Maximized Community Involvement
Thoughtful Planning
Healthy Living

Make Things Happen!

A training activity of the Massachusetts Consortium for Children with Special Health Care Needs to support successful transition to adulthood

TRANSITION PLANNING CURRICULUM

MASSACHUSETTS CONSORTIUM for Children with Special Health Care Needs
A Program of New England SERVE

In collaboration with the Massachusetts Department of Public Health, as part of "Moving Forward Together," a grant funded by the Maternal and Child Health Bureau, HRSA, U.S. Department of Health & Human Services (Grant # D70MC04497)

April 2008

A Program of New England SERVE

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Make Things Happen is an initiative of the Massachusetts Consortium for Children with Special Health Care Needs and is part of the "Moving Forward Together" Project of the Massachusetts Department of Public Health. It is supported in part by project # D70MC04497 from the Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services.

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Acknowledgements

The *Make Things Happen* initiative would like to thank the following individuals for their support, advice, guidance and direct participation in the project.

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***Deborah Allen**, ScD*
***Susan Epstein**, MSW*
***Alexa Halberg**, BA*
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***Fran Basche**, MA (Former Director, "Moving Forward Together" project)*
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Executive Summary

The Massachusetts Consortium for Children with Special Health Care Needs developed and implemented a statewide training on transition to adulthood for care coordinators, case managers and other professionals who provide support to youth with special health care needs (YSHCN) across a variety of practice settings. The *Make Things Happen* training was a three year effort beginning in 2005 and made possible through funding from the Massachusetts Department of Public Health. The objectives of the training were to broaden participants' knowledge about transition issues for YSHCN and to enhance their skills in working with youth and families through transition into adulthood. The primary focus of the training was health-related transition issues. However, the training also touched on a range of other topics relevant to adult life, such as long-term financial planning, housing, relationships, socialization, post-secondary education and employment.

The training curriculum was developed through an intensive process that included a needs assessment, pilot testing, and post-implementation evaluation. Through this process, project staff created a curriculum designed to raise expectations about what youth can achieve, build specific transition-related skills among participants, increase participants' knowledge about transition-related resources, and promote a collaborative approach among community service providers who work with youth and families during transition. The following objectives defined the focus of the training:

- Raise participants' expectations of what youth can envision and aspire to for their adult life;
- Expand participants' knowledge of the transition process for YSHCN, relevant resources and key issues facing families and youth and as they move into adulthood;
- Improve participants' skills in supporting youth and families and in helping them plan for transition to adult life and the adult service system;
- Help participants recognize the important role they can play in the transition process; and
- Emphasize a shared decision-making and partnership model of transition planning among youth, their families and the professionals with whom they work.

The completed curriculum comprises seven modules designed to achieve these objectives:

- Transition: What Is It and How Do You Plan For It?
- Health and Healthy Living
- Youth Panel
- Transitioning to the Adult Service System
- Developing a Transition Plan
- Pulling it All Together
- Key Messages Revisited

The *Make Things Happen* curriculum was delivered in three regional workshops across the state. Ninety-six individuals were trained. The results of the evaluations conducted after each training session and observation of the dynamics of the participants at each session indicated that there were several elements that were most critical to accomplishing these objectives:

- Youth panel presentation and discussion;
- Illustrating ways in which care coordinators can engage youth and families in conversations about transition planning and the transition process;
- Hands-on practice using the Transition Planning Checklist;
- Exposure to local resources; and
- Networking with other professionals in the field.

Introduction

In 2005, the Massachusetts Consortium for Children with Special Health Care Needs (Consortium) received a three-year contract from the Massachusetts Department of Public Health to train care coordinators, case managers and other professionals on transition to adulthood for youth with special health care needs (YSHCN). This project grew out of previous work of the Consortium's Transition Task Force in 2002-2004, which assessed and documented the state of transition services for YSHCN in Massachusetts. In its 2004 brief, "Transition Issues for Youth with Special Health Care Needs in Massachusetts," the key Task Force recommendation was that the Consortium provide training for existing care coordinators in the state to better address the needs of youth as they transition to adulthood. The Task Force suggested that the Consortium develop and implement a targeted training for care coordinators, case managers and other professionals who work with youth and families across multiple service systems.[1] The *Make Things Happen* initiative, funded through the Massachusetts Department of Public Health, was an outgrowth of this recommendation.

Make Things Happen targeted care coordinators, case managers and other professionals from various organizations who work with youth with special health care needs and/or their families across the state. These organizations include health plans, state agencies, private primary care and pediatric practices, schools and other community-based service agencies. A primary focus of the training was on health-related transition issues. However, the training also covered a range of other topics related to adult life, such as long-term financial planning, housing, relationships, socialization, post-secondary education and employment.

The goal of the *Make Things Happen* training program was to increase the capacity of the care coordination system in Massachusetts to better serve YSHCN as they transition to adulthood. The primary strategy for accomplishing this was to enhance the skills of the care coordinators and case managers who work with them. To this end, the following objectives were identified for the training:

- Raise participants' expectations of what youth can envision and aspire to for their adult life;
- Expand participants' knowledge of the transition process for YSHCN, relevant resources, and key issues facing families and youth and as they move into adulthood;
- Improve participants' skills in supporting youth and families and in helping them plan for transition to adult life and the adult service system;
- Help participants recognize the important role they can play in the transition process; and
- Emphasize a shared decision-making and partnership model of transition planning among youth, their families and the professionals with whom they work.

[1] See "Transition Services for Youth with Special Health Care Needs in Massachusetts: Background Brief," October 2004 Revised - http://www.neserve.org/maconsortium/pdf/Transition_to_Adulthood/Transition_Issues_for_YSHCN_in_MA_corr_1-06.pdf).

This document describes the *Make Things Happen* transition training curriculum and the process through which it was developed. It is intended to serve as a guide for those wishing to implement a similar training. Specific suggestions are also offered to inform those who might adapt this curriculum for different audiences or specific practice settings

Curriculum Development Process

Transition Advisory Group: The Consortium transition training initiative was guided by an advisory group led by two co-chairs. The Advisory Group was comprised of a broad cross-section of individuals with expertise in the critical facets of transition, including health care, education, employment and recreation. The group met three times a year from January 2006-June 2008. The group advised project staff on key issues in preparing and implementing the training program, including:

- Training objectives,
- Development of a needs assessment strategy,
- Review of existing transition materials and resources,
- Design of training approaches and materials,
- Outreach to and recruitment of training participants,
- Strategies for evaluation, and
- Final recommendations based on the training experience.

The initial focus of the advisory group was on development and testing of a preliminary curriculum. When the pilot phase was completed at the end of Year 1, the work of the group shifted to evaluation and refinement of the curriculum, and implementation of three state-wide trainings in Years 2 and 3.

Needs Assessment: The first step in developing the training curriculum was to conduct an assessment to determine what care coordinators need to be effective working with YSHCN around transition. Five focus groups were held with care coordinators and case managers, the target audience for the training. The focus groups were designed to refine our understanding of the "world" of care coordinators, particularly with respect to their transition-related work, and to identify transition-related information needs and most effective training approaches for the target population.

Focus groups were conducted with:

- Neighborhood Health Plan case managers;
- Massachusetts Department of Public Health care coordinators who work with children/youth with special health care needs;
- Children's Hospital Boston case managers;
- A mixed group from Community Case Management, the Massachusetts Department of Mental Retardation and Shriner's Hospital; and
- A cross section of care coordinators from various state agencies, MassHealth and several health plans.

Four additional needs assessment meetings were held with consumers (youth and families) for the purpose of understanding families' needs for support, information and resources around transition issues. Parents and youth were engaged in discussions about their experiences with care coordination and their needs and perspectives on the range of transition topics, including health care, education, employment, housing, guardianship and recreation. Two meetings were held in the Boston area, one with parents and one with the Boston Youth Advisory Council and two similarly composed groups met in the Springfield area.

Finally, information gathering also included a focus group comprised of a wide range of other organizations involved in transition-related training. Organizations participating included the Federation for Children with Special Needs, Department of Mental Retardation, Department of Education, Institute for Community Inclusion and Yesodot (a community-based, family-centered and family-directed support program for individual with disabilities and their families). The purpose of this meeting was to identify other initiatives and activities on transition in the state and to promote further collaboration among transition training providers to maximize impact.

Expert Consultation: Two national experts in the area of transition advised the project on its direction and activities and provided information on other important resources and contacts -- Patti Hackett, MEd, Co-Director, Healthy & Ready to Work National Resource Center and Betty Presler, ARNP, PhD, Transition Task Force and Cerebral Palsy Coordinator, Shriner's Hospital for Children, Lexington, Kentucky.

Pilot Training: Guided by the findings of the needs assessment and advice of the two transition consultants, a preliminary curriculum was developed and piloted in October 2006. The full curriculum was presented to 17 pilot participants. In addition, participants were asked to assist in an in-depth evaluation of the content, format and effectiveness of the curriculum. Based on this feedback, modifications were made to format and content.

Implementation: The contract called for the project to train a total of 75 participants in three all-day trainings across the state. These trainings were held in March, June, and November 2007 in Framingham (Eastern MA), Holyoke (Western MA), and Shrewsbury (Central MA). A total of 96 individuals were trained.

Evaluation and Refinement: After each of the first two trainings in March and June of 2007, the Advisory Group and project staff used evaluations from participants, staff and advisory group members who attended the training to assess how effective each training module was in accomplishing the intended learning objectives. From this, recommendations for further refinements of the curriculum emerged. The final curriculum, as described here, represents content and format that evolved from this two-year iterative process of assessment, implementation, evaluation and refinement.

Considerations in Design of the Curriculum

As the curriculum was developed and refined, the following key elements emerged from the evaluations as critical to assure maximum effectiveness of the training.

Avoid Information Overload: Transition to adulthood for YSHCN is a dynamic, complex process that encompasses many major areas of life (employment, education, living situation, relationships, etc.). Information appropriate and useful for care coordinators pertaining to even *one* domain (for example, key issues for YSHCN relating to employment and the local, state and national resources that can help youth and families in this area) would comprise an overwhelming amount of information. It was a challenge to provide enough information about important transition domains without burdening participants with "information overload." This concern led to an emphasis on skill building, as described below.

Emphasize Practical Skill Building: This training was conceptualized as a basic "Transition Training 101." To better serve families, care coordinators require in-depth knowledge about local, state and national programs and resources across multiple service systems, as well as skills for developing collaborative relationships with youth, families and other providers and for facilitating effective planning processes. Seven hours of training is not sufficient to effectively address these needs. Over the course of implementing and evaluating the pilot and first two trainings, we concluded that the emphasis would be best placed on development of practical skills, using the transition checklist and training exercises. The provision of information about resources became a secondary aspect of the curriculum. A "Transition Resource Book" was developed specifically for this training and distributed to each participant to meet their information needs (see *Provide Training Materials* section below for information on how to access the resource book materials online). The book was introduced in the first part of the day and references to it during the afternoon exercises helped illustrate how it can be used in work with youth, families and others involved in the transition process.

Provide Time for Networking: Pilot participant evaluations indicated that the opportunity to meet and talk with other professionals was very important to care coordinators and case managers. It is also important to promote a shared decision making and partnership model of transition planning that involves all key people involved in a youth's life. The *Make Things Happen* training curriculum and agenda reflect this objective.

The structure of the day included time for small group activity, a lunch period that did not involve a speaker or activity and a couple of short breaks. It was clear that participants appreciated this time to connect with each other. It was also important to allow time at the start of the day for introductions; participants indicated that even if they knew each other by name or title, many had never had the opportunity to meet and talk. These connections can be the launch pad for further collaborative efforts on behalf of YSHCN and their families.

Include Youth's Personal Stories and Experiences: The Youth Panel module of the training served to further promote the notions of shared decision-making and partnership in the transition process. In participant evaluations, it was consistently rated the most effective and meaningful portion of the day. It also served to promote and showcase youth leadership in affecting systems change. Given the diversity of transition issues, experiences, and possible life "trajectories" among YSHCN, we felt that the panel discussion would be most comprehensive if it included youth with a variety of special health care needs, life goals and experiences, as well as youth at different stages in their transition process (still in high school, in college, in the workforce, in a residential setting, etc.). It was also beneficial to enlist a facilitator who knew or was at least familiar with the panelists. This helped create a conversation that was more in-depth and interactive among panelists and between panelists and the audience.

Because transition is such a complex and challenging process for a youth and his/her family, it is not uncommon to hear reports about how difficult it has been for a particular youth to make his or her way to adulthood. In this training, we wanted to emphasize the *positive* - what are the resources, who are the people, and what are the experiences and steps that were most *helpful* to successful transitioning. In preparing the youth panelists and the facilitator for this segment, we encouraged them always to think in terms of the messages and advice they would give to others in order to raise expectations and aspirations and move ahead.

Offer Regional Trainings: Given the goal of improving the capacity of the care coordination system in Massachusetts, the Consortium Task Force felt it was important to offer training on a regional basis. The thinking was that regional events could promote partnership and collaboration among stakeholders within communities across the state. The *Make Things Happen* training program reflected this objective by offering trainings in Eastern, Central, and Western Massachusetts. The time built into the curriculum for networking and for activities in which participants work together promoted collaborative professional relationships and further advanced this objective. Furthermore, the "Transition Resource Book" included a number of regional and state-wide resources. The goal of promoting active involvement of care coordinators and case managers in the transition process was aided greatly by emphasizing what is available locally to help in that effort.

Provide Training Materials: As noted earlier, the project produced a "Transition Resource Book" for participants in the *Make Things Happen* training. It was created as a reference tool to disseminate information about local, state and national resources helpful to youth, families and providers. Given the enormous volume of transition information available in print and electronic formats, the Resource Book was created to be a *sampling* of resources and tools relating to each of the six major life domains and pertinent to Massachusetts families. As such, it is not an exhaustive collection of materials on transition and was created in binder format so that new information could easily be added. *Appendix G* contains an annotated guide of all items included in the "Transition Resource Book." Those wishing to create their own transition resource book can use this guide to identify the types of materials to include when creating a customized set of transition resources. Each item in the list contains a link to its URL (where available).

Practice Strategies for Engaging Youth and Families: We were committed to providing training participants with *strategies* for engaging youth and families in conversations about transition planning and the transition process. Not only did we want to illustrate these strategies, we also wanted to build in time for the care coordinators to practice using these strategies.

Care coordinators and case managers need practical skills for helping YSHCN and their families. Transition is a large, complex and often overwhelming topic for both families and care coordinators to approach. We felt that the training would be most helpful to the participants if they were provided with ways to negotiate all these complexities by breaking the topic areas into manageable smaller pieces. We wanted to help participants by having "tools," learning about and practicing *how to* engage with families and youth in conversations about transition planning and the transition process. For these reasons, the afternoon portion of the training focused on learning about and practicing how to work with families. We broke the large group into smaller working groups. They were given the task of developing a set of guiding questions to use in talking with a "sample" youth, about whom they were given some very basic information. Participants had been given a checklist of topic questions to assist them in this effort ("Transition Planning Checklist"). We then brought the large group together again to talk, think and share the most effective questions and strategies for having these conversations. At the conclusion of this segment, and the training itself, participants are provided with a handout entitled "When All is Said and Done," which highlights the most important steps that care coordinators can take and how they can encourage others (families and providers) to support the transition process.

As described above, the process used to develop, evaluate and modify the training program was an extensive and iterative one. Because considerable time and care were invested in considering the value and effectiveness of each content element, as well as how it was delivered, we believe the resulting curriculum includes a number of elements which ensure its relevance and usefulness.

How to Use the Curriculum

This curriculum includes seven modules (s*ee Table 1*). For each module, we describe how it fits into the overall goals of the training ("Purpose"), a suggested format and length, specific learning objectives and a content outline. The outline identifies the topics to be addressed in the module. Presenters can use this outline to develop a presentation that covers all of the information critical to the module's topic.

Overall Learning Objectives

At the conclusion of the training, participants will be familiar with the following information:

1. What are the key issues for youth with special health care needs as they transition into adulthood? These issues include: developing independent living skills, secondary education services and supports, after high school options (employment and post-secondary education), health and healthy living, benefits/housing/ finances/legal concerns, and recreation and social relationships.
2. How to better support youth and their families to address these issues during transition and help them develop and incorporate these into a transition plan.
3. The wide range of circumstances that exist for youth with special health care needs and the options and resources that are relevant to these various circumstances.
4. How to locate information about and refer youth and family to agencies, organizations, services, benefits and programs that can support youth as they transition into adulthood.
5. How to use practical tools, strategies and resources as they work with youth and families during transition.
6. The unique challenges YSHCN face in transitioning to the adult health care system, in developing and maintaining a healthy lifestyle and in minimizing secondary health conditions.

Target Audience

Care coordinators, case managers, and other professionals who work with youth and families across multiple service systems regarding transition into adulthood.

Training Format

A one-day, seven hour training, including a 15-minute morning break and a one-hour lunch and networking break. (*See Appendix A for a sample agenda*.)

Key Messages

The curriculum is designed to highlight and reinforce four key messages:

- ***Start transition planning early:*** Encourage youth and families to start planning early for transition to the adult service system and to create a vision statement for the youth's life as an adult.

- ***Raise expectations:*** Encourage participants to examine any pre-conceived notions they may have of what a youth can or cannot do as an adult and encourage them to talk with parents and the youth about their expectations for the youth's future.
- ***Care coordinators and other professionals have a critical role to play in the transition process:*** Emphasize the reasons why their role is significant in helping families to address the various transition issues, in supporting them in that process. Illustrate and practice ways in which a care coordinator can engage with families.
- ***Work collaboratively:*** There are many people who can help youth and their families during the transition process, such as those in the school system and the pediatrician's office. Seek them out and collaborate with them as much as possible.

Table 1. Training Modules

Module	Time (min)	Learning Objective(s) Addressed	Module Format	Supporting Materials
1. **Transition: What Is It and How Do You Plan For It?**	30	1,2,3	Single presenter	• MA Consortium Transition Checklist • MA Consortium Transition Resource Book
2. **Youth Panel**	60	1,2,3,4,5	Facilitated panel discussion	None
3. **Health and Healthy Living**	45	1,2,3,4,5,6	Single presenter	• MA Consortium Transition Checklist • MA Consortium Transition Resource Book
4. **Transitioning to the Adult Service System**	30	1,2,3,4	Single presenter	• MA Adult Service System Hand-out
5. **Developing a Transition Plan**	30	1,2,3,4,5	Guided discussion and group exercise using case vignette	• MA Consortium Transition Checklist • MA Consortium Transition Resource Book • Case Vignette
6. **Pulling It All Together**	90	1,2,3,4,5	Guided discussion and role play	• MA Consortium Transition Checklist • MA Consortium Transition Resource Book • Breakout Group Activity: Case Vignette • A Transition Planning Conversation: Using the *Make Things Happen* "Ashley" Vignette
7. **Key Messages Revisited**	30	1,2,3,4,5,6	Facilitated discussion	• "When All is Said and Done" handout

A description of Training Modules 1-7 is included on the following pages.

Module

1 Transition: What Is It and How Do You Plan For It?

Purpose Set the Stage

This section sets the stage for the day, providing basic information about what transition is all about, the many domains it includes, and the planning and resource tools that are associated with the training program. It is also the time to reinforce the message that care coordinators have a critical role to play in moving the transition planning process along. A parent who has been involved with the process can add a personal touch to this introduction, helping to make it concrete and more real, even adding an inspirational feel to the importance of this training program.

Format Single Presenter

- Suggested presenter: a parent-professional with skills and experience in transition planning

Time 30 minutes

- 20 minutes: presentation
- 10 minutes: questions and discussion

Learning Objectives

At the end of this module, participants will:

- Understand that transition is about moving towards adulthood, in all its various forms, with the goal of maximizing an individual's independence.
- Understand that care coordinators can and should play a central role in facilitating the transition process for YSHCN by early and thoughtful planning, connecting/staying connected to the various players, and encouraging action.
- Be familiar with the Transition Checklist as a helpful planning tool, addressing activities of daily living, secondary education, post-secondary education and employment, health care and healthy living, benefits, housing, legal & financial concerns, recreation/leisure, socialization and companionship.

What transition is:

- Can mean different things to different people
- Always comes with strong emotions
- About moving towards adulthood and maximum independence

What transition is not:

- A single point in time
- A one-dimensional process about switching to adult medical providers, higher education, employment or independent living

Transition planning should *Make Things Happen*:

- M = Maximized community involvement, through education, employment, recreation, independent living, and housing
- T = Thoughtful planning
- H = Healthy living

Care coordinators can facilitate the transition process through:

- Connecting themselves to various players
- Being familiar with and attentive to all transition domains
- Encouraging and supporting action
- Working as "team coaches" and "cheerleaders"

The Transition Checklist is used because:

- It is important to talk with youth and families about planning and the future
- It will help identify critical questions and guide planning conversations
- It addresses the variety of important domains:
  - ADL's (Activities of Daily Living)
  - Secondary education
  - After high school (employment and post-secondary education)
  - Health care and healthy living
  - Benefits, housing, legal and financial concerns
  - Recreation, leisure, socialization, companionship

Summing it all up:

- Working as a team makes a huge difference
- Care coordinators are supporting families as they move forward
- The earlier planning starts, the better the outcomes
- Use all available resources and contacts
- Share resources with youth, families, and professional colleagues
- Educate others involved in the youth's life
- *Make Things Happen*!

Sampling of key local and state resources:

- URLs, contact information for organizations and agencies, sample planning tools

Supporting Materials

- Massachusetts Consortium for CSHCN Transition Checklist (*Appendix B*)
- Massachusetts Consortium for CSHCN Transition Resource Book
- PowerPoint presentation to reinforce content if possible

Module 1

QUICK TIPS:

- Encourage presenter to share personal stories of his or her own child's transition
- Create environment of open discussion and sharing
- Emphasize an approach that focuses on the positive and what works well in the transition process

Module

2 Youth Panel

Purpose Add Real-World Inspiration

To add inspiration, color and reality to the day's messages by having participants hear from and talk with youth who have "lived transition," putting a face on the challenges. When a panel of youth and young adults shares their own experiences and insights about how others can help in the transition journey, the topics addressed in the day's training take on greater and more personalized meaning.

Format Moderated Panel Discussion

- Suggested panel: 3-4 youth/young adults, high school age to mid-twenties, who represent a variety of health care needs and living situations or plans.
- Ideally, the moderator should be familiar with the members of the panel.

Time 60 Minutes

- 45 minutes panel discussion
- 15 minutes questions from participants

Learning Objectives

At the end of this module, participants will:

- Understand key issues that youth face as they transition into adulthood
- Be familiar with what is important to youth in terms of the kinds of support and resources they need and want
- Better understand the unique challenges that YSHCN face regarding transition and health

Content Outline

Questions posed to the panel:

- Tell us about yourself: What are you doing now – are you in high school? College? Employed? Your living situation?
- What have been the biggest challenges for you as you've worked to transition, or have successfully transitioned, into adult health services, employment, college, living on your own, or becoming more independent?
- What services, programs or people have been *most helpful* to you as you are transitioning or have transitioned into adulthood?

- What messages or guidance from others have been most helpful to you in moving towards adulthood?
- What do you think is most important for people working in agencies and organizations to understand about youth with special health care needs transitioning into adulthood?

Supporting Materials

None

Module 2

QUICK TIPS:

- Assist youth/young adults with transportation to and from training
- Ensure an accessible location
- Enlist a facilitator who knows the youth/young adults well, perhaps one who has worked with them around recreational activities
- Emphasize the positive and what works – we all know too well what doesn't work and the challenges youth and families face

Module

3 Health and Healthy Living

Purpose Be Aware of All that Health Encompasses

To motivate participants to be alert to the array of health-related issues that YSHCN face as they become adults and to think about strategies for how to help youth take better care of their own health.

Format Single Presenter

- Suggested presenter: a pediatrician with experience working with YSHCN

Time 45 Minutes

- 35 minutes: presentation
- 10 minutes: questions and discussion

Learning Objectives

At the end of this module, participants will:

- Better understand the health risks that YSHCN face (such as risky health behaviors relating to diet, substance abuse and exercise), constraints on their access to preventive care, and challenges in finding adult doctors and providers.
- Better understand the pivotal role they can play in helping youth learn to manage their health care services and maintain their health.
- Better understand the importance of involving not only the youth, but also family members and others who are actively involved in their daily lives in supporting youth to manage their own health care and develop and maintain a healthy lifestyle.

Content Outline

Health and wellness – What does it mean?

- Is defined on individual level
- Must be considered in larger context
- Does not mean "problem free"
- Evolves over time
- All of the following are related and contribute to living and growing well and thriving:
  - Physical, mental, spiritual health
  - Thinking and learning
  - School and work
  - Personal relationships
  - Community participation
  - Independence

Health habits and lifestyle are part of a person's whole life.

- Diagnosis of primary condition is one part of the picture
- YSHCN are at risk of developing secondary health conditions. These are influenced by: personal characteristics (age, race, gender, class, etc.); personal risk factors (family history/genetics, behaviors); and public health factors (environmental exposures, access to care).

Habits and lifestyle are important in preventing secondary conditions.

- Specific health issues for adults with SHCN, e.g., gynecological issues, sexual health, obesity, dental/oral health, gastrointestinal issues, osteoporosis, heart disease, stroke, diabetes, asthma, cancer, injury and violence, infectious disease, depression, chronic pain
- Healthy People 2010 defines health standards for country
- What is the standard of care we can expect to achieve these objectives?
- Can individuals with SHCN expect the same standard of care? YES!
- Challenges for individuals with SHCN receiving same standard of care:
  - Accessibility: building, exam, room, table
  - Weights and measures
  - Getting the history – there are tools/techniques for better communication, which means better history
  - Getting full exam
  - Separating diagnosis from the big picture – thinking about the whole person
  - Expecting the same standard of care

Good health and healthy living guidance includes:

- Access to information and anticipatory guidance
- Addressing adolescent/young adult risk behaviors – sex, tobacco, substance abuse, violence, behaviors that lead to injury, etc.
- Addressing other factors that contribute to ill-health, e.g., unhealthy dietary habits, physical inactivity
- Consideration of barriers: embarrassment, lack of knowledge, fear, false assumptions (e.g., individuals with disabilities don't have sexual relations)

Care coordinators play pivotal role in helping youth learn to manage their health care and maintain healthy lifestyle – how?

- Encourage appropriate screenings
- Provide risk counseling, e.g., smoking, exercise
- Involve family members
- Discuss and promote importance of self-determination in health and health care
- Use Transition Checklist to identify key factors to support youth and families around health and health living issues, such as:

- Encourage youth to meet privately with doctor
- Assess need for health advocate/proxy/agent
- Review need to address health issues in IEP
- Assess youth's ability to assume increasing responsibility for managing own health care, e.g., understanding condition and medications, making appointments
- Discuss readiness to transfer to adult provider
- Remind youth and family about implications of "age of majority" (youth turning 18)
- Review health insurance situation

Case example for illustration and discussion.

Sampling of resources, checklist and tools available to assist in this process.

Supporting Materials

- Massachusetts Consortium for CSHCN Transition Checklist (*Appendix B*)
- Massachusetts Consortium for CSHCN Transition Resource Book
- PowerPoint presentation to reinforce content if possible

Module 3

QUICK TIPS:

- Focus on all aspects of health, not just issues related to transferring to adult provider
- Emphasize control youth can have over his/her health, e.g., lifestyle choices, risk behaviors, self-management

Module

4 Transitioning to the Adult Service System

Purpose See the Big Picture

To familiarize participants with the big picture of the Massachusetts adult service system --- the various agencies that provide supports to adults with special health care needs. The session offers both the overview and the flavor of the realities and complexities of the system and how it differs from the system for children.

Format Single Presenter

- Suggested presenter: upper level state administrator of transitional planning services

Time 30 Minutes

- 20 minutes: presentation
- 10 minutes: questions and discussion

Learning Objectives

At the end of this module, participants will:

- Understand the critical differences between services for children; through high school/turning 22 and the adult service system
- Understand the importance of early and timely referral to adult service agencies;
- Understand potential variations in eligibility requirements across adult service agencies and the ways in which access to these services can be initiated, such as the 688 Referral;
- Understand the notion of "age of majority" and its implications for access to educational and adult services; and
- Be aware of the array of resources available to care coordinators, case managers, family professionals, youth and families to assist them in navigating the adult service system.

Content Outline

NOTE: *In late 2007, the Commonwealth of Massachusetts Executive Office of Health and Human Services embarked on an effort to improve the eligibility and referral process from child services to adult services in the state. This effort is expected to be completed in early to mid-2008 and it is anticipated that eligibility criteria and procedures will change significantly from what currently exists. As a consequence, this module does not refer to specific eligibility requirements or procedures for any of the relevant adult service agencies. For further information on agency responsibilities, procedures, and eligibility requirements for state adult services, contact the Massachusetts Bureau of Transitional Planning at 617-573-1600.*

Transition Process Begins

- State mandate: Student on IEP must have Department of Education Transition Planning Form (TPF) developed and maintained with IEP
- Individual with Disabilities Education Act (IDEA) mandate: Student on IEP must have transition issues addressed in IEP in effect at time student turns 16
- Mandates for students on 504 plan TPF not required

Age of Majority

- Define "Age of Majority"
- In Massachusetts, the age of majority is 18
- School's responsibility to youth and families regarding effect on educational services

Eligibility for Adult Services

- Triggers that move youth into adult service system:
  - Graduates from high school
  - Turns 22
  - Passes MCAS (impact may vary depending on school system)
- Varies from agency to agency and even within an agency, depending on:
  - Nature and/or severity of condition
  - Age
  - Family circumstances
  - Whether individual has IEP or 504 Plan
  - Whether individual receives SSI or SSDI
  - Whether individual receives services through DYS or DSS

Procedures to Access Adult Services

- It's never too early to start transition planning, but certainly by the time individual is 15 years old
- "688 Referral":
  - What it is
  - Who qualifies
  - Procedures for initiating – when should it be done?
- Provide information about adult service agencies
- Other options?

Child World vs. Adult World

- The difference between service "entitlements" and service "protections"
- Individual with Disabilities Education Act (IDEA) provides entitlements to children through high school; this means schools must provide services

- Americans with Disabilities Act and the Rehabilitation Acts provide services protections; this means that although needed services and supports may be formally identified, there is no guarantee that they will be provided since they depend on state budget and availability as well as changing requirements at the federal level
- Highlight important milestones and issues to youth and family, e.g., age of majority, triggers to adult services

Supporting Materials

- Massachusetts Adult Service System hand-out (*Appendix C*)

Module 4

QUICK TIPS:

- Don't get mired in details – overview is best. However, if curriculum is adapted for specific population or setting, then details, such as eligibility requirements of adult agencies, could be addressed here.

Module

5 Developing a Transition Plan

Purpose Plan a Strategy

The topic of transition is large and complex and therefore can feel daunting for care coordinators and case managers to approach. The Transition Checklist and its companion Resource Book can be extremely helpful tools for care coordinators and case managers, providing strategies, specific approaches and resource information as they work with youth and their families. This segment of the training program is critical as it allows participants to practice using the Transition Checklist and Resource Book, to "dive in" using a real life example. Participants will leave the training feeling more comfortable and equipped to work with families in their caseload.

Format Small Group Exercise

- Small groups discuss a case vignette.

Time 45 Minutes

Learning Objectives

At the end of this module, participants will:

- Know how the Transition Planning Checklist and Transition Resource Book can be used to assist youth and families
- Be familiar with key questions to ask of youth and family regarding transition planning
- More effectively engage in conversations with youth and families about transition issues and planning

Content Outline

Instructions to the large group:

- We will be working together in smaller groups for 45 minutes.
- The case vignette that is being distributed is intentionally vague in details. Use the Transition Planning Checklist to plan a discussion with the youth described in the vignette and/or her family. Also use your own experience as you decide what topics and questions to address.
- One member of each breakout group should serve as the recorder since at the conclusion of the breakout session, the large group will come together and hear from each other the questions they developed for guiding a transition planning conversation. (See Module 6)

Participants are divided into groups of 6–8.

- In an effort to ensure that there is diversity in each group and that people who already know each other do not sit together, use a count-off or other technique to form the groups.
- Assign each group a different topic area from the Transition Planning Checklist with which to start their discussion. (A sign on each table identifying that topic area can be useful.) The intent is to assure that all the large domain areas are addressed by the end of the group sessions by having the different groups start at different points on the checklist. Groups are encouraged to proceed through the rest of the checklist once they have addressed their starting topic area.

Supporting Materials

- Massachusetts Consortium for CSHCN Transition Checklist (*Appendix B*)
- Massachusetts Consortium for CSHCN Transition Resource Book
- Breakout Group Activity: Case Vignette (*Appendix D*)

Module 5

QUICK TIPS:

- Do "hands-on" work with Transition Planning Checklist
- Mix work groups so that participants from same agency or organization are spread across groups
- Create a case vignette that is very general and doesn't provide a lot of detail about the youth's life – this will initiate conversation within the groups

Module

6 Pulling It All Together

Purpose Learn From Each Other

Continuing the conversations started in the previous module ("Developing a Transition Plan"), participants learn from each other and from the trainers about techniques to use in engaging with youth and their families in conversations about transition-related issues and services.

Format Guided Discussion (Large Group)

Time 75 Minutes

Learning Objectives

At the end of this module, participants will:

- Understand the importance of starting transition planning as early as possible and creating a vision statement for the youth's life as an adult
- Understand the importance of collaborating with others involved in transition planning and services for a youth
- Identify key questions to ask of youth and family regarding transition planning
- Know how to more effectively engage in conversations with youth and families about transition issues and planning

Content Outline

The large group comes back together to hear the outcomes of the small group discussions, supplemented with the facilitators' input about appropriate questions and topics to raise with the youth described in the vignette on the various transition large topic areas. *(The specific conversation questions which can be used as a starting point or as a supplement are included in Appendix E.)*

Domains:

- Activities of Daily Living
- Secondary Education
- After High School
- Health Care and Healthy Living
- Benefits, Housing, Legal & Financial Concerns
- Recreation and Leisure

Additional information and activity:

- After the group has developed its own questions and perspectives on the youth described in the case vignette, the facilitator may fill in other details about the youth (e.g. interests, social situation, and vocational interests) and then ask the following discussion question:
  - Based on the small group discussions and questions for transition planning conversation that you generated in your groups, do you think that answers to those questions would have provided you with the information you would need to help the youth and family in the planning process?

Supporting Materials

- Massachusetts Consortium for CSHCN Transition Checklist (*Appendix B*)
- Massachusetts Consortium for CSHCN Transition Resource Book
- Breakout Group Case Vignette handout (*Appendix D*)
- A Transition Planning Conversation: Using the *Make Things Happen* "Ashley" Vignette (*Appendix E*)
- PowerPoint presentation of sample questions if possible

Module

7 Key Messages Revisited

Purpose Reinforce the Message

To reinforce the key "take away" messages of the training and to provide an opportunity for final discussion and networking.

Format Open Discussion (Large Group)

Time 30 Minutes

Learning Objectives

At the end of this module, participants will:

- Understand the importance of examining pre-conceived notions they and others may have of what a youth can or cannot do as an adult and in expanding their expectations for an individual's future
- Illustrate how care coordinators and other professionals can play an important role in the transition process
- Understand the importance of collaborating with others involved in transition planning and services for a youth

Content Outline

This module is an opportunity to reinforce the key messages of the training session, field any additional questions, and share informational materials, brochures and announcements related to the transition topic.

- Because there is such a vast amount of information and strategies related to transition covered in this training, participants are given a handout with guidance on the priority steps to take. The handout includes similar priority steps to share with parents and providers. (The handout is entitled "When All is Said and Done… If You Do Nothing Else…")

Supporting Materials

- "When All is Said and Done --- If You Do Nothing Else…" (*Appendix F*)

APPENDIX A

Sample Transition Training Agenda

8:00 – 8:30 am	**Registration and Coffee**
8:30 – 9:00 am	**Welcome and Introductions**
9:00 – 9:30 am	**Transition: What Is It and How Do You Plan For It?**
9:30 – 10:15 am	**Health and Healthy Living**
10:15 – 10:30 am	**Break**
10:30 – 11:30 am	**Youth Panel**
11:30 am – Noon	**Transitioning to the Adult Service System**
Noon – 1:00 pm	**Lunch and Networking**
1:00 – 1:45 pm	**Developing a Transition Plan**
1:45 – 3:00 pm	**Pulling It All Together**
3:00 – 3:30 pm	**Key Messages Revisited and Wrap-up**

APPENDIX B: Transition Checklist[1]

Checklist instructions: The timeline provided here can be modified as developmentally appropriate for your family member/adolescent client. Use your judgment as to which items apply. Assessment and planning in the following areas can be used to anticipate needs, build on strengths, and link youth to appropriate supports and services. For Care Coordinators and Case Managers: ***This timeline will be most helpful when attached to the outside of a client's chart and referred to frequently.***

Note: The emphasis in this checklist and timeline is on preparation for adulthood. While some of these areas may be addressed within the secondary education setting, care coordinators/case managers can be most helpful in focusing on the adult years.

	Ages 11-13	Ages 14-16	Ages 17-19	Ages 20-22
I. ACTIVITIES OF DAILY LIVING (ADL)				
Assess the youth's skills and needs in the following areas: • Self-care (personal, hygiene, dressing) • Housekeeping (meal planning, shopping and cooking; maintaining and cleaning living space; cleaning and maintaining clothing; dealing with emergencies) • Consider need for personal care/home care provider • Assess youth's interest and skills in self-advocacy • Discuss importance and role of self-determination		☐	☐	☐
Identify new skills that can be learned and develop training plan		☐	☐	☐
Research resources/supports available for youth to develop these skills and increase independence in ADLs		☐	☐	☐
Evaluate mobility needs • Ability of youth to be independent in walking within and between all buildings used for daily activities • Consider youth's employment, education and recreation plans in context of mobility skills Identify needed and reasonable equipment/adaptations	☐	☐ ☐	☐ ☐	☐ ☐
Develop plan for acquiring equipment/adaptations identified above		☐	☐	☐
Review youth's travel/transportation needs and skills: • Need for and ability to access transportation, special transportation services, or other transportation option in the community • Ability to access and complete driver's education, identify adaptive driving programs, equipment, and vendors			☐	☐
Develop plan for acquiring skills, resources, equipment identified above		☐	☐	☐
Discuss and support youth's interests and skill development and link with relevant programs and services		☐	☐	☐
Assess youth's interest and skills in self-advocacy relating to planning and receiving training relating to their ADL skills		☐	☐	☐
Discuss importance and role of self-determination in making decisions about their ADL skills and training		☐	☐	☐

[1] This list is based on three excellent resources: 1) Blomquist, KB, Brown, G, Peerson, A, & Presler, EP. (1998) Transitioning to Independence: Challenges for Young People with Disabilities and Their Caregivers. Orthopaedic Nursing,17(3), 27-35; 2) Provider Transition Checklist and Timeline, in Transition Planning for Adolescents with Special Health Care Needs and Disabilities: A Guide for Health Care Providers (2000), Institute for Community Inclusion at Children's Hospital, Boston., pp 17-19; 3) Directions: Resources for Your Child's Care (2004), MA Department of Public Health.

	Ages 11-13	Ages 14-16	Ages 17-19	Ages 20-22
II. SECONDARY EDUCATION				
Ask the youth and family how you can participate in the Individualized Education Program planning process	☐	☐	☐	☐
Determine how youth and family would like you involved in achieving IEP goals	☐	☐	☐	☐
Discuss areas to include in IEP: • Health-related topics • ADL training • Services such as OT, PT, counseling • Vocational goals	☐	☐	☐	☐
Consider/discuss implications of passing MCAS on student's future planning and continuing services in secondary school	☐	☐	☐	☐
Make sure the youth and family know that federal law requires that transition planning must be included in the IEP in effect when the student turns 16. This means planning usually must begin by age 15, focusing on the student's course of study as it relates to the youth's long-term plans • Connect with school staff to ensure that transition planning is being done • Assist youth and family in developing and revising the Vision Statement • Explore vocational program vs. traditional education options		☐	☐	☐
Advise youth and family that starting at age 16, needed transition services must be included in the student's IEP. They should focus on the goals, objectives, activities and services related to transition. • Connect with school staff to reinforce need for statement of needed transition services. • Reinforce need to include health-care topics in service needs, as appropriate • Ensure that life skills development is addressed in IEP's service plan • Discuss including Occupational Therapist input/guidance in process		☐	☐	☐
Advise families that at age 18, a student has the right to make all decisions in relation to special education programs unless the family has petitioned the court for guardianship or the student has chosen to share or delegate decision-making to a parent • Assist in arranging any needed evaluation			☐	☐
Ensure that the adolescent and family understand that the entitlement to special education services ends when the youth graduates, withdraws from high school or reaches age 22 • Ensure youth and family understand that passing MCAS can be a sufficient requirement for "graduating"			☐	☐
Remind the youth and family that 2 years before leaving school, Chapter 688 referrals for those on IEPs must be made to adult service agencies • Assist family with these connections through the secondary school			☐	☐
Assess youth's interest and skills in self-advocacy regarding his/her education goals	☐	☐	☐	☐
Discuss importance and role of self-determination regarding his/her education and IEP	☐	☐	☐	☐
III. AFTER HIGH SCHOOL: POST-SECONDARY EDUCATION/EMPLOYMENT				
Initiate discussion of employment visions and goals • Explore options for assessing skills and interests		☐	☐	☐
Discuss work ethics, professional behaviors, employer expectations • Help youth and family identify the steps needed to address these issues and incorporate in student's IEP if appropriate		☐	☐	☐

	Ages 11-13	Ages 14-16	Ages 17-19	Ages 20-22
Help youth and family to understand the importance of "creative" ways to acquire job-related experiences as a young person: volunteer work, internships, camp employment, other community experiences	☐	☐	☐	☐
Initiate discussion of different routes to employment such as higher education, technical training or supported employment • Help youth and families to understand the different kinds of job supports and resources		☐	☐	☐
Reinforce the importance of networking for employment and to build necessary skills (job interviewing, resume preparation) • Help youth explore and identify ways in which they can network			☐	☐
Remind the youth and family that at age 14, individualized transition planning should focus on developing a vision for employment and education • Connect with school staff to ensure transition planning is underway • Help youth and families in including employment/vocational goals and action steps in student's IEP		☐	☐	☐
Advise families that at age 18, a student has the right to make all decisions in relation to special education programs, including employment planning, unless the family has chosen otherwise or has petitioned the court for guardianship			☐	☐
Make sure family understands that public benefits such as SSI provide incentives for employment			☐	☐
Discuss post-secondary options and resources, including colleges, community college, vocational programs • Help youth to understand how post-secondary programs differ from secondary with respect to supports provided • Discuss needed accommodations and how they might be accessed • Direct youth to financial aid information		☐	☐	☐
Discuss the role of the American Disabilities Act, and Section 504 in employment and post-secondary education		☐	☐	☐
Assess youth's interest and skills in self-advocacy in pursuing employment and post-secondary education	☐	☐	☐	☐
Discuss importance and role of self-determination in making employment and post-secondary decisions	☐	☐	☐	☐
IV. HEALTH CARE AND HEALTHY LIVING				
Assess youth's needs for a health advocate/agent/proxy to provide for and communicate about health-related needs	☐	☐	☐	☐
Review need to include health related topics in the IEP	☐	☐	☐	☐
Encourage the youth to meet privately with his/her provider for part of the office visit		☐	☐	☐
Assess youth's ability to assume increasing responsibility for his/her health care management, including: • Understanding health care condition and medications • Handling prescription needs • Scheduling medical appointments and related transportation • Requesting, reviewing copies of medical reports, letters, test results • Playing active role in appointments with providers		☐	☐	☐
Assess how dental needs are being addressed			☐	☐
Discuss youth's readiness for transfer to an adult health care provider • Encourage youth/family to discuss transferring with his/her pediatric provider(s) • Assist with identification of possible providers • Encourage youth to meet and interview adult providers			☐	☐
Remind family that when youth becomes a legal adult at age 18, decisions about health care, finances and other adult concerns become the youth's decision unless legal steps for guardianship/ conservatorship have been taken			☐	☐

	Ages 11-13	Ages 14-16	Ages 17-19	Ages 20-22
Review health insurance situation: continuing coverage through family; Medicaid/Medicare; educational or employment benefits			☐	☐
Remind the primary medical provider to enter into such discussions with the youth about risk behaviors and abuse.		☐	☐	☐
Assess youth's interest and skills in self-advocacy in managing their health care and in supporting their health choices	☐	☐	☐	☐
Discuss importance and role of self-determination in managing their health care and creating a healthy lifestyle • Discuss how to avoid secondary conditions relating to lifestyle and health choices	☐	☐	☐	☐
V. BENEFITS, HOUSING, LEGAL & FINANCIAL CONCERNS				
Highlight and assess youth's need for assistance with managing personal finances; help with information related to financial supports and accommodations • Paying bills • Checking/savings accounts • Debit/credit cards			☐	☐
Contact the school to ensure coordination with its life skills development program	☐	☐	☐	☐
Discuss public benefit work incentive programs, such as Social Security and MassHealth, and how youth can utilize them		☐	☐	☐
Help family identify any need, and resources, for assistance related to financial planning, document preparation (e.g., special needs trusts), estate management		☐	☐	☐
Help family review needs, and resources, for legal assistance related to guardianship, conservatorship		☐	☐	☐
Identify supports that will be needed to facilitate housing vision (e.g., personal care supports), adaptations, skill development training • Consider physical, emotional, and equipment supports			☐	☐
Assess youth's interest and skills in self-advocacy in managing their finances and benefits and making housing choices			☐	☐
Discuss importance and role of self-determination in making decisions about housing and managing their personal finances			☐	☐
VI. RECREATION/LEISURE, SOCIALIZATION, COMPANIONSHIP				
Assess youth's current level of involvement in the community, including school activities, clubs, organizations, cultural activities, religious groups, etc.	☐	☐	☐	☐
Discuss in-home and community recreation options	☐	☐	☐	☐
Discuss youth's interests in activities for fun, physical and mental fitness • Help identify resources • Help identify new skills or activities in which youth has interest	☐	☐	☐	☐
Help families develop strategies to foster friendships and avoid social isolation • Consider activities that can be done in/around home, neighborhood and school as well as in the community	☐	☐	☐	☐
Assess what information about health care needs should be available to increase access to recreational activities	☐	☐	☐	☐

	Ages 11-13	Ages 14-16	Ages 17-19	Ages 20-22
Consider/assess youth's personal behaviors, strengths, and needs which will contribute to personal fulfillment. Help identify resources, supports as necessary: • Anger management • Ability to solve problems, make decisions • Self-awareness and self-confidence • Organizational skills • Self-advocacy skills • Perception of self	☐	☐	☐	☐
Consider/discuss youth's interpersonal relationships • Connection with positive role models • Ability to make and keep friends • Dating; sexual activity	☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐
Explore the role that youth's culture and religion may play in long-term planning • Independence • Socialization • Health	☐	☐	☐	☐
Assess youth's interest and skills in self-advocacy in building social relationships, and participating in recreational/leisure/personal activities	☐	☐	☐	☐
Discuss importance and role of self-determination in their relationships and recreation and social activities	☐	☐	☐	☐
Link youth to programs and resources that will help them develop social relationships and find/participate in recreational/leisure activities	☐	☐	☐	☐

APPENDIX C

Massachusetts Adult Service System

1. The Massachusetts Rehabilitation Commission

Administrative Offices
27 Wormwood Street
Boston, MA 02210-1616
MRC Main Information Numbers: 1-800-245-6543 (Voice/TDD) or (617) 204-3600

The Massachusetts Rehabilitation Commission (MRC) assists individuals with disabilities to live and work independently. The MRC provides comprehensive services to people with disabilities that maximize their quality of life and economic self-sufficiency in the community. Multiple programs in the MRC work collaboratively to help individuals with disabilities. These programs are:

- *The Vocational Rehabilitation (VR) Services Program*- VR assists people who have a disabling condition who would like to find or return to work. VR also works closely with employers in the community to help create job openings and to help increase employer awareness regarding the benefits of diversity in the workplace. To be eligible for VR services from a State VR agency, a person must have a physical or mental impairment that is a substantial impediment to employment; be able to benefit from VR services in terms of employment; and require VR services to prepare for, enter, engage in, or retain employment.
- *The Community Services (CS) Program*- CS offers Brain Injury and Specialized Community Services, Protective Services for persons with physical disabilities who may be abused by their caregiver, Supported Living Services, Independent Living Center Services, Independent Living Programs for individuals turning 22, an Assistive Technology Program to enable individuals with severe disabilities equal access to employment and community life, Home Care assistance for persons with disabilities ages 18-59, and Consumer Involvement to improve the Commission's services.
- *The Disability Determination Services (DDS) Program*- DDS is funded by the Social Security Administration (SSA) and determines the initial and continued eligibility for federal SSI and SSDI benefits. Special outreach efforts are made to homeless shelters and individuals with HIV. The SSA makes disability payments under two programs: the Social Security Disability Insurance for workers (and their children or surviving spouses) who have Social Security coverage and the Supplemental Security Income (SSI) for people with little or no income and resources.

[The Commonwealth of MA Official Website Homepage: http://www.mass.gov. MA state agency information downloaded from http://www.mass.gov/?pageID=mg2subtopic&L=4&L0=Home&L1=State+Government&L2=Branches+%26+Departments&sid=massgov2&L3=All+Agencies.; the Bureau of Transitional Planning information downloaded from (http://www.sec.state.ma.us/cis/ciscig/e/e21e24.htm#e24, 11/07/07]

2. Department of Mental Health

Central Office
25 Staniford Street
Boston, MA 02114
Phone: 617-626-8000
TTY: 617-727-9842

DMH- Central Area Office
Worcester State Hospital
305 Belmont Street
Worcester, MA 01604
Phone (508) 368-3838
TTY (508) 752-0127

DMH- Metro Area Office
85 East Newton Street
Boston, MA 02118
Phone (617) 626-9200
TTY (617) 626-9257

DMH- Northeast Area Office
P.O. Box 387
Tewksbury, MA 01876-0387
Phone (978) 863-5000
TTY (978) 640-1193

DMH- Southeast Area Office
165 Quincy Street
Brockton, MA 02302
Phone (508) 897-2000
TTY (508) 897-2224

DMH- Western Area Office
P.O. Box 389
Northampton, MA 01061-0389
Phone (413) 587-6200
TTY (413) 586-6592

The Massachusetts Department of Mental Health (DMH), as the State Mental Health Authority, promotes mental health through early intervention, treatment, education, policy, and regulation so that all residents of the Commonwealth may live full and productive lives. DMH assures and provides access to services and supports to meet the mental health needs of individuals of all ages, enabling them to live, work and participate in their communities. The Department sets policy, promotes self-determination, protects human rights, and supports mental health training and research. Children, adolescents, and adults who meet both clinical and service need criteria of the DMH regulations are eligible for DMH community-based services. The array of community services include:

- residential options for children and adults
- case management
- in-home treatment for children and adolescents
- flexible supports for adults and children in the community
- outpatient services
- dual diagnosis treatment
- clubhouses (DMH eligibility not required)
- day treatment
- skills training
- supported employment

3. Department of Mental Retardation

Central Office
500 Harrison Avenue
Boston, MA 02118
Phone: (617) 727-5608
TTY: (617) 624-7783

DMR- Central West Region
171 State Avenue
Palmer, MA 01069
Phone (413) 284-1500
TTY: (413) 284-1554

DMR- Northeast Region
Hogan Regional Center
PO Box A
Hathorne, MA 01937
Phone (978) 774-5000

DMR- Metro Region
200 Trapelo Road
Waltham, MA 02452
Phone (781) 314-7501

DMR- Southeast Region
68 North Main Street
Carver, MA 02330
(508) 866-5000

The Department of Mental Retardation (DMR) is dedicated to creating, in partnership with others, innovative and genuine opportunities for individuals with mental retardation to participate fully in and contribute to, their communities as valued members. The types of specialized services and supports include day supports, employment supports, residential supports, family supports, respite, and transportation. DMR provides these services through facilities and community-based state operated programs and by contracting with 235 private provider agencies. DMR services and programs include:

[The Commonwealth of MA Official Website Homepage: http://www.mass.gov. MA state agency information downloaded from http://www.mass.gov/?pageID=mg2subtopic&L=4&L0=Home&L1=State+Government&L2=Branches+%26+Departments&sid=massgov2&L3=All+Agencies.; the Bureau of Transitional Planning information downloaded from (http://www.sec.state.ma.us/cis/ciscig/e/e21e24.htm#e24, 11/07/07]

- *Spectrum of Services*- DMR strives to provide individuals and families with clear information on regulations, policies, specialized services and supports, and community resources in a manner that is responsive to diverse ethnic, cultural, and linguistic groups.
- *Autism Spectrum Services*- The Home and Community-Based Services (HCBS) Waiver Program is a Medicaid program designed to provide services to help children with autism to remain in their homes and actively participate in their families and in their communities. This Waiver Program is designed to provide one-to-one behavioral, social, and communication-based interventions through a service called Expanded Habilitation, Education.
- *Provider Licensure and Certification*- An emergency evacuation plan and forms, a quick guide and manual to the licensure and certification process, licensure and certification guidelines, and training materials are available.
- *Contracting and Procurement*- The links available present information that providers and others may use to conduct business when providing contracted services to DMR.

4. Department of Public Health

DPH - Main Office
250 Washington Street
Boston, MA 02108-4619
(617) 624-6000
TTY (617) 624-6001

DPH- Boston Regional Health Office
10 Malcolm X Blvd.
Roxbury, MA 02119

DPH - Central Regional Health Office
180 Beaman Street
West Boylston, MA 01583
(508) 792-7880
TTY: (781) 774-6619

DPH- Metrowest Regional Health Office
5 Randolph Street
Canton, MA 02021
(978) 851-7261

DPH- Northeast Regional Health Office
East Street
Tewksbury, MA 018765
(781) 828-7700

DPH- Southeast Regional Health Office
5 Randoph Street,
Canton, MA 02021
(781) 828-7700
TTY: (781) 774-6619

DPH- Western Regional Health Office
23 Service Center, Northampton, MA 01060
(413) 586-7525

The Department of Pubic Health is dedicated to our mission, to serve all the people in the Commonwealth, particularly the under served, and to promote healthy people, healthy families, healthy communities and healthy environments through compassionate care, education and prevention.

DPH Mission

- We believe in the power of prevention.
- We work to help all people reach their full potential for health.
- We ensure that the people of the Commonwealth receive quality health care and live in a safe and healthy environment.
- We build partnerships to maximize access to affordable, high quality health care.
- We are especially dedicated to the health concerns of those most in need.
- We empower our communities to help themselves.
- We protect, preserve, and improve the health of all the Commonwealth's residents

Below is a list of the bureaus and programs of the Massachusetts Department of Public Health:

Communicable Disease Control
Environmental Health Assessment
Family and Community Health
Quality Assurance and Control
Health Information, Statistics, Research, and Evaluation
HIV/AIDS
Hospitals
Laboratory Sciences

[The Commonwealth of MA Official Website Homepage: http://www.mass.gov. MA state agency information downloaded from http://www.mass.gov/?pageID=mg2subtopic&L=4&L0=Home&L1=State+Government&L2=Branches+%26+Departments&sid=massgov2&L3=All+Agencies.; the Bureau of Transitional Planning information downloaded from (http://www.sec.state.ma.us/cis/ciscig/e/e21e24.htm#e24, 11/07/07]

Library System
Massachusetts Tobacco Control Program
Office of Healthy Communities
Office of Multicultural Health
Regional Health Offices
State Office of Pharmacy Services
Substance Abuse Services
State Laboratory Institute

5. Massachusetts Commission for the Blind

MCB- Boston Office
48 Boylston Street
Boston Ma 02116-4718
Phone: (617) 727-5550 VOICE
TDD (617) 626-7685

MCB-Worcester Office
390 Main Street
Suite 620
Worcester, Ma 01608-2111
Phone (508) 754-1148

MCB- Springfield Office
436 Dwight Street
Room 109
Springfield, Ma 01103
Phone (413) 781-1290

MCB- New Bedford Office
800 Purchase Street
Suite 290
New Bedford, Ma. 02740-6344
Phone (508) 993-6140

The Massachusetts Commission for the Blind (MCB) provides the highest quality rehabilitation and social services to blind individuals, leading to independence and full community participation. MCB accomplishes this critical mission by working in partnership with legally blind consumers, families, community agencies, health care providers, and employers. MCB is committed to principles such as offering individuals choices among services tailored to meet their unique needs and eliminating barriers to employment and community integration. A confidential register of legally blind individuals is also maintained to ensure that these individuals receive services and benefits for which they are eligible and to collect important information on the causes of blindness. MCB programs & services include:

- *Vocational Rehabilitation*- VR offers an Assistive Technology for the Blind Program that may be able to help in the workplace, classroom, or the management of the individual's home, and Employment Services where a MCB Employment Specialist works cooperatively with the VR counselor to prepare individuals for the job search process.
- *Independent Living Social Services*- Services are for legally blind individuals who need assistance to become more independent.
- *Specialized Services for Specific Populations*- Services are provided for children, elders, and deaf/blind multi-handicapped populations.
- *Rehabilitation Teaching*- Rehabilitation Teachers provide skills evaluation and instructions in the home and on job sites geared towards improving skills and enhancing independence.
- *Orientation and Mobility*- The Orientation and Mobility Department provides individualized training programs within the home, neighborhood, workplace, and community to help bring the individual back to independent travel.
- *Medical Assistance*- MCB provides health care services for residents of the Commonwealth who are legally blind and financially and medically needy. It is the state agency in Massachusetts that administers most MassHealth Services (commonly known as Medicaid) for legally blind persons.
- *Vending Facility Program*- This program prepares persons who are blind for a challenging and rewarding career in concessions management.
- *Ferguson Industries for the Blind*- Ferguson Industries for the Blind provides legally blind persons with employment opportunities in a variety of areas.
- *Consumer Assistance & Program Support (CAPS)*- CAPS provides counselors whose responsibility is to ensure that Commission staff and the legally blind community work together in achieving common goals.

[The Commonwealth of MA Official Website Homepage: http://www.mass.gov. MA state agency information downloaded from http://www.mass.gov/?pageID=mg2subtopic&L=4&L0=Home&L1=State+Government&L2=Branches+%26+Departments&sid=massgov2&L3=All+Agencies.; the Bureau of Transitional Planning information downloaded from (http://www.sec.state.ma.us/cis/ciscig/e/e21e24.htm#e24, 11/07/07]

6. Massachusetts Commission for the Deaf and Hard of Hearing

Executive Office
150 Mount Vernon Street, Fifth Floor
Dorchester, MA. 02125

MCDHH- Southeastern Massachusetts Regional Office
61 Industrial Park Road
Plymouth, MA 02360

MCDHH- Western Massachusetts Regional Office
Springfield State Office Building
436 Dwight Street, Suite 204
Springfield, MA 01103

MCDHH- Central Massachusetts Regional Office
340 Main Street, Suite 700
Worcester, MA 01608

The Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH) is the principal agency in the Commonwealth on behalf of people of all ages who are deaf and hard of hearing, established by Massachusetts General Laws, Chapter 6 §191-197. All functions and services are carried out in order to enable deaf and hard of hearing individuals to have access to information, services, education, and opportunities which will be equal to those of able-bodied people who hear. These services will enable each deaf and hard of hearing individual to live productively and independently while assuming fullest responsibilities as a citizen. MCDHH responsibilities include but are not limited to advocacy, ensuring the accessibility and quality of existing services, and recommending new services as needed. Other duties are providing or ensuring provision of direct specialized services including case management, interpreter services, technology services including telecommunication and assistive listening devices, independent living services, and information services. MCDHH services are as follows:

- *Communication Access, Training, and Technology Services*- The CATTS Department acts as the initial information resource for the public related to issues of deafness and hearing loss, including communication access training.
- *Case Management and Social Services*- Deaf, late-deafened, and hard of hearing people (birth through elderly) in need of social, educational, and human services are eligible for MCDHH case management. State and private agencies seeking information, consultation or technical assistance related to Deaf, late-deafened, and hard of hearing clients are also eligible for MCDHH services.
- *Interpreter/CART Referral Services*- The Department for Interpreter/CART Services provides a statewide Interpreter and CART Referral Service.
- *Independent Living Services for Deaf and Hard of Hearing*- Participants work with Independent Living Specialists for the Deaf to set and achieve their own personal goals for independent functioning in family, school, employment, and community situations.

7. Massachusetts Department of Social Services

24 Farnsworth Street
Boston, MA 02210
Phone (617) 748-2000

DSS- Southeast Regional Office
141 Main Street
Brockton, MA 02401
Phone (508) 894-3700

DSS- Greater Boston Regional Office
Esquire Building
50b Park Street
Dorchester, MA 02122
Phone (617) 822-4840

DSS- Central Regional Office
25 Winthrop Street
Suite 300
Worcester, MA 01604
Phone (508) 929-2130

DSS- Metro Regional Office
30 Mystic Street
Arlington, MA 02474
(781) 641-8200

DSS- Regional Office
1537 Main Street, 2nd Floor
Springfield, MA 01103
Phone (413) 452-3350

DSS- Northeast Regional Office
Everett Mills
15 Union Street, 2nd Floor
Lawrence, MA 01840
Phone (978) 557-2700

[The Commonwealth of MA Official Website Homepage: http://www.mass.gov. MA state agency information downloaded from http://www.mass.gov/?pageID=mg2subtopic&L=4&L0=Home&L1=State+Government&L2=Branches+%26+Departments&sid=massgov2&L3=All+Agencies.; the Bureau of Transitional Planning information downloaded from (http://www.sec.state.ma.us/cis/ciscig/e/e21e24.htm#e24, 11/07/07]

The Massachusetts Department of Social Services (DSS) is committed to protecting children and strengthening families. When children are abused or neglected by the people responsible for caring for them, DSS will intervene to ensure the safety of the children. The Family Support Unit of the MA DSS has two main goals: to build the capacity of high risk communities to support families and prevent child abuse and neglect, and to integrate a strengths-based approach into the Department's practice. DSS programs and services include:

- *Foster Care*- DSS works first and foremost to keep families together. Foster care services and licensing information are available.
- *Adoption*- Children come into the care of DSS at different ages and under different circumstances. The Department works closely with the child's parents to make their home a safe environment for the child, and in the majority of cases the child returns home. Children who cannot safely return home need permanency, and their goal is often changed to adoption. While they wait for placement with an adoptive family, most of the children are in foster homes and a few are in residential treatment centers.
- *Adolescent Services*- DSS is committed to providing adolescent services that stress positive development and youth empowerment. The Adolescent Services Unit at DSS Central Office provides programming and support to all youth 14 and older who are in the Department's care and custody. The Department encourages youth to take an active role in all aspects of planning for services.
- *Domestic Violence and Children*- Services protecting children and battered women experiencing family violence are available.
- *Collaborative Assessment Program (CAP)*- This program provides a single point of entry into DSS and/or DMH services for youth who have serious emotional disturbance and are at risk of residential placement.

8. Department of Youth Services

Tower Point
27 Wormwood Street, Suite 400
Boston, MA 02210-1613
Phone (617) 727-7575

DYS- Central Regional Office
Sharp Building - 288 Lyman Street - P.O. Box 1380
Westboro, MA 01581
Phone (508) 792-7611

DYS- Metropolitan Regional Office
425 Harvard Street
Dorchester, MA 02124
Phone (617) 740-0100

DYS- Northeast Regional Office
360 Merrimack Street, Building 9
Lawrence, MA 01843
Phone (978) -686-4014, ext.400

DYS- Southeast Regional Office
Murray Building - 60 Hodges Ave
Taunton, MA 02780
Phone (508) 824-1484

DYS- Western Regional Office
280 Tinkham Road
Springfield, MA 01129
Phone (413) 783-0781

The Department of Youth Services (DYS) is the juvenile justice agency of the Commonwealth of Massachusetts. The mission of DYS is to protect the public and prevent crime by promoting positive change in the lives of youth committed to its custody, and by partnering with communities, families, government, and provider agencies. This mission is accomplished through interventions that build knowledge, develop skills, and change the behavior of the youth in its care. DYS operates a total of 98 programs for youth under its care which includes 63 facilities, ranging from staff secure group homes to highly secure locked units and 35 programs to service youth who live in the community (residing with a parent, guardian, foster parent or residing in an independent living program). DYS programs and services are as follows:

- *Client Services*- The Client Services unit oversees the delivery of a host of clinical and support services.
- *Clinical Services*- Upon commitment to DYS (within the first 30 to 45 days), youth receive a comprehensive assessment.
- *Health Services*- DYS provides health services to all clients who are in out-of-home placements.
- *Victim Services*- The Victim Services Unit provides information, support and notification to victims of juvenile crime whose offenders are in the custody of DYS.

[The Commonwealth of MA Official Website Homepage: http://www.mass.gov. MA state agency information downloaded from http://www.mass.gov/?pageID=mg2subtopic&L=4&L0=Home&L1=State+Government&L2=Branches+%26+Departments&sid=massgov2&L3=All+Agencies.; the Bureau of Transitional Planning information downloaded from (http://www.sec.state.ma.us/cis/ciscig/e/e21e24.htm#e24, 11/07/07]

- *Community Services*- Community Reentry Centers are located in cities and towns with the highest concentrations of at risk youth.
- *Substance Abuse*- Substance abuse prevention and intervention services are offered by DYS to their clients.
- *Juvenile Justice Legal Issues*- A mission of the DYS is to provide a comprehensive and coordinated program of delinquency prevention and services to delinquent children and youth referred or committed to the Department by the courts. These services are designed to advance public safety and prevent crime by promoting the acquisition of pro-social skills and providing positive opportunities for juvenile offenders.
- *Policies*- The DYS Policies and Procedures are available.
- *Education*- The DYS Education, Job Training and Employment Services Unit provides a comprehensive and integrated range of services based on the needs, experiences, and competencies of the youth.

9. Bureau of Transitional Planning

Executive Office of Health and Human Services
1 Ashburton Place, Room 1109
Boston, MA 02108
Phone: 617-573-1600

Within the Executive Office of Human Services, the Bureau of Transitional Planning is responsible for implementation of Chapter 688 of the Acts of 1983 which entitles severely disabled Chapter 766 students, as defined in the statute, to transitional plans as of age 22. These plans will link them to appropriate adult service delivery agencies.

[The Commonwealth of MA Official Website Homepage: http://www.mass.gov. MA state agency information downloaded from http://www.mass.gov/?pageID=mg2subtopic&L=4&L0=Home&L1=State+Government&L2=Branches+%26+Departments&sid=massgov2&L3=All+Agencies.; the Bureau of Transitional Planning information downloaded from (http://www.sec.state.ma.us/cis/ciscig/e/e21e24.htm#e24, 11/07/07]

APPENDIX D

Break-Out Group Activity

Case Vignette

Ashley is a 16 year-old girl with cerebral palsy who lives with her parents and two siblings. Her father works full-time for the post office and her mother works part-time as an administrative assistant. She's just started the 11th grade and her favorite subjects are English, Social Studies and Geography.

She uses a power wheelchair for mobility at school, although she can walk short distances with crutches. She has slight speech impairment, although her speech is understandable most of the time. She has only partial use of her hands. Ashley also has a swallowing dysfunction which puts her at risk for aspiration when she eats. When IQ tested, Ashley scored at 85. She is mostly in mainstream classes, but does receive additional educational supports and accommodations, particularly in math.

Ashley has received Supplemental Security Income and MassHealth benefits since shortly after she was diagnosed with cerebral palsy at the age of 3 months. Ashley receives most of her health care from a Cerebral Palsy clinic at a local hospital. Her mother handles all of her medical care, schedules and accompanies her to all medical appointments and also assists Ashley with activities of daily living, such as getting dressed and bathing.

Ashley has been in Girl Scouts since she was seven years old, starting as a Brownie. During the summer, Ashley usually goes to camp for several weeks, which she enjoys very much and she takes an active role in camp activities. When she is not at camp during the summer, she mostly spends time at home reading and watching television.

In Your Break-Out Group

- What questions would you ask Ashley and her family to help in transition planning?
  - For example, "Do you (does Ashley) take any medications?"
  - For example, "Do you have any ideas about what you'd like to do after you finish high school?"
- Ask one person in your group to record your questions.

Thank you to Linda Long-Bellil of the Center for Health Policy and Research at University of Massachusetts Medical School and Dr. Bev Nazarian of UMass Medical Center for their assistance in creating this case vignette.

APPENDIX E

A TRANSITION PLANNING CONVERSATION
Using the Make Things Happen "Ashley" Vignette

ACTIVITIES OF DAILY LIVING:

1. Do you need help with personal care, such as personal hygiene, dressing, eating, and other household and money management responsibilities?
    a. Youth Transition Survey: 8-page self assessment tool for youth http://www.hrtw.org/tools/documents/A6AZ_YOUTH_assessment.doc
    b. These checklists were developed by the Youth In Transition Project (1984-1987) at the University of Washington Division of Adolescent Medicine Adolescent Autonomy Checklists *Skills At Home* http://depts.washington.edu/healthtr/Checklists/home.htm
    c. New Mexico CMS Youth Transition Plan in English and Spanish Comprehensive checklist from New Mexico's Children's Medical Services including health knowledge, daily living, education and employment, living arrangements, transportation, recreation/social relationships, emergency plans, and record keeping. http://www.hrtw.org/tools/documents/ANM_CMS_Transition_Plan_English.doc
    d. Now that we've talked about the needs you have (using the assessment), decide if appropriate to talk about need for personal care attendant (PCA).
    e. See Chapter 2, Resource Book, on Independent Living Centers and MA Turning 22 Program
2. How comfortable do you feel speaking up to get what you need or want?
    a. Family Voices Kids as Self-Advocates http://www.fvkasa.org/
    b. Partners for Youth with Disabilities http://www.pyd.org/
3. Are there new skills you'd like to learn around managing your life, like food shopping, banking and money management
    a. MA ILC's http://www.virtualcil.net/cils/query-iandr.php?state=ma (list in Resource Book)
    b. Contact school staff about availability of skills training
4. Are you comfortable and able to get to the places you need and travel in your community, and around school?
5. Need more equipment? Travel training? Other DME?
    a. Contact school
    b. Is there a need to involve mobility assessments through specialized providers? Speak to PCP for referral if needed
6. Is driving a car something you want to be able to do?
    a. See Resource Book

This hand-out is part of the "Ashley" case vignette training exercise in *the Make Things Happen* transition training. It serves as an example of the kinds of questions that might be asked during conversations with a youth and his or her family about the youth's transition to adulthood.

SECONDARY EDUCATION:

1. Are you attending and participating in your IEP meetings?
2. Have you and your family taken the time to write a vision statement for your IEP?
3. Does your IEP specify all the services you need through your school?
    a. MA Department of Education – Special Education Services information http://www.doe.mass.edu/sped/iep/
4. Are you getting the services you need through your school, such as OT, PT and other specialized services or skills training?
5. Have you thought about what you want to do when you leave high school?
6. Has your school completed the Transition Planning Form (TPF)?
7. Has a 688 Referral been made? If so, to which agency?
8. Where do things stand with MCAS?

AFTER HIGH-SCHOOL:

1. Have you had any work-related experience, such as volunteer work, summer jobs, or community experiences?
2. Have you thought about ways to get more work-related experience while you're still in school?
3. Have you thought about the kind of job you'd like?
4. Have you thought about continuing your education after high school? If so, have you thought about the kinds of supports you'd need to do this.
5. I know you're receiving SSI, do you know about the work incentives that SSI offers so that you can work and keep your SSI benefits?

HEALTH CARE AND HEALTHY LIVING:

1. Do you need help talking with your doctors or nurses? If you don't need help communicating, are you meeting privately with your doctor for at least some of your visit?
2. Does your IEP cover health issues and does it need to?
3. Are you able to describe your health condition?
4. Have you thought about becoming more independent in managing your health care, such as scheduling appointments, handling your health insurance?
5. Do you see a dentist twice a year?
6. Have you and your doctor talked about changing to an adult doctor when it's time?
7. Are you getting the medical care and insurance coverage that you need?

BENEFITS, HOUSING, LEGAL, AND FINANCIAL CONCERNS:

1. What thinking and planning has been done around the need for guardianship and/or conservatorship?
2. Are you getting any help at school with managing your money?
3. Do you need information about public benefits, such as work incentive programs?
4. Have you given any thought as to where Ashley will live as an adult?

This hand-out is part of the "Ashley" case vignette training exercise in *the Make Things Happen* transition training. It serves as an example of the kinds of questions that might be asked during conversations with a youth and his or her family about the youth's transition to adulthood.

RECREATION/LEISURE, SOCIALIZATION, COMPANIONSHIP:

1. How do you spend your free time?
2. Are you involved in any sports activities?
3. Will you be continuing in Girl Scouts?
4. Who are your special friends?
5. Do you want any help getting involved in any activities?
6. Do you know about recreational programs for kids who have disabilities? If not, would you like to know more?
7. Do any of your health needs affect how much you can get together with other kids or get involved in activities?

ADDITIONAL INFORMATION:

- Gets along with her peers
- Teachers and parents are concerned about her being isolated
- She likes music, reading books, and is interested in politics and social issues
- She says when she grows up, she'd like to have a job where she can help people
- She used to get PT and OT at school, but these services have been discontinued
- Her family has had a successful working relationship with the Girl Scout organization in providing accommodations for Ashley. But now, although she wants to continue, she's encountering challenges with the organization as the activities and scouting requirements become more involved and complex.

Looking back on the questions you discussed in your group and this discussion, would you have an accurate picture of Ashley's life and the things to address relating to her transition to adulthood?

This hand-out is part of the "Ashley" case vignette training exercise in *the Make Things Happen* transition training. It serves as an example of the kinds of questions that might be asked during conversations with a youth and his or her family about the youth's transition to adulthood.

APPENDIX F

When All Is Said And Done -- If You Do Nothing Else…

FOR CARE COORDINATORS:

1. Work with the youth and the family to create a vision statements for the youth's future.
2. Connect with the school – get involved in IEP meetings and know the school staff involved with the youth.
3. Ensure that health issues are addressed in the IEP.

FOR PARENTS:

1. Work with your child to start managing their own health care, e.g., ordering medications and supplies, seeing providers alone when possible.
2. Connect with the school – get involved in IEP meetings and know the school staff involved with your child.
3. Start transition planning early and thinking about options after high school, long-term legal and financial issues (e.g., eligibility for public benefits, guardianship).

FOR PROVIDERS:

1. At around age 13, start seeing your teenage patient alone at least for part of an appointment.
2. Start talking with the youth and family about when and how they will transfer to an adult provider and when they're ready, help them find one.
3. Address broader health issues with the youth, such as nutrition, risky health behaviors, sexuality, and exercise.
4. If a youth has a care coordinator or case manager, connect with them at least once a year.

APPENDIX G

Transition Resource Book Contents

This appendix is an annotated list of all items included in the "Transition Resource Book" created as a reference tool for participants in the *Make Things Happen* training to disseminate information about local, state and national resources helpful to youth, families and providers. Given the enormous volume of transition information available in print and electronic formats, the Resource Book was created to be a *sampling* of resources and tools relating to each of the six major life domains and pertinent to Massachusetts families. As such, it is not an exhaustive collection of materials on transition and was created in binder format so that new information could easily be added. Those wishing to create their own resource book can use this annotated list as a guide to identify the types of resources to include in a customized binder. Each item in the list contains a link to its URL (where available).

SECTION 1: GENERAL RESOURCES

1. **Transition Checklist.** *Massachusetts Consortium for Children with Special Health Care Needs, provided as Appendix B of this document; also available at*: *http://www.neserve.org/maconsortium/pdf/Transition_to_Adulthood/MTH_Curric_Appendix_B_Transition_Checklist.pdf, March 22, 2007.* A transition checklist and timeline developed to help assess a youth's particular skills and needs in the various life areas to be considered during the transition process, such as education, employment, activities of daily living, health, benefits, finances, and more. The checklist can be used to plan for future actions and link youth to appropriate supports and services.

2. **Internet-Based Resources.** *Massachusetts Consortium for Children with Special Health Care Needs, March 2007.* A list of general transition-related, internet-based resources produced as part of the MA Consortium for CSHCN *Make Things Happen* transition training curriculum. Available at: *http://www.neserve.org/maconsortium/pdf/Transition_to_Adulthood/MTH_Transition_Resource_Book_Web_List.pdf*

3. **Massachusetts State Resources.** *National Dissemination Center for Children with Disabilities, retrieved from http://www.nichcy.org/stateshe/ma.htm, March 22, 2007.* A list of Massachusetts state agencies and organizations that provide services and support youth and adults with disabilities and special health care needs.

4. **Transition Planning for Youth with Disabilities**, *article by Linda Long-Bellil in Disability Issues, Spring 2006, Vol.26, No.1, a publication of the MA Medicaid Infrastructure and Comprehensive Employment Opportunities Grant and Spaulding Rehabilitation Hospital, retrieved from http://www.masschec.org/AccessDocument.cfm?document=DisIssuesSpring06%2Epdf, March 22, 2007.* The Disability Issues newsletter is published quarterly and shares current information about the world of disability, new initiatives, and other helpful information to the disability community in MA.

5. **Pathways To Success By 21 (P21) Resources: Graduation Rate Summit March 5, 2007, The Power of Community Partnerships Program Binder Compilation,** *retrieved from http://www.p21.us/resources/summit_binder_compilation.doc, March 22, 2007*. Describes initiatives and resources from youth-serving state agencies and descriptions of innovative practices identified through the Pathways to Success by 21 (P21) program, a statewide effort to improve the future prospects for vulnerable youth ages 16-21 across the Commonwealth of Massachusetts including those who are in school and those who are out-of-school and out-of-work.

SECTION 2: ACTIVITIES OF DAILY LIVING (ADL)

1. **A Guide to Driving**, *prepared by Maggy Haugen, Southwest Institute for Families and Children with Special Needs, retrieved from www.hrtw.org/tools/pdfs/AZ_A%20Guide%20to%20Driving.pdf, March 22, 2007.* A useful resource for people with physical limitations who drive or want to drive, this brochure outlines the steps involved in getting a learner's permit and driver's license, as well as other important driving information and resources.

2. **Types of Transportation Services**, *retrieved from the Massachusetts Rehabilitation Commission website at http://www.mass.gov/?pageID=eohhs2terminal&L=6&L0=Home&L1=Consumer&L2=Disability+Services&L3=Transportation&L4=Understanding+Transportation+Systems&L5=Community+Transportation+Information&sid=Eeohhs2&b=terminalcontent&f=mrc_c_trans_community_types&csid=Eeohhs2, March 22, 2007.* Describes the variety of transportation options available in the community including public transportation options and options for special populations such as individuals with disabilities.

SECTION 3: SECONDARY EDUCATION

1. **College Prep Timeline**, *PACER Center, Commission for Children with Special Health Care Needs, retrieved from http://www.chfs.ky.gov/NR/rdonlyres/D7A797D8-351F-407B-9032-EE70DF2A376B/0/CollegePrepTimeline.pdf, March 22, 2007.* A timeline for students to follow to help them plan for college.

2. **Top Ten Things to Think About As You Prepare For Your Transition to Adulthood**, *article by Joyanne Cobb, George Washington University HEATH Resource Center, July 2004, retrieved from http://www.heath.gwu.edu/node/679, March 22, 2007.* A top ten tip list for transitioning students to help them anticipate the necessary steps to a successful transition, identify areas where they can seek guidance from family and counselors, develop self-advocacy skills, and build confidence in achieving postsecondary education goals.

3. **Special Education Chapter 688 Brochure**, *retrieved from the Massachusetts Department of Education (DOE) website at http://www.doe.mass.edu/sped/688/, March 22, 2007.* A brochure describing the Chapter 688 referral process and MA DOE Chapter 688 information.

4. **A Citizen's Guide to Turning 22/Chapter 688 Brochure**, *MA Transitional Planning Program, Special Education to Adult Life, Health and Human Services, Rev. January 4, 2007.* A brochure describing the key points of Chapter 688, eligibility, transitional planning, and important contact information.

5. **Vocational Rehabilitation Services for High School Students with Disabilities**, *retrieved from the MA Rehabilitation Commission website at http://www.mass.gov/?pageID=eohhs2terminal&L=5&L0=Home&L1=Consumer&L2=Family+Services&L3=Services+for+Youth&L4=Services+for+Youth+with+Disabilities&sid=Eeohhs2&b=terminalcontent&f=mrc_c_vr_voc_students&csid=Eeohhs2, March 22, 2007.* Information on vocational rehabilitation services and questions and answers for high school students with disabilities.

6. **Vocational Rehabilitation Services Information for Parents**, *retrieved from the MA Rehabilitation Commission website at http://www.mass.gov/?pageID=eohhs2terminal&L=5&L0=Home&L1=Consumer&L2=Family+Services&L3=Services+for+Youth&L4=Services+for+Youth+with+Disabilities&sid=Eeohhs2&b=terminalcontent&f=mrc_c_vr_voc_parents&csid=Eeohhs2, March 22, 2007.* Information on vocational rehabilitation services and questions and answers for parents.

SECTION 4: AFTER HIGH SCHOOL: POST-SECONDARY EDUCATION/ EMPLOYMENT

1. **Rights and Responsibilities To Ensure Educational Access For Students with Disabilities**, *by Patricia Carlton, Jennifer Hertzfeld, and Ann Yurcisn, George Washington University HEATH Resource Center, retrieved from http://www.heath.gwu.edu/files/active/0/factsheet_rights_responsiblities.pdf, March 22, 2007.* A fact sheet providing information on educational access for students with disabilities.

2. **Understanding One's Disability Leads to Job Success**, *written by Deborah Leuchovius and Sue Fager, Parent Advocacy Coalition for Educational Rights (PACER) Center, retrieved from http://www.pacer.org/tatra/resources/jobSuccess.asp, March 22, 2007, adapted from an article in the PACESETTER, Winter 2003, Vol.26, Issue 1.* An article explaining that an understanding of oneself and one's disability is key to becoming an effective self-advocate and essential for success in education and employment. Also includes a list of online resources on disclosing a disability.

3. **The 30-Day Placement Plan: A Road Map to Employment**, *article by Danielle Dreilinger in Disability Issues, joint publication of the Massachusetts Medicaid Infrastructure and Comprehensive Employment Opportunities Grant (MI-CEO) and Spaulding Rehabilitation Hospital, Fall 2005- (Vol.25, No.3), retrieved from http://www.masschec.org/AccessDocument.cfm?document=DisabilitiesIs%5FFall%5F05%2Efinal%20pdf%2Epdf, March 22, 2007.* The Disability Issues newsletter is published quarterly and shares current information about the world of disability, new initiatives, and other helpful information to the disability community in MA. The 30-Day Placement Plan is a month-long plan aimed towards finding a job.

4. **Youth in Transition Employment and Health Care Education Resources**, *University of Massachusetts Medical School Center for Health Policy and Research, MI-CEO homepage retrieved from http://www.masschec.org/youth/TransitPlanning.aspx?linkidentifier=id&itemid=410 March 22, 2007.* A list of employment and education options, agencies, organizations, and other resources.

5. **Work and You: Your Special Health Care Needs in the Workplace**, *HRTW Tools & Tips developed by Patti Hackett, Lee Gordon, Jennifer Jones, and Faye Manaster, Health and Ready to Work (HRTW) National Center in partnership with the Shriners Hospital for Children and KASA, retrieved from www.hrtw.org/tools/pdfs/work_and_you.pdf, March 22, 2007.* This tip sheet provides information on health issues to think about when getting ready to apply or start a new job and includes information on helpful resources.

SECTION 5: HEALTH CARE AND HEALTHY LIVING

1. **Health Care Transition Workbook: Ages 12-14**, *Health Care Transition Initiative of the Institute for Child Health Policy at the University of Florida, workbook developed by John Reiss and Robert Gibson, 2005, retrieved from* http://hctransitions.ichp.ufl.edu/ddcouncil/resources/module5/HCT_Workbook_12-14.pdf, *March 22, 2007.* This workbook helps parents and children think about future goals, needs for transition, and identify current independent health care efforts by children ages 12-14.

2. **Health Care Transition Workbook: Ages 15-17**, *Health Care Transition Initiative of the Institute for Child Health Policy at the University of Florida, workbook developed by John Reiss and Robert Gibson, 2005, retrieved from http://hctransitions.ichp.ufl.edu/ddcouncil/resources/module5/HCT_Workbook_15-17.pdf, March 22, 2007.* This workbook helps parents and youth think about future goals, needs for transition, and identify current independent health care efforts by youth ages 15-17.

3. **Health Care Transition Workbook: Ages 18 and Older**, *Health Care Transition Initiative of the Institute for Child Health Policy at the University of Florida, workbook developed by John Reiss and Robert Gibson, 2005, retrieved from http://hctransitions.ichp.ufl.edu/ddcouncil/resources/module5/HCT_Workbook_18up.pdf, March 22, 2007.* This workbook helps parents and young adults think about future goals, needs for a smooth transition into an adult-oriented health care, and identify current independent health care efforts by young adults ages 18 and older.

SECTION 6: BENEFITS, HOUSING, LEGAL & FINANCIAL CONCERNS

1. **Independent Living Centers in Massachusetts**, *retrieved from the MA Rehabilitation Commission website at http://www.mass.gov/?pageID=eohhs2terminal&L=5&L0=Home&L1=Consumer&L2=Disability+Services&L3=In-home+and+Community+Living+Supports&L4=Independent+Living+Programs+and+Services&sid=Eeohhs2&b=terminalcontent&f=mrc_c_il_centers&csid=Eeohhs2, March 22, 2007.* A list of contact information for independent living centers in MA.

2. **Turning 22 Independent Living Program**, *Massachusetts Rehabilitation Commission (MRC), Rev. April 2006, retrieved from http://www.mass.gov/Eeohhs2/docs/mrc/22il.pdf, March 22, 2007.* Description of the three major components of the Turning 22 Independent Living Program in Massachusetts: Supported Living Program, Transition to Adulthood Program, and Ancillary Supports.

3. **Project IMPACT: Benefits Planning**, *Massachusetts Rehabilitation Commission.* A flyer advertising benefits planning, specialists, and an IMPACT Referral Form.

4. **HRTW Tools and Tips: Comparing IDEA, 504 and ADA**, *created by Cynthia Glimpse, the Health and Ready to Work National Center in partnership with the Shriners Hospitals for Children and KASA, retrieved from http://www.hrtw.org/tools/hrtw_go_tools.php, March 22, 2007.* Description of the three laws that impact children and youth with disabilities: the Individuals with Disabilities Education Act (IDEA) reauthorized in 1997, Section 504 of the Rehabilitation Act of 1973, and the Americans with Disabilities Act (ADA) of 1990. Resources provided.

5. **Estate Planning For Families With Sons or Daughters with Special Needs**, *prepared by the Elder and Disability Law Group at Rosenberg, Freedman & Goldstein, Newton, MA.* Information on special needs planning to help families identify and maximize the personal, family, financial and government benefits for an individual with disabilities.

6. **Planning for Now and the Future: Social, Legal and Financial Concerns**, *by Ruth I. Freedman and Donald N. Freedman, based on a chapter by the authors in Life Course Perspectives on Adulthood and Old Age, edited by Marsha Mailick Seltzer, Marty Wyngaarden Krauss and Matthew P. Janicki (American Association on Mental Retardation 1994).* This paper discusses and identifies long-term planning issues and conflicts faced by families caring for young adults with special needs.

7. **The Special Needs Planning Guide: How to Prepare for Every Stage of Your Child's Life**, *by John W. Nadworny and Cynthia R. Haddad, Brookes Publishing Co., March 2007.* A thorough, easy-to-read resource that gives parents advice and strategies on how to address financial and legal factors, government benefits, family and support factors, emotional factors, staying connected with others, and using strong emotions to fuel advocacy; includes tools families need to create an effective action plan for their finances -- planning checklists and forms, a helpful glossary of financial terms, "planning pointers" that help readers remember key points, and extended case studies dramatizing other families' evolving challenges and solutions.

SECTION 7: RECREATION/LEISURE, SOCIALIZATION, COMPANIONSHIP

1. **Taking Charge of Having Fun: A Handout for Adolescents and Young Adults with Special Health Care Needs and Disabilities**, *produced by the Institute for Community Inclusion at Children's Hospital, Boston, as part of the MA Initiative for Youth with Disabilities, a project of the MA DPH, retrieved from http://beta.communityinclusion.org/transition/pdf/rec.pdf, March 22, 2007.* This handout provides information regarding transition and recreation for adolescents and young adults with special needs and includes information on additional resources relating to recreation for children and youth with disabilities and chronic health conditions.

2. **Parental Roles in Facilitating and Supporting an Active Lifestyle for a Child with a Disability**, *the National Center on Physical Activity and Disability Lifetime Sports, retrieved from http://www.ncpad.org/lifetime/fact_sheet.php?sheet=450&view=all&print=yes, March 22, 2007.* This article provides information for parents to encourage an active lifestyle for their child by exhibiting a positive attitude, goal setting, facilitating independence and self-sufficiency, among other helpful tips.

3. **Exercise and Disability: Physical Activity is Within Your Reach**, *Mayo Foundation for Medical Research (MFMER), June 22, 2006, retrieved from http://mayoclinic.com/print/exercise/SM00042/METHOD=print, March 22, 2007.* This article provides exercise tips that will help maintain independence and improve quality of life for individuals with disabilities and chronic conditions.

SECTION 8: NOTES

This section provides space for personal notes.