be eligible for Home and Community Based Waiver services.
- Package of services includes some that MassHealth does not otherwise cover.
- Income eligibility for HCBW is 3x the SSI federal benefit rate ($2199 in 2016). Also SSI-like asset limit $2000/$3000.

MassHealth CommonHealth: Adults

- To be eligible, an adult must:
  - Meet the SSI disability standard;
  - Be ineligible for MassHealth Standard; and
  - Work an average of 40 hrs per month (or 240 hrs over a 6 month period); **OR**
  - Meet one-time deductible; and
  - Pay a premium based on income & family size.

MassHealth CommonHealth: Children (under age 18)

- To be eligible, a child must:
  - Meet an SSI disability standard;
  - Be ineligible for MassHealth Standard (i.e., family income over 200% federal poverty guidelines (fpg) up to age 1, 150% fpg age 1 – age18); and
  - Pay a premium based on income & family size.

Keeping MassHealth While Working
Loss of SSI

- Does MassHealth eligibility stop if an SSI recipient makes too much money to receive SSI benefits, even with all the deductions available?
- Probably not – individuals should be eligible for “1619b Medicaid” or MassHealth CommonHealth.

SSI Benefits and Work
1619b Medicaid

- 1619b Medicaid is continued Medicaid for SSI recipients who make too much money to be eligible for an SSI cash payment
- These individuals can be "deemed" eligible for MassHealth - if they continue to meet all other SSI eligibility criteria, including the asset limit, AND if they meet the "**Medicaid Test**."

SSI Benefits and Work
1619b "Medicaid Test"

- The individual must:
  - have been eligible for SSI for at least 1 month;
  - remain medically disabled;
  - need MassHealth in order to work; and
  - have insufficient income to replace Medicaid and SSI.

Medicare

- Medicare comes with Social Security Insurance benefits based on disability, e.g., SSDI, the Disabled Adult Child benefit for dependents or survivors.
- Most must wait for 24 months of eligibility for Medicare. Exceptions: those with ALS or End Stage Renal Disease.

Medicare and Work

- For SSDI recipients, Medicare continues as long as the individual is eligible for SSDI (after the 24 mo. waiting period).
- Medicare continues through the trial work period and EPE.
- Medicare can continue for several years after SSDI SGA termination, as long as the person remains medically disabled.

Eligibility Redeterminations

- SSI non-disability eligibility reviews – about yearly.
- Continuing disability reviews for children and adults.
- Age-18 reviews for SSI eligible children who turn age 18.

Continuing Disability Reviews

- Continuing Disability Reviews:
  - SSA must review disability eligibility of most SSI/DI recipients at least every 3 years.
  - Recipients deemed likely to medically improve may be reviewed more frequently.
  - Recipients deemed permanently disabled are reviewed less frequently, usually every 7 yrs.
  - Medical Improvement Standard used.

Age -18 Reviews

- Children must be redetermined under the adult disability standard within one year from the date they attain age 18.
- SSA will notify a recipient that a review has begun and will invite the recipient to submit evidence of continuing disability.
- This NOT a CDR – it is a determination as to whether the young person is eligible under the adult disability standard.

CDR and Age 18 Review Appeal Process

- Terminations are appealable and continuing benefits available through ALJ hearing if appeal filed within 10 days and continuing benefits requested at each step of appeal. Otherwise, appeal period is 60 days.

- If lose on appeal, no collection overpayment if good faith belief that individual was still disabled and eligible for benefits and cooperated with the process. Must file Request for Waiver form.

Free Counseling on Work and Benefits

- Free service available to SSI and SSDI recipients who are working or planning to work;
  - Project Impact, for MRC customers, 800-734-7475
  - BenePlan, for all others, 877.YES.WORK

Representative Payee Policy

- Every beneficiary has the right to manage his/her own benefits.
  - Unless s/he is a minor or has been adjudicated legally incompetent.
- However, SSA may determine that a beneficiary's interests are better served with a representative payee.
- 20 C.F.R. 404.2001, 416.601, GN 00502.010

Representative Payee Responsibilities

- Use benefits on behalf of beneficiary only.
- Determine payment manner and purposes, under SSA guidelines.
- Properly receive & account for benefits & expenditures.
- Notify SSA of any change affecting benefits.
- Submit accounting at SSA request.
- Notify SSA of any change affecting performance.
- 20 CFR 404.2035, 416.635, POMS GN 00600.000 *et seq.*

Other Ways a Representative Payee Can Help

- Help beneficiary establish a budget and make financial decisions.
- Explain Social Security or SSI benefits.
- Ensure beneficiary is aware of current and retroactive payments.
- Help beneficiary find other services.
- Negotiate with creditors and landlords.
- Recommend another if/when can no longer serve.
- POMS GN 00502.114B.

Qualifying to Receive Benefits Without a Payee

- A beneficiary found incapable by SSA and in need of a payee can request to have his/her capability redetermined.
- SSA will interview the beneficiary face to face and will contact the current payee
- The beneficary should present medical, other professional and/or lay evidence of ability to manage benefits in his/her best interests.

Useful Websites

- www.socialsecurity.gov
- www.ssa.gov/payee
- www.mass.gov/MassHealth
- www.masslegalservices.org
- www.cms.hhs.gov/home/medicare.asp

Medicaid Waivers and Other Useful Programs for Disabled Younger Adults and Children

Mass NAELA Webinar Series on Special Needs Planning
Session 4 of 7
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Annette M. Hines
Special Needs Law Group of Massachusetts, P.C.
Mark W. Worthington
Professor, Western New England University School of Law

Introduction

- Most of us elder law attorneys understand Institutional Medicaid, the Frail Elder Waiver, PACE, and also somewhat how MassHealth Standard can help the non-elderly disabled.
- Less of us understand how other MassHealth Waivers and certain MassHealth programs can also help the non-elderly disabled.

Introduction

- The Big Picture
  - Who MassHealth helps, and who it doesn't
- The Programs – Eligibility [these slides – the rest of the issues on this slide are discussed orally]
- The Programs – Benefits
- Connection and Relation to DDS, Real Lives, etc.
- Concluding Remarks

For Those Who Would Otherwise be Institutionalized

- One set of Waivers and Programs we are covering today are for those who would otherwise be institutionalized, and how they relate to the non-elderly disabled
  - Home & Community Based Services Waivers (HCBSW)
  - Kaileigh Mulligan
  - PACE (Program for All-inclusive Care of the Elderly)

Waiver? What is this "Waiver"?

- Statute provides CMS can issue Medicaid Waivers to states in certain respects. The primary ones are:

- Section 1115 Research & Demonstration Projects
  - States can try different ways to deliver the same or greater levels of services for the same or lower cost. 5 year demonstration period, renewable.
- Section 1915(b) Managed Care Waivers
  - States can apply for waivers to provide services through managed care delivery systems or otherwise limit people's choice of providers.
- Section 1915(c) Home and Community-Based Services Waivers
  - States can apply for waivers to provide long-term care services in home and community settings rather than institutional settings. Must demonstrate same or lower cost as institutionalization. Services can include: standard medical services (including but not limited to case management, homemaker, home health aide, personal care, adult day health services, habilitation (both day and residential), and respite care), non-medical services, and other types of services that may assist in keeping people in non-institutional settings. Transfer of asset penalties apply.

Other Programs

- The other set of programs we discuss today are not specifically for those who would be “otherwise institutionalized”, and how these relate to the non-elderly disabled.
  - Work Waiver
  - AFC (Adult Foster Care)
  - PCA (Personal Care Attendant)

Otherwise Institutionalized – Elderly Only

- Frail Elder Waiver (a HCBS Waiver)
- PACE

These are the ones most elder law attorneys are most familiar with. Although only for older persons, briefly:

Otherwise Institutionalized – Elderly Only

- Frail Elder Waiver – 130 CMR §519.007(B)
- Eligibility
  - 60 or older
  - If under 65, permanently & totally disabled
  - In need of nursing facility services (130 CMR §456) and would otherwise be institutionalized
  - Financial
    - Income and assets of spouse disregarded
    - Less than $2,000 countable assets
    - Less than 300% Federal Benefit Rate income, or you are in "six month deductible land"
    - *Regulations state* that transfer of asset penalties apply.

Otherwise Institutionalized – Elderly Only

- PACE – 130 CMR §519.007(C)
- Eligibility
  - 55 or older
  - If under 65, permanently & totally disabled
  - In need of nursing facility services (130 CMR §456)
  - Financial
    - Income and assets of spouse disregarded
    - Less than $2,000 countable assets
    - Less than 300% Federal Benefit Rate income, otherwise tortuous six-month deductible should apply but in practice much easier system of ratable deductible over each month.
    - *Regulations state* that transfer of asset penalties apply.

Otherwise Institutionalized – No or Low Minimum Age

- HCBS Waivers
  - Intellectual Disability
  - Young Children with Autism
  - Traumatic Brain Injury
  - Acquired Brain Injury
  - Money Follows the Person
- Kaileigh Mulligan

HCBSW – Financial Eligibility

- Note that all HCBS Waivers have the same financial eligibility requirements (except for the Young Autism Waiver):
  - Income and assets of spouse disregarded
  - Less than $2,000 countable assets
  - Less than 300% Federal Benefit Rate income, or six-month deductible
  - Transfer of asset penalties apply

HCBSW – Financial Eligibility

- *Important Note: Disregard of spousal assets for HCBS Waivers appears scheduled to disappear sometime around October to December 2016, thanks to the Affordable Care Act. See Susan Levin's post to the MassNAELA listserv July 14, 2016 (the day after this Webinar).*

HCBSW - Intellectual Disability

- 130 CMR §519.007(D)
- (1) Adult Residential Waiver
  - Receive residential habilitation and other specified waiver services in a provider-operated 24-hour supervised residential setting
- (2) Community Living Waiver
  - Receive certain waiver services, other than residential habilitation, at home or in the community
- (3) Adult Supports Waiver
  - Receive certain waiver services, other than residential habilitation, at home or in the community

HCBSW - Intellectual Disability

- Eligibility for any of the three requires:
  - Intellectual or developmental disability by DDS standards
  - Certified by MassHealth to be “in need of inpatient care at an intermediate-care facility for the mentally retarded”
  - 18 or older, if under 65 permanently and totally disabled
  - Financial
    - Income and assets of spouse disregarded
    - Less than $2,000 countable assets
    - Less than 300% Federal Benefit Rate income, or six-month deductible
    - Transfer of asset penalties apply
  - Each is a Capitated Program

HCBSW - Intellectual Disability

- Adult Residential Waiver Eligibility also requires
  - Needs one or more DDS services under Adult Residential HCBSW
  - Needs residential habilitation
- Community Living Waiver Eligibility also requires
  - Needs one or more DDS services provided under, and only under, Community Living HCBSW
- Adult Supports Waiver Eligibility also requires
  - Needs one or more DDS services provided under, and only under, Adult Supports HCBSW

HCBSW –
Young Children with Autism

- 130 CMR §519.007(E)
- Receive certain waiver services at home or in the community
- Eligibility
  - Under age 9, on MassHealth Standard
  - Certified by MassHealth to be "in need of inpatient care at an intermediate-care facility for the mentally retarded" and would otherwise be institutionalized
  - Confirmed diagnosis of an autism spectrum disorder (which includes autistic disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS), Rhett's syndrome, childhood disintegrative disorder, and Asperger's)
  - Can be safely served in the community
  - No asset test
  - Capitated Program

HCBSW –
Traumatic Brain Injury

- 130 CMR §519.007(F)
- Receive specified waiver services in the home or community
- Eligibility
  - Has Traumatic Brain Injury
  - Certified by MassHealth to be in need of nursing facility services or chronic or rehabilitation hospital services
  - 18 or older, if under 65 permanently and totally disabled
  - Needs Mass Rehab Commission services under this Waiver
  - Able to be safely served in the community
  - Financial
    - Income and assets of spouse disregarded
    - Less than $2,000 countable assets
    - Less than 300% Federal Benefit Rate income, or six-month deductible
    - Transfer of asset penalties apply
  - Capitated Program

HCBSW – Acquired Brain Injury

- 130 CMR §519.007(G)
- (1) Residential Habilitation Waiver
  - Receive residential habilitation and other specified waiver services in a provider-operated 24-hour supervised residential setting
- (2) Non-Residential Habilitation Waiver
  - Receive specified waiver services, other than residential rehabilitation, in the home or community

HCBSW – Acquired Brain Injury

- Eligibility for either:
  - 22 or older, if under 65 permanently and totally disabled
  - Acquired, after reaching the age of 22, a brain injury including, without limitation, brain injuries caused by external force, but not including Alzheimer's disease and similar neuro-degenerative diseases, the primary manifestation of which is dementia
  - Certified by MassHealth to be in need of nursing facility services or chronic disease or rehabilitation hospital services
  - Inpatient in a nursing facility or chronic disease or rehabilitation hospital with a continuous length of stay of 90 or more days at the time of application for the waiver
  - Financial
    - Income and assets of spouse disregarded
    - Less than $2,000 countable assets
    - Less than 300% Federal Benefit Rate income, or six-month deductible
    - Transfer of asset penalties apply
  - Capitated Program; open enrollment period

HCBSW – Acquired Brain Injury

- Residential Habilitation Waiver also requires
  - Not expected to incur annual MassHealth expenditures in excess of the individual cost limit specified in the Residential Habilitation Waiver
  - Needs residential habilitation under the Residential Habilitation Waiver
  - Is able to be safely served in the community within the terms of the Residential Habilitation Waiver

HCBSW – Acquired Brain Injury

- Non-Residential Habilitation Waiver also requires
  - Not expected to incur annual MassHealth expenditures in excess of the individual cost limit specified in the Non-Residential Habilitation Waiver
  - Needs residential habilitation under the Non-Residential Habilitation Waiver
  - Is able to be safely served in the community within the terms of the Non-Residential Habilitation Waiver

Money Follows the Person

Purpose: Get you out of the Nursing Home and back into the Community

Three Types (one 1115 Waiver and two HCBS Waivers):

- Section 1115 Demonstration Waiver
- 130 CMR §519.007(H)(1) – Residential Supports Waiver
- 130 CMR §519.007(H)(2) – Community Living Waiver

Money Follows the Person

- Section 1115 Demonstration Waiver
- Provides supports while still in nursing home or hospital, such as housing-search assistant, assessments for assistive technology, financial assistance buying furniture, first month's rent, and setting up utilities.
- Demo can provide limited assistance once out of the Facility.
- Hat tip to Boston Center for Independent Living.

HCBSW – Money Follows the Person

- 130 CMR §519.007(H)(1) – Residential Supports Waiver
  - Receive residential support services and other specified waiver services in a 24-hour supervised residential setting
- 130 CMR §519.007(H)(2) – Community Living Waiver
  - Receive specified waiver services, other than residential support services, in the home or community

HCBSW – Money Follows the Person

- Eligibility for either of the MFP HCBS Waivers:
  - 18 or older, if under 65 permanently and totally disabled
  - Certified by MassHealth to be in need of nursing facility services, chronic disease or rehabilitation hospital services, or, for participants 18 through 21 years of age or 65 years of age and older, psychiatric hospital services
  - Inpatient in a nursing facility, chronic disease or rehabilitation hospital, or, for participants 18 through 21 years of age or 65 years of age and older, psychiatric hospital with a continuous length of stay of 90 or more days, excluding rehabilitation days
  - Must have received MassHealth benefits for inpatient services, and be MassHealth eligible at least the day before discharge
  - Financial
    - Income and assets of spouse disregarded
    - Less than $2,000 countable assets
    - Less than 300% Federal Benefit Rate income, or six-month deductible
    - Transfer of asset penalties apply
  - Each is a Capitated Program; open enrollment period

HCBSW – Money Follows the Person

- Residential Supports Waiver also requires
  - Must be assessed to need residential habilitation, assisted living services, or shared living 24-hour supports services within the terms of the MFP Residential Supports Waiver
  - Is able to be safely served in the community within the terms of the MFP Residential Supports Waiver
  - Is transitioning to the community setting from a facility, moving to a qualified residence, such as a home owned or leased by the applicant or a family member, an apartment with an individual lease, or a community-based residential setting in which no more than four unrelated individuals reside.

HCBSW – Money Follows the Person

- Community Living Waiver also requires
  - Needs one or more of the services under the MFP Community Living Waiver;
  - Is able to be safely served in the community within the terms of the MFP Community Living Waiver; and
  - Is transitioning to the community setting from a facility, moving to a qualified residence, such as a home owned or leased by the applicant or a family member, an apartment with an individual lease, or a community-based residential setting in which no more than four unrelated individuals reside.

Kaileigh Mulligan

- 130 CMR §519.007(A).
- Purpose: to enable severely disabled children to stay home
- Nationally known as a "Katie Beckett" waiver program, this is a Section 1115 waiver.

Kaileigh Mulligan

- Eligibility – Non-financial
  - Child under age 18
  - Meets definition of Social Security disabled
  - Requires Hospital or Nursing Home level of care (see very detailed definitions at 130 CMR §519.007(A)(3) and (A)(4)).
  - MassHealth determination that
    - care provided outside an institution is appropriate; and
    - the estimated cost paid by the MassHealth agency would not be more than the estimated cost paid if the child were institutionalized.

Kaileigh Mulligan

- Eligibility - Financial
  - Less than $2,000 countable assets
    - Program has no transfer of asset penalties
  - Income less than $72.80/month, otherwise a deductible
  - Assets and Income of Parents not counted

CommonHealth Work Waiver

- 130 CMR §505.004(B); §519.012
- A disabled person under age 64 and ineligible for MassHealth Standard (typically because over-income) may be eligible for CommonHealth, which requires a premium payment (130 CMR §506.011(B)(2))
- CommonHealth (itself a Section 1115 Waiver program) normally requires a one-time deductible if over age 18.

CommonHealth Work Waiver

- BUT if work 40 hours or more per month, then:
  - NO one-time deductible
  - NO age limit (can be age 65 and over)
  - NO income test (except to determine premium)
  - NO asset test

Adult Foster Care

- 130 CMR §408
- Eligibility
  - Disabled child age 16 or older on MassHealth Standard or CommonHealth
  - Adult Foster Care Caregiver receives $1,500/mo
  - Caregiver cannot be parent of minor, or legal guardian

Personal Care Attendant

- 130 CMR §422
- Eligibility
  - MassHealth Standard or CommonHealth
  - PCA services are prescribed by doctor or nurse practitioner responsible for member’s care
  - Assistance is needed with 2 or more ADLs
  - MassHealth has determined that PCA services are medically necessary
  - MassHealth has granted a prior authorization for PCA services.

Personal Care Attendant

- Cannot get both PCA and certain other MassHealth benefits, such as AFC.
- Caregiver cannot be parent of minor, or legal guardian
- PCA will be covered in more depth as part of our next session in this Webinar series on July 27th: "Medically Fragile Children and Adults"

Plan Ahead

Remaining Sessions in this Webinar Series on Special Needs Planning:

- Wednesday, July 27 – Medically Fragile Children and Adults
- Wednesday, August 24 – Guardianship for Younger Adults
- Bonus Session: Wednesday, September 28 – A Special Needs Practice and the Special Needs Family
- Saturday October 1, 2016: In-person Special Needs Planning Unprogram, location TBD

Community Based Intensive MassHealth Services

Tim Sindelar

tim@hshmlaw.com

In Home Nursing Supports

- Home Health generally: 130 CMR 403
- Complex Care – 130 CMR 403.302
- Nursing service: 130 CMR 403. 420(A)

Community Case Management

Services include:

- a comprehensive needs assessment performed by a pediatric nurse case manager
- An in-person visit with the member
- A member-focus, clinically appropriate service plan
- A single point to access community long term care services: nursing, home health aide, personal care attendant, physical, occupational and speech and hearing therapy, durable medical equipment, and oxygen and respiratory equipment
- An expedited service authorization plan
- Case manager participation in hospital and institutional discharge planning meetings.
- Insurance identification and referrals
- Case collaboration with other care providers, as appropriate

Complex Care

- Complex-Care Member – a MassHealth member, under the age of 22 at enrollment, whose medical needs, as determined by the MassHealth agency or its designee, are such that he or she requires a nurse visit of more than two continuous hours of nursing services to remain in the community. 130 CMR 403.402

Comprehensive Needs Assessment

The comprehensive needs assessment identifies, but may not be limited to identifying

- (a) services that are medically necessary, covered by MassHealth, and required by the member to remain safely in the community;
- (b) services the member is currently receiving; and
- (c) any other case management activities in which the member participates

Service Plan

The case manager

- (a) develops a service plan, in consultation with the member, the member's physician, the primary caregiver, and where appropriate, the home health agency that
- (i) lists those MassHealth-covered services to be authorized by the case manager;
- (ii) describes the scope and duration of each service;
  - (iii) lists service arrangements approved by the member or the member's primary caregiver; and
  - (iv) informs the member of his or her right to a hearing, as described in 130 CMR 403.414

Clinical Criteria for Nursing Services

- A nursing service is a service that must be provided by a registered nurse, or by a licensed practical nurse or licensed vocational nurse under the supervision of a registered nurse, to be safe and effective, considering the inherent complexity of the service, the condition of the patient, and accepted standards of medical and nursing practice.

- 130 C.M.R. § 403.420(B)(1)

Criteria for Nursing Services

- (1) there is a clearly identifiable, specific medical need for nursing services;
- (2) the services are ordered by a physician for the member and are included in the physician's plan of care;
- (3) the services require the skills of a registered nurse, or of a licensed practical nurse or licensed vocational nurse under the supervision of a registered nurse, in accordance with 130 CMR 403.420(B);
- (4) the services are medically necessary to treat an illness or injury in accordance with 130 CMR 403.410(C); and
- (5) prior authorization is obtained where required in compliance with 130 CMR 403.413.

Evaluation Tool Concerns

- Technical, long, complex, confusing;
- Unpredictable or varying needs;
- Treatment of time for skilled assessments
- Over-emphasis on "multi-taksing";
- Fails to comprehend the reality of RN shifts/scheduling
- Insufficient deference to treating physicians

General Limits On PDN

- (F) Least Costly Form of Care. The MassHealth agency pays for home health agency services only when services are no more costly than medically comparable care in an appropriate institution and the least costly form of comparable care available in the community.
- (G) Safe Maintenance in the Community. The member's physician and home health agency must determine that the member can be maintained safely in the community.

Specific Limits

- (1) A member may be eligible for up to a maximum of 112 hours of continuous skilled nursing services per calendar week if he or she meets the criteria for nursing services as stated in 130 CMR 403.420 and has obtained prior authorization from the MassHealth agency or its designee.

Exceptions to 112 hours per week cap

- (2) Members may be eligible on a short-term basis, not to exceed three months, for continuous skilled nursing services over the maximum amount if such additional services are determined to be medically necessary by the MassHealth agency or its designee, and at least one of the following criteria is met:
- (a) the member’s physician has submitted a determination in writing that the death of the member will likely occur within three months and a request has been made that the member be permitted to die at home;

More exceptions to 112 hours per week cap

- (b) the member has repeated, acute exacerbations of, or develops acute complications in addition to, a chronic medical condition that would result in an acute hospitalization;
- (c) the member has been discharged following a lengthy acute hospitalization and may be clinically unstable in the community. Before providing such services, the home health agency must telephone the MassHealth agency or its designee with information about the need for such additional services on a weekly basis; or
- (d) the member meets the clinical criteria for nursing services and the primary caregiver is temporarily unavailable because he or she:
- (i) has an acute illness or has been hospitalized;
- (ii) has abandoned the member or has died within the past 30 days;
- (iii) has a high-risk pregnancy that requires significant restrictions; or
- (iv) has given birth within the four weeks prior to a request for additional services.

Litigation Strategies re CAP

- For those under 22 EPSDT
- Over 22 - ADA challenges. See:, e.g.
  - Radaszewski v. Maram, 383 F.3d 599, 608, 616 (7th Cir. 2004)
  - Grooms v. Maram, 563 F.Supp.2d 840 (N.D. Ill. 2008) a
  - Sidell v. Maram, 2009 U.S. Dist. LEXIS 131324 (C.D. Ill. 2009).
  - Jones v. Dept. of Public Aid, 373 Ill.App. 3d 184, 867 N.E.2d 563 (2007);

Adult Foster Care

- Adult Foster Care (AFC), also called Adult Family Care, is a program for frail elderly adults and adults with disabilities who cannot live alone safely. AFC adults live with trained paid caregivers who provide daily care. Caregivers may be family members (except legally responsible relatives), or non-family members.

- The program is for adults who need daily help with personal care, but want to live in a family setting rather than in a nursing home or other facility. The caregiver provides meals, companionship, personal care assistance, and 24-hour supervision. Caregivers may be individuals, couples, or larger families.

- Caregivers receive up to $18,000 per year from MassHealth to provide care to MassHealth members who otherwise would need institutional care. Service providers, including a social worker and registered nurse, train the caregiver and provide ongoing support.

- Note: Adult Foster Care / Adult Family Care (AFC) now includes the pilot project, Enhanced Adult Family Care (EAFC).

AFC Eligibility

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

AFC Levels of Care

- **Level I** is for people who need daily assistance with at least one of the following activities of daily living (ADL): bathing, dressing, toileting, transferring from one position to another, ambulating (walking or wheelchair assistance), or eating
- **Level II** is for people who need assistance with three or more ADLs; or two or more ADLs, plus caregiver intervention for one or more of these behaviors: wandering, resisting care, being physically or verbally abusive, or socially inappropriate or disruptive behavior.

AFC Caregivers

- Caregivers can be family members or non-family members. However, caregivers cannot be spouses, parents of minor children, or legally responsible relatives.

- Caregivers must be approved by the program (interview, references, CORI check), and be able to provide 24-hour supervision.

Group Adult Foster Care

- Group Adult Foster Care (GAFC) is a MassHealth program that pays for personal care services for eligible seniors and adults with disabilities who live in GAFC-approved housing. Housing may be a GAFC assisted living residence or other GAFC housing. To qualify, residents must be eligible for MassHealth and need help with at least one daily personal care task such as bathing or dressing.

- GAFC only pays for the cost of personal care services and medication management when you live in approved housing. It does not pay housing costs.

Group Adult Foster Care Eligibility

- be at least 22 years old
- be income eligible for MassHealth Standard
- live in an assisted living facility or other housing that participates in GAFC
- need daily assistance with one or more personal care tasks such as bathing, dressing, toileting, meal preparation, and/or moving about
- have a physician's statement of your condition
- be screened and approved for the program

Personal Care Attendant (PCA) cont.

- Population Served: Serves eligible members of all ages and disabilities.
- Other conditions/limitations: All PCA services require prior authorization from MassHealth or designee; members must appoint a surrogate if they are assessed as requiring a surrogate to manage the PCA program; PCA services for the Department of Developmental Services (DDS) eligible members who receive residential supports from DDS must be provided in accordance with Interagency Service Agreements (ISA's) between EOHHS and DDS.
- Program Manager: Betsy Connell, Barbara Barrows

Personal Care Assistants

- approval from your doctor for PCA services;
- a chronic or permanent disability that prevents you from performing your own personal care; and
- a need for physical (hands-on) assistance with at least two of seven activities of daily living (ADLs) (mobility, bathing/grooming, dressing/undressing, passive range-of-motion exercises, taking medications, eating, and toileting).

Who can Be PCAs

- must be legally authorized to work in the United States
- must be able to understand and carry out your instructions
- cannot be your spouse, legally responsible relative, or your surrogate (or parent/foster parent if the MassHealth member is a minor)
- must be willing to be trained and supervised by you or your surrogate

Durable Medical Equipment (DME) and Oxygen/Respiratory

130 CMR 409.000 and 427.000

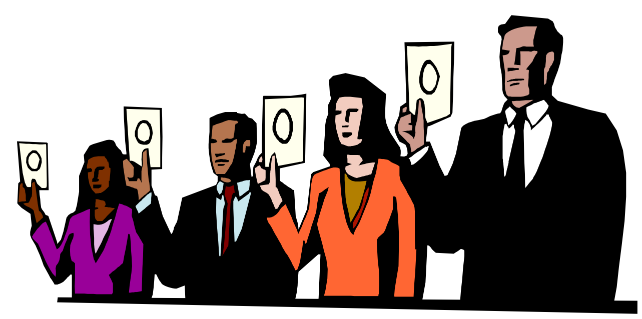
- **Description**: Provides members with medically necessary equipment, accessories, or supplies in member's home. Certain customized DME may be provided to members in nursing facilities. Services include the purchase, rental, and repair of customized equipment, mobility equipment, absorbent products, Personal Emergency Response System (PERS), enteral and parenteral products, and oxygen and respiratory equipment, and instruction in its use, as appropriate. Other insurance covers DME/Oxygen.
- **Member Eligibility**: MassHealth regulations at 130 CMR 450.105 define the coverage types for DME and Oxygen.
- **Providers**: 22 Oxygen & Respiratory providers and 161 DME providers, not including pharmacies who provide certain DME. Providers may specialize in the provision of certain DME. For example, there are currently 4 DME providers in Massachusetts who specialize in provision and service of customized mobility equipment.
- **Population served**: All ages.

Durable Medical Equipment (DME) and Oxygen/Respiratory cont.

- **Other Conditions/Limitations:** Services must be medically necessary in accordance with regulations and guidelines. Many products/services have maximum allowable units. Non-covered services are specified in the regulation. Prior authorization is required for many products/services. Covered service codes, modifiers, service limitations, and prior authorization (PA) requirements are listed in the *DME and Oxygen Payment and Coverage Guidelines Tool* available on the MassHealth website.
- **Program Manager:** Lynda Scully

Appeals

- **Every member has the right to an appeal a decision made by the Division**
- **The appeal must be filed in a timely manner.**
- **The form to appeal is on the back of the division's notice.**
- **Or a member may obtain a *"Request for a Fair Hearing"* form.**
- **Some members may be entitled to aid pending until their appeal is heard.**
- **Mail your appeal request form to the *Board of Hearings at 2 Boylston St., Boston, MA 02116* or fax to (617) 210-5820.**
- **Questions about a notice or how to ask for an appeal should be directed to a MassHealth Enrollment center at 1-888-665-9993.**



Maxim Healthcare Services

Haven Andrews-Area Vice President

History of Maxim Healthcare in MA

- Started as Centrus Premier Home Care based in Plymouth in 1988 by Jean Coughlin & Paul Egan
- Centrus was acquired by Maxim in 2005
- Changed name to Maxim Healthcare on 1/1/16
- We specialize in long term medically complex home care services.
- In MA this is called Private Duty Nursing or Continuous Skilled Nursing
- We provide both skilled and personal/unskilled care
- Patient Census: 54% Adult/46% Pediatric
- Typical Patients require trach care, ventilator management, g-tube care, seizure management, and other complex medical needs

Six Branch Locations

1. Plymouth
2. Taunton
3. Needham
4. Wilmington
5. Worcester
6. West Springfield

Contact us Today and Experience the Maxim Difference in Massachusetts

TAUNTON
350 Myles Standish Blvd., Suite 102
Taunton, MA 02780
Phone: 508-622-3225
Fax: 855-696-7517
Toll Free: 855-218-7219
E-mail: tauntonhh@maxhealth.com

PLYMOUTH
225 Water St., Suite A-150
Plymouth, MA 02360
Phone: 508-747-3521
Fax: 877-394-4763
Toll Free: 800-698-8200
E-mail: plymouthbranchhh@maxhealth.com

WILMINGTON
226 Lowell St., Suite B7
Wilmington, MA 01887
Phone: 978-658-3092
Fax: 855-696-7518
Toll Free: 866-492-5289
E-mail: wilmingtonma@maxhealth.com

NEEDHAM
110 Second Ave.
Needham, MA 02494
Phone: 781-400-7080
Fax: 866-914-5859
Toll Free: 877-606-2946
E-mail: bostonhh@maxhealth.com

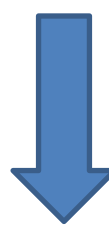
SPRINGFIELD
25 Capital Dr., Suite 25
West Springfield, MA 01089
Phone: 413-746-3711
Fax: 866-941-4299
Toll Free: 866-547-2782
E-mail: springfieldoffice@maxhealth.com

WORCESTER
770 West Boylston St., Unit A
Worcester, MA 01606
Phone: 508-754-8205
Fax: 855-415-4967
Toll Free: 866-492-3734
E-mail: worcesterma@maxhealth.com

WWW.MAXIMHOMECARE.COM

Patient Intake Process

- Referral from facility, family member, law firm, advocate, community based worker, or CCM.



- We would gather all patient demographics, potential payers, and clinical information.
- Sometimes the patient has already been referred to CCM, other times we would make the referral.
- CCM completes their assessment and issues authorization

Patient Intake Process

- At this point we are investigating all potential payers
- **MassHealth is always the payer of last resort**

- We would complete benefit check for all primary insurance and potentially long term care insurance benefits.

- Very few Primary health insurance plans will pay for Private Duty Nursing so MassHealth usually ends up paying.

Patient Intake Process

- Primary Insurances that will at times carry PDN benefit:

1. Cigna
2. United
3. Tricare
4. Some BCBS Plans
5. VA
6. Aetna
7. Worker's Compensation

Patient Intake Process

- We would always first submit a request to the primary insurance.
- Most of the times we receive a denial.
- After denial is received we can bill MassHealth.
- CCM will complete assessment on periodic basis and either increase, decrease, or keep authorization the same.

Admission

- 1-3 hour process
- Scheduling will start and be ongoing process
- Personality Fits-Biggest challenge
- Agency on call 24/7 for any type of clinical or scheduling needs
- Patient has the right to change caregivers at their discretion
- Patient can work with multiple providers. This is called “co-vending”
- Nursing is not guaranteed. Some agencies are better than others.
- **There must be some form of a back-up caregiver**

Trends in Medically Complex Nursing in MA

- Hours don't seem to be getting cut as much as they did in the past by CCM. Change since the assessment tool.
- Increase in the number of the Adult patients. Different set of challenges.
- More families have seemed to improve their advocacy skills and networks
- Getting all hours filled. MassHealth hasn't increased their reimbursement rates in over 10 years.
- Challenge drawing legislator and administration attention

MFP Program

- Maxim is also a provider for the state's "Money Follows the Person Program"
- Designed to get patients who have been in a facility for 90+ Days
- Transition Coordination is included with the program including-house search, home modification, social supports
- Many patients receive 40+ hours per week. Mainly unskilled services but can be combined with PDN

Trends with the State

- State just introduced new PA process for patients receiving Home Health Aide Services and Intermittent Nursing
- Patients hours are getting cut.
- Many are appealing and working with the disability law center.
- One of these stories was covered by Fox 25 News

http://www.myfoxboston.com/news/special-needs-services-cut-as-state-investigates-suspected-fraud/259933537

Maxim Healthcare Services

- Statewide Capability
- Almost 30 Years of Experience
- Dedicated Recruitment and Clinical Teams
- Diversified Service Offering including PDN, Intermittent Services, and Personal Care/Unskilled Services
- Primary Focus on those patients who have long term care needs in the Community
- Experts in the Market

Maxim Healthcare Services

- I'm happy to consult anytime
- Haven Andrews, Area Vice President

haandrew@maxhealth.com

252-327-0995

Search for me on LinkedIn.

Special Needs Practice
and the
Special Needs Family

Webinar Presentation for MANAELA

by

Seunghee Cha

September 28, 2016

Special Needs Practice

- What is it? What is so "special" about a special needs practice?
- How is it similar to and different from elder law or traditional estate planning?
- Substantive areas of law
- Ethical issues: Who is the Client?
- The business side of the practice

Similarities

- Estate planning
- Long-term care concerns:
  (housing, health care, day services)
- Capacity issues
- Guardianship/Conservatorship (when less restrictive alternatives are not viable)
- Estate/Probate/Trust administration
- Tax planning

Differences

- Planning for the future
  - Clients' goals
  - Reasonable expectations
  - Likely outcomes
- Diverse beneficiaries
- Housing solutions
- Role of siblings
- Government agencies/benefits
  - Department of Developmental Services
  - Department of Children and Families
  - Special education
  - Department of Mental Health
  - Social Security Administration
  - Medicare/Medicaid/MassHealth
  - HUD/Massachusetts Dept. of Housing and Community Development
  - Department of Transitional Assistance (SNAP)
  - Federal and state veteran's benefits

Substantive Areas of Law

- Estate planning
- Guardianship/Conservatorship
- Special education
- Advocacy for governmental benefits and services
  - SSI/SSDI eligibility
  - DDS and/or DMH eligibility
  - MassHealth/Medicaid
  - Section 8
  - Food stamps
- Health Insurance
- Trust administration (fiduciary standards & investing)
- Settlement planning (working with PI attorneys)
- Domestic relations (advising family law attorney)
- Civil Rights/Constitutional law
- Employment
- Litigation

Ethical Issues

- Who is the client?

  Conflicts of interest
  - "Typical" conflicts
  - Conflicts that evolve over time
  - Multiple family members with disabilities

- Client's/beneficiary's capacity

  Ongoing assessment
  Maintaining confidentiality
  Protecting client

- Rights of persons with disability

Developing the Practice

- Know your client's needs.

- Engage in "special needs" communities.

  Family-oriented associations
  (ARC, autism support groups, Downs Syndrome Congress, local parent advisory groups for public school districts)

  Professional groups
  - Academy of Special Needs Planners (ASNP)
  - Special Needs Alliance
  - Stetson University National Special Needs Conference

- Educate.

- Determine scope of practice.

- Identify your ideal client.

Questions or Comments?

Seunghee Cha
Bulkley, Richardson and Gelinas, LLP

7 N. Pleasant Street
Second Floor
Amherst, MA 01002
(413) 256-0002
scha@bulkley.com

Amherst Springfield Boston

Autism, Disability, Adulthood: The Real Story

Susan Senator
susansenator.com
@susansenator

"In this book…the wonderful Susan Senator gives voice to those who are too often voiceless—folks with ASD who seek what they deserve—lives of purpose and possibilities."—Ron Suskind, author of *Life Animated, A Story of Sidekicks, Heroes and Autism*

AUTISM ADULTHOOD

Strategies and Insights for a Fulfilling Life

SUSAN SENATOR

Author of *Making Peace with Autism*

Why Do Families Fear Adulthood and Special Needs?

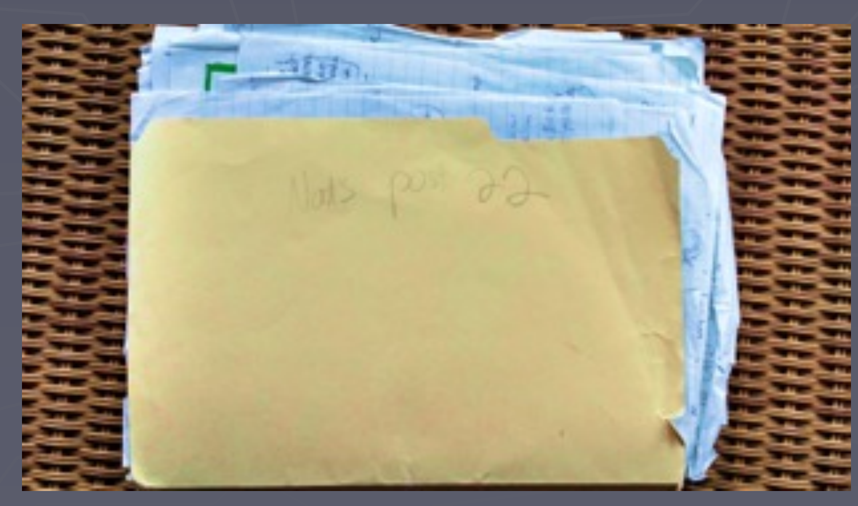
Graduation: End of the Mandate

What do people do after?

Plan for *your* kid

…Write it ALL down!

(Start a folder)



Find or Be a Supportive Peep

(Other families)

Buy Mentors a Coffee

Our guys need tools for planning

Nathaniel Isaac Batchelder

Objective: To work at a job with at least one well-defined task, preferably having to do with organizing and storing.

Education: May Center, Randolph, Massachusetts. Graduated 2011 with distinction.

Experience

November 2011 – Present: Stockperson, CVS Drugstore. Duties involve stocking all coolers with drinks, keeping area clean of spills.

2009 – 2011: Coupon Messenger and Package Assembler, Papa Gino's Pizza. Responsible for disseminating advertisement flyers throughout local neighborhood. Also in charge of assembling large volumes of pizza and entree boxes and stacking them up when finished. Worked with very few breaks.

2007-2011: Delivery, Office, and Cafeteria Assistant, May Center. Multiple responsibilities include carrying messages from school to corporate employees; entering data into PCs; taking snack orders for classrooms, assembling orders, and delivering to the classrooms; setting up and wiping down counters and tables before and after lunch. Took joy in completion of all tasks.

2006-2007: Delivery Assistant, Meals on Wheels. Responsible for carrying meal trays into homes of elderly and disabled. Friendly and professional demeanor maintained at all times.

Other Relevant Experience: Sorting, washing, and folding laundry; partial vacuuming;

"Live in 'parment"

— Nat

I can live on my own

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www.autismhousingpathways.net

Visualize: Home and Day

- Live with parent? Semi-independent, or independent?
- Staffing needs/training?
- Roommate preferences?
- City, town, suburb, farm?
- Any particular culture/theme/activities?
- Work? Learn? Play? Experiment?

Lifestyle Options

Juniper Hill Farms roommates at the Farmers' Market

Customize if you can

The "Higashi Homes" of Charles River Arc

The "Chinese Home" of Advocates, Inc.

Less Traditional Home Options

Farmsteads
Communities, “Villages”
Shared Living
Adult Family Care

Watch Out for The New Medicaid Rules!

Traditional Day Options

- Bridgewell's Rosewood Program
- Charles River's ACES Program
- Nashoba Learning Group Program
- Autism Services Association Work Program

See ADDP.org for more ideas
Ask your DDS liaison, too

Or… Make It Up

Rising Tide Car Wash

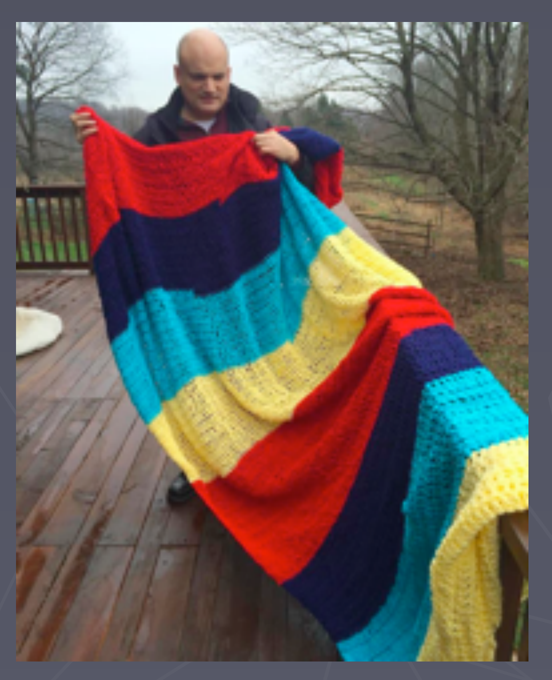
Anthony At Your Service

Memory Stones by Pete

Blankets By Brad

HandwritingRepair.com

Puzzles Bakery
Chocolate Spectrum
The Power Café
Kevin's Lawnmowing
The Teaching Hotel
Sam's Art
Scott's Poetry



But…Are You Your Brother's Keeper?

Be honest with the siblings

Offer choices

BUT

Give them their own lives

Finding Caregivers

- State agency (DDS, Mass Rehab, DMH)
- Service provider
- Local public school teachers/aides
- Universities, community colleges
- Church groups
- The people in your life
- Your children and extended family

You and Your Agency: Your New BFF

- Present your vision and goals
- Know your negotiables
- Know your bottom line
- Be positive
- Ask questions/follow up

Things Do Go Wrong

- Doing business with friends
- Losing staff
- Miscommunication
- New behavior(s)
- Medical issues

Change Happens

Nat: from group home to shared living…

And now back home.

Regrouping

- Give yourself time to heal
- Seek out supports
- Learn the new options
- Find respite
- Learn from what happened
- Let it go – let him go

Don’t Fear The Reaper

Instead,
Cultivate a Community
Grow Future Caregivers

It’s Never Over…

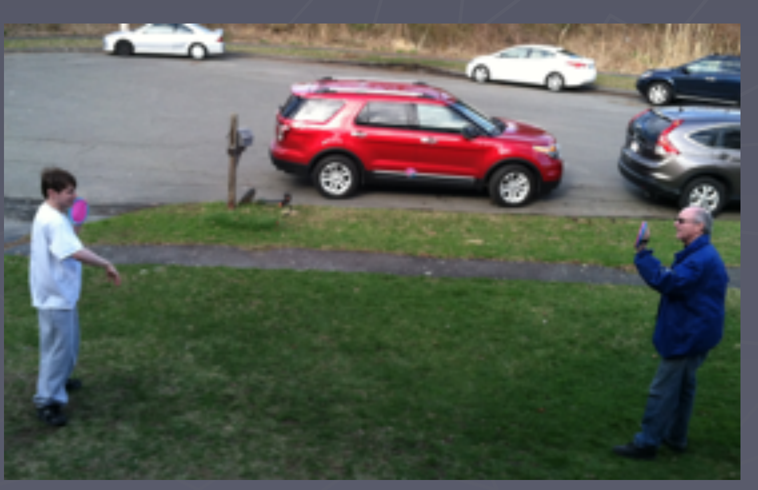
But, yeah, that’s life.

Find Ways To Enjoy It!

Make his community yours

Let him do his thing

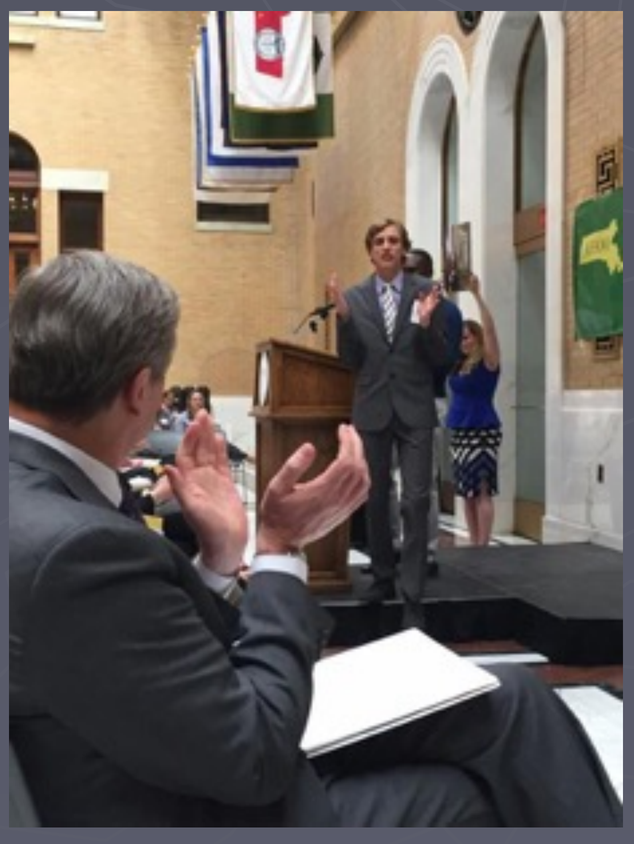
Be silly together



Stay connected

Remember, Growth Happens at ANY AGE

Susan and her brother Alan



Nat and his governor

It's Not Easy, But You *Can* Bridge The Cliff

Because you are not alone!

FIRST STEPS AND BEYOND:
Incorporating Shared Decision Making in Massachusetts Mental Health Services

Report and Recommendations from the 2009 Summit

August 20, 2010

Jonathan Delman, JD, MPH, PhD (cand.)
Mary Ellen Foti, MD
Lisa Mistler, MD, MS

Tamar Skolnick

While the construct of compliance can serve to silence and conceal the complex treatment decision-making processes of people with long-term disorders, shared decision-making is predicated on breaking silence and enhancing dialogue between practitioners and clients.

Pat Deegan[1],
Pat Deegan, Phd & Associates, LLC,

A note from Dr. Foti… "As the State Medical Director of the MA Department of Mental Health, I represent our practitioners and practices. Seeing patients as true partners and expert in their history and health can be challenging. Simply put, we were not trained that way. However, we have the motivation and competence to change – what is needed are effective pilot programs, demonstrations, and system wide trainings that model shared decision making and effectively address providers' concerns."

A note on language from Jonathan Delman… "There is no universal terminology to describe the people who have receive(d) psychiatric services even among those of us with lived experience of mental illness and/or distress. When discussing the provider-person relationship, I tend to use the term "client" as my best shorthand. This is because I am an attorney, and I was taught that I have an ethical duty to zealously represent my clients according to their wishes."

Executive Summary

ation in the recovery process and a shared decision-making
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- On June 25th 2009, Consumer Quality Initiatives (CQI) and the Massachusetts Department of Mental Health (DMH) held a policy summit in Waltham Massachusetts entitled: "*Shared Decision Making in Mental Health Services: First Steps towards a Statewide Approach*." Over 100 members of various stakeholder groups attended, watched the plenary presentations, and participated in the afternoon break-out groups.
- "Shared decision-making" has been defined as "an interactive process in which physicians [providers] and patients [clients] simultaneously participate in all phases of the decision-making process and together negotiate a treatment to implement". It is now considered a cornerstone of recovery-oriented mental health services.
- Recent studies show that a large majority of people with mental illnesses want to be active participants in treatment decision making and are capable of doing so.
- While summit participants agreed that SDM is a desired norm of mental health service provision, it's not commonly seen in practice, and in fact there are significant barriers to achieving SDM.
- Participants identified several barriers to achieving SDM in MA mental health, including:
    - SDM challenges the current norms and attitudes of provider agency operations and staff practices, requiring new policies and trainings to overcome staff resistance.
    - Providers often assume that a client wants to maintain a current level of participation in decision making, even though the client may want more.
    - Clients will have various perspectives on the notion of participation in treatment decision making, often arising from their cultural background.
    - Many people, regardless of their mental status, are not comfortable making choices, particularly when there is little support and information.
    - We are still in the process of identifying the most effective and feasible client decision support tools.
    - Peer specialists have the potential to serve as effective decision coaches, but we are only beginning to learn how to successfully include peers specialists as part of treatment teams.
- Based on these findings, the plenary presentations, and the reports of the breakout groups, we recommend the following first steps for establishing SDM in Massachusetts:
    - Call to Action: Policy Leaders Send a Clear Message that SDM is Critical to High Quality Care
    - Establish a Multi-Stakeholder SDM Task Force, and Seek Funding for It
    - Create a SDM Website for Massachusetts
    - Conduct a Series of Stakeholder Needs Assessments
    - Develop a Workforce Training Strategy
    - Formalize the Role of the Peer Specialist in Providing Decision Support
    - Address Risk/Liability Concerns, and Propose Legislation
    - Address Racial and Ethnic Factors in SDM

Introduction

Over the last decade, the public mental health system in the United States has begun to shift from a traditional, medical model of care, toward the provision of "recovery-oriented" services. This movement has been driven by consumers and other stakeholders who observed that the traditional service system has focused primarily on symptom reduction and client stability, thereby failing to foster a sense of encouragement and hope among consumers.[2] The traditional approach has not included consumers and family members as equal partners in the treatment process. [3]

The recovery-oriented approach to mental health care goes beyond symptom management by supporting clients to "live, work, learn, and participate fully in their communities."[4] Recovery-oriented practitioners identify and promote an individual's strengths. They respect a person's right to make his or her own decisions, and they emphasize relapse prevention and crisis planning.[5] The recovery model of care embraces the "dignity of risk," where the possibility of success outweighs the fear of failure within a system that supports and values every person.[6] The recovery movement gained momentum in 2003 with the establishment of the President's New Freedom Commission on Mental Health, and with publication of the Commission's report, *Achieving the Promise: Transforming Mental Health Care in America.*[7]

Shared Decision Making (SDM) has been defined as "an interactive process in which physicians [providers] and patients [clients] simultaneously participate in all phases of the decision-making

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Endnotes

[2] Anthony, W. A., Cohen, M. R., Farkas, M., & Gagne, C. (2002). Psychiatric rehabilitation. Boston, MA: Center for Psychiatric Rehabilitation.,

[3] Id.

[4] President`s New Freedom Commission on Mental Health: Reports. (2003, July 22). *President`s New Freedom Commission on Mental Health*. Retrieved July 23, 2009, http://www.mentalhealthcommission.gov/reports/reports.htm

[5] Jacobson N, Curtis L: Recovery as policy in mental health services: strategies emerging from the states. Psychiatric Rehabilitation Journal 23(4):333-341.

[6] Deegan PE, Drake RE (2006). Shared decision making and medication management in the recovery process. *Psychiatric Services, 57*, 1636-1639.

[7] Id at 3.

process and together negotiate a treatment to implement."[8] As stated in the President's New Freedom Commission report, SDM with regard to treatment and services is a foundation of the recovery-oriented approach.[9]

On June 25th 2009, Consumer Quality Initiatives ("CQI") and the Massachusetts Department of Mental Health ("DMH") held a policy summit in Waltham, Massachusetts entitled, "*Shared Decision Making in Mental Health Services: First Steps Towards a Statewide Approach."* Over one hundred invited guests gathered to learn about the principles of SDM, and to discuss the opportunities and challenges of its implementation in Massachusetts. Attendees included mental health providers, consumers, family members, researchers, policy leaders and other government officials. Financial support for the summit was provided by the Robert Wood Johnson Foundation's Community Health Leaders program.[10]

This White Paper reviews early efforts to strengthen the role of the consumer in treatment decision making; it describes SDM and its benefits and challenges; and it summarizes the proceedings of the SDM summit. Finally, it presents a series of recommended first steps for incorporating SDM in Massachusetts' mental health services. The White Paper and its recommendations draw extensively from the presentations and discussions that took place at last year's summit. The authors call for bold changes and improvements to our mental health delivery system.

Background

- Early Endeavors at Consumer Involvement in Mental Health Decisions in Massachusetts
- What is Shared Decision Making?
- Benefits of SDM
- Barriers to SDM
- Overcoming Barriers with Decision Supports
- A Visual Summary of SDM

Early Endeavors at Consumer Involvement in Mental Health Decisions in Massachusetts

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[8] Charles, CA., Whelan, T., Gafni, A., Willan, A., & Farrell, S. (2003). Shared treatment decision making: What does it mean to physicians? *Journal of clinical oncology*, *21*(5), 932-936.

[8], Id at 3.

[10] Author Jonathan Delman was a 2008 recipient of a Robert Wood Johnson Community Health Leader award. http://www.rwjf.org/pr/product.jsp?id=36028#content.

Consumers of mental health services in Massachusetts have, for many years, voiced concerns about the lack of information they receive from their psychiatrists regarding their general treatment, and their medications in particular. In 1987, a group current and former mental health consumers came together to form a grassroots advocacy organization called Massachusetts People/Patients Organized for Wellness, Empowerment, and Rights ("M-POWER") to document and address their common concerns.

Soon after its inception, M-POWER was flooded with stories of consumers who had received little or no information from their psychiatrists about treatment options. Many people had experienced serious medication side effects from prescribed treatments, and a significant number felt coerced into taking medications. Psychotropic medications may produce harmful and uncomfortable side effects, which over time can have a substantial impact on a person's quality of life.

In 1991, members of the Boston Chapter of M-POWER studied the legal and ethical requirements of Informed Consent to Treatment ("Informed Consent"). Informed Consent requires that prior to prescribing a treatment, the mental health provider shares information with the client on available treatments and the corresponding benefits and risks of each. The client then uses that information to make a treatment decision for him or herself.

M-POWER members organized a campaign to establish Informed Consent as clear and deliberate policy of DMH, the state mental health authority.[11] In 1996, after a period of negotiations, DMH reached consensus with M-POWER and implemented a policy of Informed Consent. The policy required providers to fully disclose and discuss treatment and/or medication options with a client, and it required that the client assert consent by signing a written form that outlined the agreed-upon treatment. The form, which was signed in triplicate, was then kept on file by the psychiatrist, the client, and within the client's medical record.

Although the Informed Consent policy was well thought out, its implementation was patchy at best. In early 2000, M-POWER members joined the DMH Medical Director to meet with a statewide group of DMH psychiatrists; members learned that many psychiatrists continued to believe that sharing side effect information with patients served little or no value. Throughout the 2000's, consumer evaluative studies in MA conducted by CQI continued to show patient dissatisfaction with the information psychiatrists provided to them about medications.[12]

Toward the late 2000's, DMH and its partners began to take steps to promote SDM between psychiatrists and clients. In 2008, the Massachusetts Behavioral Health Partnership ("MBHP")

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[11] General History | The Transformation Center. (n.d.). *The Transformation Center*. Retrieved June 25, 2010, from http://www.transformation-center.org/advocacy/history/general.shtml

[12] Consumer Quality Initiatives. (2007). *INFORMED CONSENT: Strategies to improve the experience of Massachusetts mental health consumers.* Retrieved from http://www.cqi-mass.org/pdfs/CQI%20Issue%20Brief-%20Informed%20Consent%20to%20Meds.pdf

selected Pat Deegan's *CommonGround* clinical decision support model[13] for use with clients seeing psychiatrists at three outpatient clinics in Massachusetts. With the *CommonGround* model, the waiting areas of the three clinics were transformed into Decision Support Centers that featured peer specialists and "a user-friendly Internet-based software program with which clients could create a one-page, computer-generated report for use in the medication consultation."[14]

In 2009**,** DMH procured a new treatment model called Community Based Flexible Supports ("CBFS") for its contracted outpatient treatment services. Services provided under the CBFS activity code were required to be person-centered, "responsive to the preferences and needs of individuals and their families and focused on rehabilitation and recovery."[15] Although the CBFS model has represented a welcome shift toward recovery-oriented services, it does not include a defined methodology or process for provider/consumer communications that represents person-centered planning.

What is Shared Decision Making?

SDM is defined as "an interactive process in which physicians [providers] and patients [clients] simultaneously participate in all phases of the decision-making process and together negotiate a treatment to implement."[16] Essential components of SDM are: establishing a context in which clients' views about treatment options are valued and deemed necessary, transferring technical information, making sure clients understand this information, helping clients base their preference on the best evidence coupled with their own values and knowledge about themselves; eliciting clients' preferences, sharing treatment recommendations, and making explicit the component of uncertainty in the clinical decision-making process.[17]

SDM begins with the premise that the client chooses what role he/she prefers in the decision making process and the provider seeks to understand and respect the client's choice throughout their partnership. SDM recognizes that both providers and clients have important knowledge to contribute to the decision making process.[18] Providers are seen as having the most accurate and

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[13] About CommonGround. (n.d.). *Pat Deegan, PhD & Associates*. Retrieved July 19, 2009, from http://www.patdeegan.com/AboutCommonGround.html

[14] Deegan PE, Rapp C, Holter M, Riefer M (2008). Best Practices: A Program to Support Shared Decision Making in an Outpatient Medication Clinic. *Psychiatric Services*, *59*, 603-605.

[15] The Massachusetts Department of Mental Health Community Based Flexible Supports Factsheet posting: http://www.mass.gov/Eeohhs2/docs/dmh/community_based/cbfs_factsheet.doc

[15] Charles, C., Gafni, A., & Whelan, T. (1999). Decision-making in the physician-patient encounter: Revisiting the shared treatment decision-making model. *Social Science & Medicine*, *49*(5), 651-661.

[17] Compared to person-centered planning, which involves the client and all of his/her service providers, shared decision making may be viewed as a process specific to a provider (often a psychiatrist) and the client, plus his/her chosen support network (family, peer specialists, friends).

[18] Adams, JR., & Drake, RE. (2006). Shared decision-making and evidence-based practice. *Community Mental Health Journal*, *42*(1), 87-105.

current information regarding the nature of the client's health condition, its course, and the treatment options.[19] Clients are seen as experts on their health history, values, treatment goals, and treatment preferences.[20] Thus, it is expected that the SDM process will be simultaneously informed by the best medical evidence available to the provider, and weighted according to the specific characteristics and values of the patient.[21]

SDM is not informed consent. Informed consent describes a unilateral decision made by a client who has been provided all relevant treatment information. SDM is a concurrent, fluid exchange of information between client and provider (patient and physician) in a mutual attempt to reach a consensus treatment decision(s).

Benefits of SDM

Recent studies have found that the majority of people with mental illnesses want to participate in treatment decision-making and are able to do so.[22] [23](CQI's own studies have shown that most mental health clients want to participate in making treatment decisions with their psychiatrists.) In addition, research demonstrates that when decisions reflect patient preferences, a variety of benefits result. These benefits may include increased service satisfaction, improved treatment adherence, and decreased symptom burden.[24], [25], [26] As clients become more active in decisions about their treatment, they also share more responsibility for the consequences of those decisions.[27] Active involvement in treatment decision making may lead to improved self-esteem and self-management skills.

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[19] Id. at 15.

[20] Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango). *Social Science & Medicine*, *44*(5), 681-692.

[21] Id. at 16,

[22] Hamann J, Cohen R, Leucht S, et al (2005), . Do patients with schizophrenia wish to be involved in decisions about their medical treatment? American Journal of Psychiatry 162:2383–2384

[23] Adams JR, Drake RE Wolford GL (2007). Shared decision-making preferences of people with severe mental illness. Psychiatric Services 58:1219–1221

[24] Alegria, M., Polo, A., Gao, S., Santana, L., Rothstein, D., Jimenez, A., et al. (2008). Evaluation of a Patient Activation and Empowerment Intervention in Mental Health Care. *Medical Care*, *46*(3), 247-256.

[25] Salyers, MP., Matthias, M., Spann, C., Lydick, J., Rollins, A., & Frankel, R. (2009). The Role of Patient Activation in Psychiatric Visits. *Psychiatric Services*, *60*(11), 1535-1539.

[26] Swanson, KA., Bastani, R., Rubenstein, LV., Meredith, LS., & Ford, DE. (2007). Effect of Mental Health Care and Shared Decision Making on Patient Satisfaction in a Community Sample of Patients with Depression. *Medical Care Research and Review*, *64*(4), 416-430.

[27] Schauer, C., Everett, A., del Vecchio, P., & Anderson, L. (2007). Promoting the Value and Practice of Shared Decision-Making in Mental Health Care. *Psychiatric Rehabilitation Journal*, *31*(1), 54-61.

The potential benefits resulting from SDM are particularly promising in mental health care, where most treatment options are “preference-sensitive." Effective care is where evidence of benefit clearly outweighs harm: clients should always receive this type of care, where indicated. Preference-sensitive care describes a situation where the evidence for the superiority of one treatment over another is either not available or does not allow differentiation; in this situation, there are two or more valid approaches, and the best choice depends on how individuals value the risks, benefits and side effects of treatments.[28]

Decisions regarding the use of certain psychiatric medications are preference-sensitive. For example, all antidepressants and all but one antipsychotic medication have equal efficacy when used in a population. The major difference between these medicines then becomes the varying side effects that each medication may cause for an individual.[29] Helping clients consider their options in the context of their own lifestyles is paramount in the decision making process. For example, a consumer who works in an intellectually demanding job may prefer a medication that is not sedative, while an individual who is focused on dating and sports might prefer a medication that does not cause weight gain and obesity.[30]

Barriers to SDM

Although many benefits accrue from SDM, many people with serious mental illness ("SMI") who want to be active participants in treatment decision making are not involved in the process.[31], [32] The mental health client-provider relationship carries with it particular encumbrances that have resulted in barriers to collaborative and effective decision making.[33] Some barriers that can stand in the way of SDM include the following:

- Providers sometimes assume that a client is not interested in sharing in the decision making process, when some probing and support may demonstrate otherwise.

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[26] Mistler LA, Drake RE. (2008). Shared decision-making in antipsychotic management. *J Psychiatr Pract* 14::333–344.

[29] Id.

[30] Deegan, P. E. (2007). The lived experience of using psychiatric medication in the recovery process and a shared decision-making program to support it. *PsychiatricRehabilitation Journal, 31,* 62–69., 64.

[31] Hamann, J., Cohen, R., Leucht, S., Busch, R., & Kissling, W. (2005). Do patients with schizophrenia wish to be involved in decisions about their medical treatment?. *American Journal of Psychiatry*, *162*, 2382-2384.

[32] Id. at 25.

[33] Deegan PE, Drake RE (2006). Shared decision making and medication management in the recovery process. Psychiatric Services 57:1636–1639.

- Providers may question the validity of a client's perspective; a provider may consider the client injudicious as a consequence of his or her illness.[34]
- Provider's and client's views of stability and risk may differ. As a result, clients and providers may have completely different expectations from their meetings.
- Psychiatric practice has become largely psychopharmacological evaluation and treatment monitoring. These changes have led to severe reductions in the time spent providing services directly, with visits with psychiatrists to discuss medications generally lasting in the range of 10-20 minutes[35]. Time restrictions present challenges to both psychiatrists and clients, who face the pressure of trying to fully process, weigh, and discuss multiple options within about fifteen minutes
- Many clients are reluctant to share with their providers an honest assessment of their care.[36]
- The SDM model assumes that both parties are able to comprehend the requisite information to make the best treatment decisions, but that is often not the case. Many people with mental illnesses are poorly educated, lack appropriate resources, and/or have difficulty with concentration.

Overcoming Barriers with Decision Supports

Some barriers to SDM can be overcome with appropriate supports. It is important for clients to have supports to help them obtain all relevant treatment information, and to help them clarify their values regarding the potential benefits, risks and side effects of the treatment options. With effective supports, many clients can actively participate in making treatment decisions with providers.

One common type of decision support is the client "decision aid," which provides concrete information about a health condition and the potential outcomes of different treatment options, and helps the client to clarify his or her personal values. There has been a recent push to develop decision aids for people with SMI, but few decision aids have been evaluated for their effectiveness.[37] The Substance Abuse and Mental Health Services Administration ("SAMHSA") has a Consumer/Survivor Initiative Website devoted to SDM, including SDM Webinars, communication tools, tips and briefs for mental health clients and providers. SAMHSA is also supporting the development of an "interactive, web-based decision aid focusing on a decision

[34] Id. at 30.

[35] Cruz M, Pincus H. Research on the influence that communication in psychiatric encounters has on treatment. *Psychiatric Services.* 2002;53(10):1253–1265

[36] Id. at 22

[37] Substance Abuse and Mental Health Services Administration. (2008). *Examples of Mental Health Decision Aids*. Retrieved from http://download.ncadi.samhsa.gov/ken/pdf/consumersurvivor/SAMHSA_Decision_Aid_Chart_Jan08.pdf

relevant to antipsychotic medications."[38] Like all decision supports, decision aids are designed to complement, not replace, the advice of providers.

Other types of decision supports include client self-advocacy trainings, question-formulation preparation,[39] and assistance with the development of printed provider meeting agendas[40]. Decision supports can be delivered via printed materials; via in-person or web-based presentations; or through interactive experiences such as audio-guided workbooks, electronic shared spaces such as Google groups, and personal coaching or mentoring.[41] Decision supports that are interactive not only have great potential to engage clients, but also to empower them to manage and take control of their illness.

A Visual Summary of SDM

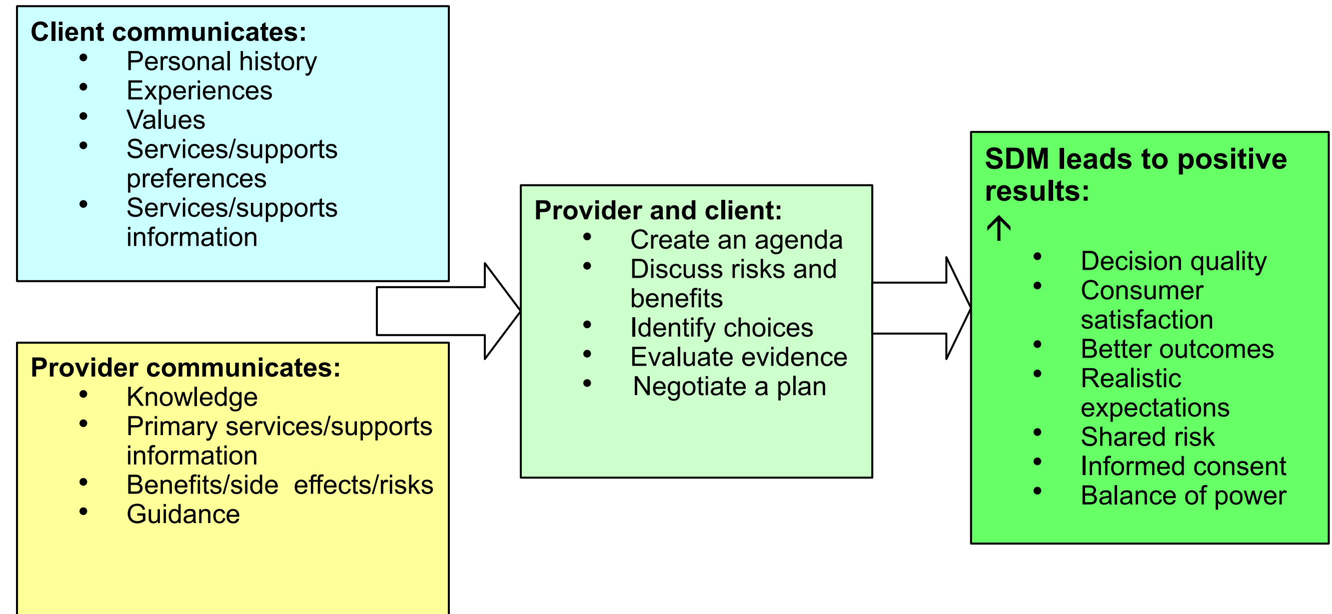
The process of SDM can be summarized in a visual way as follows:

[38] National Grantee Conference on the Mental Health Block Grant and Data. (2009, May 18). *Shared Decision-Making in Mental Health and Behavioral Healthcare*. Retrieved July 22, 2009, from nationalgranteeconference.com/presentations/Laurie%20Curtis%20and%20Melody%20Riefer.pdf

[39] Id. at 22.(With the RQP health education curriculum, trainers teach low income mental health clients to formulate, prioritize, and ask questions of their health care providers. The goal is to develop skills that promote more active participation in the clinical context and to encourage greater client self-efficacy with regard to their health care overall; early research results are promising.

[40] Sepucha, Karen R., Belkora, Jeffrey K., Mutchnick, Stephanie, Esserman, Laura J. Consultation Planning to Help Breast Cancer Patients Prepare for Medical Consultations: Effect on Communication and Satisfaction for Patients and Physicians**,** J Clin Oncol 2002 20: 2695-2700

[41] O'Connor AM, Stacey D, Rovner D et al. Decision aids for people facing health treatment or screening decision (Cochrane Review). In: The Cochrane Library, Issue 3, 2001. Oxford: Update software.



The Shared Decision Making Summit, June 2009

- **Overview of the Summit**
- **Key Findings from the Summit**

Overview of the Summit

The policy summit held by CQI and DMH, "*Shared Decision Making in Mental Health Services: First Steps towards a Statewide Approach,"* was an invigorating day of sharing among a diverse group of over 100 mental health professionals, policy leaders, consumers and family members. Held on June 25th, 2009 in Waltham, Massachusetts, the Summit was an opportunity for invited guests to learn about SDM and to discuss the opportunities and challenges of its implementation in Massachusetts. (Financial support for the summit was provided by the Robert Wood Johnson Foundation's Community Health Leaders program[42].

The day began with introductions by Jonathan Delman, CQI's Executive Director and Robert Wood Johnson Community Health Leader awardee, and Dr. Mary Ellen Foti, DMH Deputy Commissioner of Clinical and Professional Services. DMH Commissioner Barbara Leadholm and State Representative Jason Lewis (D-Winchester) followed with words of inspiration and deep interest.

[42] Id. at 9.

Plenary presentations were delivered by the leading innovators of SDM in mental health treatment: Dr. Robert Drake, Professor of Psychiatry, Community, and Family Medicine at Dartmouth Medical School, and Pat Deegan, PhD, renowned consumer/survivor, leader and designer of the *CommonGround* SDM software.

A consumer panel entitled "Consumer Perspective" and a provider panel entitled "The Provider's Challenge" followed the plenary presentations. The panelists offered their unique perspectives on the decision making process between clients and providers, and they emphasized the potential that exists for greater collaboration in these treatment decisions.

Following a networking lunch, summit participants broke into small groups to engage in facilitated, interactive dialogues about how to embed SDM in mental health policy and practice. Each group prepared and presented recommendations to the larger group based on their discussion of a specific topic. Seven working groups, each comprised of between six and ten participants, offered recommendations on a total of five topics. These topics were:

- The risks and rewards of SDM;
- Creating clinical guidelines and policy to support SDM (2 groups)
- Supports and training for clients to engage in SDM;
- Supports and training for service providers to engage in SDM with clients;
- The role of peer support in SDM (2 groups).

In depth discussion summaries for these five topics may be viewed at http://www.cqi-mass.org/shared.aspx.

Key Findings

The Summit provided a framework to obtain important input from a variety of stakeholders on implementing SDM in Massachusetts. Summit participants agreed that although SDM may be a desired norm of mental health service provision, significant barriers exist with regard to its implementation. It is clear that we are in the early stages of embracing the changes necessary to be a system characterized by SDM.

We also learned that many providers have concerns about the adoption of SDM, and that many consumers lack the resources and support to actively participate in SDM.

Some of the key barriers identified include the following:

- SDM challenges the current norms and attitudes of provider agency operations and staff practices, requiring new kinds of provider trainings. Significant staff resistance to implementing SDM is likely.
- SDM is a new concept for many in provider leadership, so extra efforts will be needed to convince administrators and clinicians to change the nature of their policies and practices.

- For providers, there is insufficient access to clinically useful scientific knowledge and facilitated communication.[43]
- Clients will have various perspectives on the notion of participation in treatment decision making, often as a consequence of their cultural background.
- Many people, regardless of their mental status, are not comfortable making choices, particularly with little support and information.
- We are still in the process of identifying the most effective and feasible client decision support tools.
- Peer specialists have the potential to serve as effective decision coaches, but we are only beginning to learn how to successfully include peers specialists as part of treatment teams.

It is clear that adoption of SDM in the Massachusetts public mental health service delivery system will require more than the development of written policy statements. Creating and sustaining a change in practice and culture always requires strong leadership, and a structured organized approach. Disseminating the best information and resources to support SDM, and monitoring and evaluating their effectiveness, is vital to the success of such an initiative.

Moving Forward: Recommendations for Incorporating SDM in Massachusetts Mental Health Services

The recommendations listed below, and described in further detail on the following pages, are based primarily on the working group discussions and recommendations from last year's SDM summit. They are also supported by the relevant literature on SDM and on organizational change. Recommended first steps to incorporate SDM in Massachusetts' mental health services include the following:

1. **Call to Action: Policy Leaders Send a Clear Message that SDM is Critical to High Quality Care**
2. **Establish a Multi-Stakeholder SDM Task Force, and Seek Funding for It**
3. **Create a SDM Website for Massachusetts**
4. **Conduct a Series of Stakeholder Needs Assessments**
5. **Develop a Workforce Training Strategy**
6. **Formalize the Role of the Peer Specialist in Providing Decision Support**
7. **Address Risk/Liability Concerns, and Propose Legislation**
8. **Address Racial and Ethnic Factors in SDM**

1. Call to Action: Policy Leaders Send a Clear Message that SDM is Critical to High Quality Care

[43] Drake RE, Cimpean D, Torrey W. (2009). SDM in mental health: prospects for personalized medicine. Dialogues in Clinical Neuroscience 11(4):455-63.

When a significant systemic change is necessary, policy leaders such as the DMH Commissioner and State Medical Director must express their personal commitment to that change. Leadership should establish this commitment by sending clear and consistent messages to stakeholders that SDM is critical to high quality mental health care. In addition, leadership should formally announce that SDM implementation is a major objective and highlight the existing projects that already fit within this objective.

An initial letter should explain why DMH is pursuing a SDM initiative; it should outline short term and long term expectations for the initiative; and it should describe what is expected of stakeholders. It is also important to acknowledge the challenges posed by the current financial climate, and the challenges that present with any large scale transformation. In its initiation and implementation of SDM across the service delivery system, DMH should embrace organizational change principles such as modeling, observational learning, and reminding staff that they have the competence to achieve this goal.

2. Establish a Multi-Stakeholder SDM Task Force, and Seek Funding for It

Organizing the SDM initiative will require the time and resources of many people. The authors have personally agreed to commit their time and resources to the SDM initiative. In addition, DMH, through its Research Centers of Excellence and other avenues, should seek grant funding to support the SDM Initiative.

A SDM task force should be established and include policy leaders, early practitioners of SDM, mental health consumer and family members, and other stakeholder representatives. Several members could be drawn directly from the group of summit attendees. The authors will also identify key opinion leaders - highly respected stakeholders who have influence over their peers' opinions and actions - to seek their buy-in and support for developing the task force. Leadership should educate and discuss with the opinion leaders the SDM initiative, either through formal meetings and presentations, or through more informal communications.

The task force should meet regularly to share information on important SDM developments, problems and opportunities; to develop mutually informed SDM strategies; and to support the implementation of SDM throughout the system. Task force discussions and deliberations should include not only face to face meetings, but also teleconferences, webinars, discussions on networking websites, and/or other online community building tools.

A successful model for this task force approach is the Transformation Committee ("TRANSCOM"), whose goal has been to develop and implement mental health peer services in Massachusetts. TRANSCOM's membership has included representatives from several consumer lead organizations, the Association for Behavioral Health ("ABH"), state agencies, and managed care organizations. TRANSCOM first developed mission and vision statements and work plans,

and it later became a subcommittee of the Mental Health State Planning Council. Ultimately, TRANSCOM assisted the consumer-run Transformation Center in developing the Massachusetts certified peer specialist training. Members helped DMH and MBHP codify the role of the certified peer specialist in various services, and they nurtured the development of the peer-lead, DMH-funded "Recovery Learning Community" model.

3. Create a SDM Website for Massachusetts

A website established specifically for Massachusetts mental health SDM activities on the DMH internet site as well as CQI's website. CQI's website, www.cqi-mass.org, currently includes a summary of last year's SDM summit; this section could be enhanced to provide key SDM information and updates to Massachusetts stakeholders, including:

- this White Paper and the results of other related proceedings;
- a summary of SDM-related research and demonstration projects that have been taking place in Massachusetts, including the use of *CommonGround;*
- a SDM bibliography and literature reviews;
- links to other key websites, including SAMHSA's SDM website (http://mentalhealth.samhsa.gov/consumersurvivor/shared.asp).

4. Conduct a Series of Stakeholder Needs Assessments and Demonstration Projects

Participants at the SDM summit agreed that a series of in-depth needs assessments should be conducted in preparation for the establishment of SDM in Massachusetts. A needs assessment is a systematic exploration of the way things are (opinions, attitudes, practices, etc) and the way they should be. The results of a needs assessment can lay the foundation for developing the initiative's goals and objectives.

At a minimum, needs assessments of two target audiences should be conducted: providers and clients. The general goals of these needs assessments should include the following:

- To identify existing supports and barriers to SDM for each group;
- To identify methods for minimizing barriers and maximizing supports for SDM;
- To maximize the opportunity to create a proposal for change that is as tailored as possible to the specific needs of each group.

a. Needs Assessment and Demonstration Projects Targeting Mental Health Providers

Summit participants offered the following specific recommendations with regard to a needs assessment targeting mental health providers:

- The provider needs assessment should review the current practices and capacity of agencies to provide administrative oversight of their services through policies, incentives, and accountability.
- The assessment should evaluate the capacity of supervisors to provide a consistent message regarding SDM.
- Because the goal and challenge is to transform the overall culture of providers, it will be important to assess the existing level of staff knowledge, attitudes and skills around SDM implementation and use.
- Academic detailing is the face-to-face education of prescribers, designed to improve their prescription practices. Academic detailing has shown demonstrated success in changing prescribing patterns. The provider needs assessment should evaluate the feasibility of implementing a program of academic detailing for psychiatrists to promote SDM.

In order to facilitate the adoption of SDM among providers, several issues must be addressed. Providers have reported that their three most often reported facilitators to using SDM have been: provider motivation, positive impact on the clinical process, and positive impact on patient outcomes.[44] Facilitating continuing medical education for current physicians as well as introducing SDM into the medical school curriculum for future physicians will be important. However, we know from the organizational change literature that education and training are necessary, but not sufficient components of changing a system.[45] Therefore, implementation should include promoting a culture of recovery and inclusion, a recognition of the value that prescribers bring to the process of SDM, as well as developing DMH as a learning organization rooted in the extensive use of data and ongoing change, improvement, and innovation.[46]

Specific recommendations include promoting pilot projects such as the polypharmacy reduction initiative, to show feasibility and positive impact on the clinical process as well as demonstrate that SDM does not have to be restricted to certain select clients or to certain psychosocial variables. Demonstration and expansion of successful projects like CommonGround can show that decision support tools facilitate the provider-client conversation without taking up extra time.

b. Needs Assessment Targeting Mental Health Clients

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[44] Gravel K, Legare F and Graham I. (2006). Barriers and facilitators to implementing shared decision making in clinicl practice: a systematic review of health professionals' perceptions. Implementation Science 1:16

[45] Mohr JJ, Batalden PB. "Integrating Approaches to Health Professional Development with Approaches to Improving Patient Care" in Continuous Quality Improvement In Health Care, 3rd Edition. McLaughlin, K and Kaluzny, A. (editors). Aspen Publishers, Maryland. 2005.

[46] Ingrid Philibert, Mary Joyce Johnston, Laura Hruska, Jane A. Shapiro, Paul Friedmann, Paul B. Gardent, Paul B. Batalden, David C. Leach (*2010*) Institutional Attributes Associated With Innovation and Improvement: Results of a Multisite Study. Journal of Graduate Medical Education: June 2010, Vol. 2, No. 2, pp. 306-312.

Summit participants offered the following specific recommendations with regard to a needs assessment targeting mental health clients:

- The client needs assessment should evaluate the extent to which clients wish to participate in services/treatment decision making, and the ways in which they wish to be involved.
- Results of the assessment should be sorted to determine how client preferences may vary relative to the following:
  - by category of client (e.g. race/ethnicity, age, gender)
  - by the type of decision (e.g. medication, vocational support, therapist)
- The assessment should evaluate which kinds of general and specific decision supports are best for helping people with mental illness to identify their needs and preferences regarding various treatment options. The assessment should seek to determine which decision supports are easiest and most likely to be utilized by clients, and which ones will help clients make high quality decisions.
- The assessment should seek to understand how decision supports can best be utilized to remove some of the anxiety people often feel when faced with difficult decisions.
- The assessment should help to determine the role certified peer specialists can play in providing decision support (see #6 below).

Stakeholders should leverage existing resources and work with interested researchers to conduct these needs assessments.

5. Develop a Workforce Training Strategy

After appropriate needs assessments are conducted and analyzed, a comprehensive workforce training strategy should be developed to prepare providers for the implementation of SDM. As described above, the provider needs assessment should assess workers' knowledge, skills and attitudes regarding SDM, along with their willingness to change their practice patterns. Training in the practice of SDM should be tailored to specific providers according to their level of access to information about service options, the experiences they have had working with consumers, and the team culture within which they work.

Different types of providers (e.g. psychiatrists, peer specialists, social workers) working in different types of environments (e.g. clinics, clubhouses, Programs for Assertive Community Treatment ["PACT"] teams) will have different training needs. Customized focus groups and informal meeting sessions should supplement the needs assessment to determine the most critical training needs for each provider group, and for providers overall.

A key finding from the 2009 SDM summit was that SDM has never been incorporated into training for behavioral health providers. Similarly, pre-service training rarely contains content on involving clients in treatment decisions. SDM training should be interactive and should target the lowest-paid least-trained staff, which often have the most contact with consumers. The feasibility

of incorporating SDM into medical education curricula should be given careful consideration. Once implemented, all training programs should be evaluated for effectiveness.

Finally, mental health providers, like consumers, should have access to decision support tools that are easy to use. To ensure that resources are used efficiently, efforts to develop decision support tools for providers should be coordinated to avoid duplication.

6. Formalize the Role of the Peer Specialist in Providing Decision Support

Peer support not only improves the well-being of people with mental illness, but it also enables mental health consumers to share information about different treatments. Through peer support groups, many consumers have obtained reliable and useful information about medications.

Additionally, "peer specialists" are mental health consumers who utilize their experience of mental health recovery to assist other consumers in articulating and reaching their personal recovery goals. More specifically, the peer specialist works with other consumers on problem solving, recovery/life goal setting, utilizing self-help recovery tools such as the Wellness Recovery Action Plan ("WRAP"), skill building, and establishing self-help groups. "Certified" peer specialists have gone through extensive training and passed an exam demonstrating their knowledge of key competencies.

In Massachusetts, certified peer specialists are offered and funded through a variety of different service delivery models, including PACT, day treatment programs, emergency service teams, and community-based flexible support teams. Not only does the peer specialist work to inspire clients, but also to guide and influence the perspectives of other treatment team members. Peer specialists also operate independently of treatment teams, as staff of the consumer-run Recovery Learning Communities.

Peers specialists are well-positioned to coach clients to actively participate in making treatment decisions with their providers. In this role, a peer specialist could train consumers to use decision support tools, provide direct assistance to consumers using decision supports, and coach consumers in preparing for a treatment meeting. Beyond certification, a continuing education course should be developed for peer specialists to learn to provide this specialized support.

7. Address Risk/Liability Concerns, and Propose Legislation

A model SDM system would provide clients and providers with access to correct, clear and concise information that is easily retrieved and updated, as well as the resources necessary to discuss relevant options without significantly draining provider resources. In addition, an SDM system must include legislation that eliminates the paternalistic physician-based and patient-

based informed consent rules and replaces them with liability protection language that recognizes the priority of autonomy and the responsibilities of provider and client as a partnership of equals. Providers would no longer have to guess regarding their legal liability and they could improve the health outcomes of their patients by enabling them to be more invested in their treatment choice.[47] Summit participants strongly encouraged the adoption of public policies to address provider liability concerns. The major concern is that SDM will lead to more frequent negative outcomes because clients may choose to forgo treatments such as medications or elect to take on significant responsibilities of daily living, such as money management or employment.

In order to address these issues, the State of Washington passed a law in 2007 that recognizes SDM as an evidence-supported activity that is likely to produce improved medical outcomes through the use of decision aids and other decision supports. The law specifically contains liability protection language, with a signed "acknowledgement of shared decision making" document serving as prima facie of informed consent, reducing the potential liability for providers. For more information about Washington's law, see Appendix A and http://www.informedmedicaldecisions.org/pdfs/legislation.pdf. (Maine and Vermont are also working on bills that will encourage SDM in medicine.)

Ultimately, when a provider and client collaborate in the treatment decision, they are prioritizing patient autonomy over beneficence (provider taking action that serves the best interests of a client). In instances of disagreement after discussion, the client's preference should determine the treatment, since the client has to live with the decision and its implications. By protecting patient autonomy and acknowledging the importance of provider opinion and analysis, SDM provides the most effective method of enabling providers to satisfy their ethical obligations to clients. Stakeholders should explore all options to limiting liability for engaging in SDM.

8. Address Racial, Ethnic and Cultural Factors in SDM

Summit participants stated that a client's racial, ethnic and cultural background can affect his or her views about particular health conditions and treatments. In several cultures, there is deep stigma associated with seeking professional mental health services, and in particular the use of psychiatric medication.[48] Likewise, the extent to which clients desire involvement in treatment decisions, and the relative appeal of specific decision supports, are likely to differ by racial,

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[47] King JS, Moulton BW. Rethinking informed consent: the case for shared medical decision-making. *Am J Law Med 2006*;32:429-501

[48] Cooper, L. A., Roter, D. L., Johnson, R. L., Ford, D. E., Steinwachs, D. M., & Powe, N. R. (2003). Patient-centered communication, ratings of care, and concordance of patient and physician race. Annals of Internal Medicine, 139, 907–915.

ethnic and cultural groups.[49] Cultural attitudes on the following factors will likely affect a client's view on SDM:

- the role of family and friends in decision making
- the acceptable level of independence from the larger group
- the level of acceptance of the clinician as the "expert"

Every SDM initiative should take racial, ethnic and cultural identity and norms into account.

[49] Id. at 42.

Money Follows the Person Waivers

"Helping People Return to the Community"

MassHealth Waivers

MassHealth makes waiver programs available that provide home- and community- based services to eligible individuals in their own homes or community settings who would otherwise require care in a nursing home or long-stay hospital. Individuals in a waiver can receive both traditional MassHealth services and the additional services available under a waiver.

Money Follows the Person Waivers

MassHealth offers two Home- and Community-Based Services (HCBS) waivers called the Money Follows the Person Waivers (MFP Waivers), which will help individuals who are qualified for the MFP Demonstration to move from a nursing home or long-stay hospital to an MFP-qualified residence in the community and obtain community-based services.

The two MFP Waivers are:

- **MFP Residential Supports (MFP-RS) waiver** – for individuals who need supervision and staffing 24 hours a day, seven days a week.
- **MFP Community Living (MFP-CL) waiver** – for individuals who can move to their own home or apartment or to the home of someone else and receive services in the community.

Eligibility Criteria for MFP Waivers

To qualify for one of these waivers, you as an applicant must:

1. be living in a nursing home or long-stay hospital for at least 90 consecutive days, excluding Medicare rehabilitation days
2. be 18 years old or older and have a disability, or be age 65 or older;
3. meet the clinical requirements for and be in need of MFP waiver services;
4. be able to be safely served in the community within the terms of the MFP waivers;
5. meet the financial requirements to qualify for MassHealth. Special financial rules exist for waivers participants;
6. meet the requirements for participation in the MFP Demonstration; and
7. transition to an a MFP qualified residence in the community. A qualified residence includes:
   - a home owned or leased by the applicant or family member;
   - an apartment with an individual lease or a community-based residential setting in which no more than four unrelated individuals reside; or
   - an assisted-living residence that has an apartment with separate living, sleeping, bathing and cooking areas, lockable entrance and exit doors, and meets other criteria.

In addition to the above, to qualify for the MFP-RS waiver, you as an applicant must need residential support services with staff supervision 24 hours a day, seven days a week.

Services Offered to Waiver Participants

All waiver participants will work with a case manager to develop their individual service plan that will reflect their goals and the waiver services and supports the waiver participant needs in the community.

Waiver services available in the MFP Residential Supports (MFP-RS) Waiver include:

- Residential Habilitation (group home)
- Shared Living – 24-Hour Supports
- Assisted Living Services
- Day Services
- Home Accessibility Adaptations

- Individual Support and Community Habilitation
- Occupational Therapy
- Peer Support
- Physical Therapy
- Prevocational Services
- Residential Family Training
- Skilled Nursing
- Specialized Medical Equipment
- Speech Therapy
- Supported Employment
- Transportation

Waiver services available in the MFP Community Living (MFP-CL) Waiver include:

- Adult Companion
- Chore Service
- Community Family Training
- Day Services
- Home Accessibility Adaptations
- Home Health Aide
- Homemaker
- Independent Living Supports
- Individual Support and Community Habilitation
- Occupational Therapy
- Peer Support
- Personal Care
- Physical Therapy
- Prevocational Services
- Respite
- Shared Home Supports
- Skilled Nursing
- Specialized Medical Equipment
- Speech Therapy
- Supported Employment
- Supportive Home Care Aide
- Transportation
- Vehicle Modification

In addition, if you are enrolled in one of the MFP waivers and need behavioral health services (mental health or substance abuse services), you will receive your behavioral health services through the Massachusetts Behavioral Health Partnership (MBHP). MBHP is the MassHealth behavioral health managed-care contractor that will work with you and your waiver case manager to help you get the behavioral health care you need.

MFP Waiver Application Process and Brochures

You may submit MFP waiver applications any time on or after April 1, 2013. A link to the waiver applications is found below.

- Application for Home- and Community-Based Services Waivers for Money Follows the Person (MFP) Residential Supports Waiver (MFP-RS)

- Solicitud de exenciones para servicios basados en el hogar y la comunidad de El dinero sigue a la persona (MFP) Exención de apoyo residencial (MFP-RS)
- Application for Home- and Community-Based Services Waivers for Money Follows the Person (MFP) Community Living Waiver (MFP-CL)
- Solicitud de exenciones para servicios basados en el hogar y la comunidad de El dinero sigue a la persona (MFP) Exención de vivienda comunitaria

A brochure with more information about the waivers is also available. Below is a link to the MFP Waiver brochure and a brochure with information about Self-directed Services in the MFP waivers.

- Money Follows the Person Waivers Brochure
- Exenciones de "el Dinero sigue a la persona" (MFP)
- Money Follows the Person Self-directed Waiver Services Brochure
- Servicios de exención autodirigidos de "el Dinero sigue a la persona" (MFP)

Send your completed MFP Waiver application to:

UMass MFP Waiver Unit
333 South Street
Shrewsbury, MA 01545

For more information about the MFP Waivers contact:

UMass MFP Waiver Unit
Tel: 855-499-5109
TTY: 800-596-1746 for persons who are deaf, hard of hearing, or speech disabled
e-mail: MFPinfo@umassmed.edu

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MetroWest Center For Independent Living

280 Irving Street, Framingham, MA 01702

V/TTY: (508) 875-7853, Fax: (508) 875-8359

Services at MWCIL (www.mwcil.org/services)

Our staff works individually with consumers. Services are free to consumers who live in the 26 town service area (*) and have disabilities. (I and R services are for anyone).

Information and Referral (*Available to anyone*)

In addition to our online resources, consumers work with staff to find answers and referrals regarding available community resources. We provide information about disability-related issues, specific situations, and independent living resources.

Peer Support

One on One peer mentoring helps people with disabilities develop mutual support, assistance, confidence and understanding. Mentoring can be provided on the phone, at MWCIL or at a consumer's home. Consumers develop independent living strategies with their Peer Counselor.

Advocacy

In addition to Community and Systemic Advocacy, MWCIL provides self-advocacy education to consumers. Consumers are encouraged to take direct roles in advocating for their own issues as well as the issues of others. MWCIL supports an individual's rights in their community by filing complaints and taking action as needed to remove illegal barriers or obtain services.

Independent Living Skills Training

Skills Training is customized to achieve each consumer's goals. Skills may relate to personal growth, or how to handle services and responsibilities. Independent Living Skills Training may includes: navigating MassHealth, navigating housing, budgeting and personal resource management, travel training, social and communication skills and more.

Options Counseling

Options Counseling s a short term service, typically for crisis situations when a consumer is considering a nursing home. This program enables individuals to make informed choices about settings and services, to understand the resources available to pay for supports and services, to be referred to appropriate experts, and to obtain assistance in connecting with appropriate resources.

Transition to Adulthood Program

TAP is specialized to work with young adults with disabilities who will be transitioning out of high school. Our mission is to work directly with young adults, help them determine their goals and find pathways to achieving these goals.

(*) MWCIL Service Area:

Ashland, Bellingham, Dover, Foxboro, Framingham, Franklin, Holliston, Hopkinton, Hudson, Marlboro, Maynard, Medfield, Medway, Millis, Natick, Needham, Norfolk, Plainville, Sherborn, Southboro, Stow, Sudbury, Wayland, Wellesley, Weston and Wrentham.

MetroWest Independent Living Center

The link below is one that would help people find a Massachusetts ILC in their area.
http://www.masilc.org/findacenter

This is a link to the website
http://www.mwcil.org/main