Navigating the Transition Years

A Publication of the Maryland Coalition of Families for Children’s Mental Health
Acknowledgements

Funding to produce this handbook was provided by:

**Substance Abuse and Mental Health Services Administration**
Center for Mental Health Services

**Maryland Department of Health and Mental Hygiene**
Mental Hygiene Administration

**Maryland State Department of Education**

Author

**Ann Geddes, PhD**
Transition Specialist
Maryland Coalition of Families for Children's Mental Health

Dedication

This handbook is dedicated to all families struggling to help their child with mental health disabilities transition to adulthood. May you find this handbook a source of information and empowerment.

The Coalition hopes that this information will be disseminated widely.
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Maryland Coalition of Families for Children's Mental Health
September 2010

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Mission

The Maryland Coalition of Families is the statewide voice for children's mental health and is dedicated to:

- Building a family-driven network of information and support and
- Improving services in all systems of care for children, youth and their families

The Coalition represents families across Maryland who are caring for a child with mental health needs. Many children have been in a psychiatric hospital, residential treatment center, juvenile justice facility, or special education program.

Families struggle to find appropriate services for their child and many families face staggering costs for treatment and other special services their child may need.

Even with the challenges of raising a child with serious emotional or behavioral needs, families have strengths and want to be full partners with professionals in planning for their child's treatment and care.

We Believe

- Children and youth with mental health needs are valued and require individualized services to achieve their full potential.
- Families are a constant in a child's life and are equal partners in planning, implementation, monitoring and evaluation of services.
- Services for children, youth and their families are provided from a strength-based approach and are responsive to the needs of the whole child and entire family.
- Local and state systems of care are family-driven and culturally competent.

For information contact:

Maryland Coalition of Families for Children's Mental Health
10632 Little Patuxent Parkway, #119  Columbia, Maryland  21044
410.730.8267  1.888.607.3637 Toll Free
info@mdcoalition.org  www.mdcoalition.org
# Navigating the Transition Years

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## Notes
In the spring of 2006, the Maryland Coalition of Families held focus groups in six locations across the state. We asked youth of transition age (defined as 14-24 years) with emotional disabilities and their families to tell us about their experience with the transition process – that period of preparing and moving from high school to the adult world. A number of common themes emerged:

- Both young adults and their families had expansive dreams for the young adult's future.
- Families, who had been lifelong advocates for their child, knew that it was time to let go but found this prospect very frightening.
- Families and youth felt that existing transition services were not well-tailored to youth with mental health needs.
- Young adults emphatically stated that they wanted to transition to adulthood—not into the adult mental health system.

Overwhelmingly, participants were frustrated by the lack of coordinated information about the many aspects of the transition process. One mother said, “Everything is so complicated, and I don’t know where to go to get help.”

This handbook is an outgrowth of the focus groups. It is an attempt to bring together in one place information and tools to navigate the transition process. The handbook is written for families, but the intent is that with this information, families can support their youth in self-advocacy.

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1 In this handbook “mental health needs” and “emotional disabilities” are used interchangeably. They denote:
- A DSM-IV diagnosis that would qualify as a disabling condition, or
- The designation by the school system of a condition which entitles a child to IDEA or Section 504 accommodations. These conditions include, but are not limited to, ADHD, mood disorders, anxiety disorders and schizophrenia.
It is worth noting here that transition-age youth with emotional disabilities are a richly diverse group. Some generalizations or topics will follow in this handbook that may or may not apply to your child. We hope that there will be some things in the following pages that will be helpful to all.

**Transition to adulthood**

The transition to adulthood can be lengthy and difficult for all young adults—not just those with mental health disabilities. For example, the 2000 census found that the average age at which children permanently move out of the family home is 30; the 2010 census will probably find that the average age has increased. As our society has become more complex, the adult milestones of completing secondary education, finding a job that pays a living wage, and leaving the family home often are not achieved until age 30 or later.²

For young adults with mental health disabilities, the transition to adulthood can be longer and more difficult. The social and emotional delays experienced by youth with mental health needs impede the skills necessary to successfully transition to adulthood.³

**Developmental characteristics of young adults with mental health needs**

Youth and young adults display developmental characteristics that can be trying and sometimes frightening to their caregivers. Due to the social and emotional delays experienced by many youth with emotional disabilities, some developmental characteristics are more typical of younger adolescents. Others are common to most young adults. They include:

- Seeking differentiation and independence from their parents
- Possessing an overwhelming desire to fit in with their peers, including having a circle of friends and a girlfriend or boyfriend
- Craving the outward displays of adult milestones, which may include the use of alcohol and/or drugs, and sexual activity
- Not wanting to self-identify as someone with a disability

Often young adults are not interested in participating in anything that looks like mental health “services”; they want spending money, a car, friends, and their own place to live – they share the goals of their non-disabled peers.

The dilemma for families is that while youth with mental health needs want the same things as other youth their age, they may lack the social skills, confidence and maturity needed to achieve their dreams. To complicate matters, it is not unusual for youth to refuse any kind of mental health services that may help them reach their goals, including taking medication.

The changing role of families

Parents and caregivers of children with mental health needs are accustomed to advocating for their child. Typically, they are involved in every aspect of their minor child’s life from education and social activities to medical care and mental health treatment. Yet the roles and responsibilities of parents and caregivers change dramatically when a child turns 18, regardless of how prepared and capable a child is at that point. Often, this places families in a difficult position. Families feel responsible for their child, but have little or no control or access to information. They may feel helpless and frustrated if their child loses ground or refuses/fails to receive appropriate support.

Through this time of transition, the task of the family is to take on a new role, one that tries to support rather than control their young adult. To help youth successfully transition to the adult world, families need to stand back and let go, while providing a safety net of support.

Above all, it is critical for families to recognize that young adults seek independence from their families and need to pursue this process. Therefore, transition plans must be developed and driven by the young adult. While this prospect makes many parents uneasy, it can be downright scary for families of youth with emotional disabilities. They find it extremely difficult to step back while their young adult meets the complex and critical challenges of the transition stage. But stepping back does not mean removing yourself entirely from the process. Young adults still need the guidance of their families. And for that reason, the more effective transition plans are youth-driven and family-guided. Plans and goals must be defined by the youth with families providing critical guidance, especially when their youth encounters barriers or perhaps stumbles along the way.

Here are some possible suggestions for adopting a youth-driven, family-guided approach:

- Your young adult’s preferences are critical. You may not like them or agree with them, but don’t dismiss them. Listen with an open mind.
- Support your young adult’s career goals. Be non-judgmental—the ultimate goal must be the young adult’s.
- Help your child to break down a major goal into smaller more manageable components, and encourage back-up plans.
- Brainstorm with them.
- Recognize that the boundaries have shifted, and that your young adult must now take responsibility for themselves.
- Stand back and sometimes let them stumble.
- Allow youth to experience natural consequences whenever possible.

“The passage from childhood to adulthood for all of us involves the ‘dignity of risk;’ the right to make mistakes and learn from them.”
--From “Growing Up Without Growing Apart”
Utah Support Network
Partnering with your child in the transition process

To develop a transition plan that is youth-driven and family-guided, you may find it helpful to complete this exercise. Answer the following questions. Think about how your child might answer the questions, or see if you can get them to respond. Where are there similarities? What are the differences? How can you move toward supporting your child's vision of their future? When might you need to allow them to experience natural consequences?

Questions

1. What are your dreams about your child's future?
2. What short-term goals do you have for your child?
3. What careers would you like your child to pursue?
4. What further education do you imagine your child attaining?
5. What barriers might get in the way of your child accomplishing their goals?
6. What independent living skills do you feel your child has acquired (banking, budgeting, cooking, shopping)? What do you think is lacking?
7. How do you anticipate your child will meet their transportation needs?
8. How do you perceive your child's social life?
Chapter 2  
High School  
Transition Planning

High school support staff
If your child has an Individualized Education Plan (IEP), a team of staff members is responsible for helping them with their transition planning and the implementation of their plan. If your child is on a 504 plan, they still have access to the services of a guidance counselor, transition coordinator, and Division of Rehabilitation Services (DORS) counselor, but you and your child may be responsible for initiating contact to access their support.

The Maryland Transitioning Youth website is a valuable resource for youth and families, covering a wide array of topics. Go to www.mdtransition.org.

The major players in a student’s transition plan are:

IEP case manager
- Ensures that age-appropriate career interest assessments are completed (or, in some schools, this may be the duty of the transition or vocational personnel)
- Helps to develop a transition plan IEP that is driven by the student

Guidance counselor
- Assists with the development of a course schedule that meets transition objectives
- Ensures that a student registers for and takes admission tests (such as the PSAT and SAT), if appropriate
- Provides information on colleges and other institutions of continuing education
- Provides guidance on applying for financial aid

Transition coordinator4
- Attends IEP meetings

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4  Sometimes transition coordinators do not make contact with transitioning youth on IEPs or 504 plans. To get the name and contact information of the transition coordinator for your child’s school, contact the Office of Special Education for your county (see appendix 1).
Develops the transition plan within the IEP for those students age 14 or older in conjunction with the student
May help develop a work-based learning or other employment experience
Assists the family and student in making agency linkages (DORS, MHA, etc.)
May function as a guidance counselor in some schools

**Division of Rehabilitation Services (DORS) counselor (See chapter 3 on DORS)**
- Attends IEP meetings beginning in a student’s second to last year of school
- Refers the student for vocational assessments
- Makes referrals to outside agencies as needed

**High school transition planning timeline**
The Individuals with Disabilities Education Act (IDEA) 2004 and the Maryland State Department of Education have both set out guidelines on the activities and timelines that IEP teams should follow to develop transition plans that help students meet their education and employment goals.

**Age 14**
- Youth attends IEP meetings. The IEP should include the student’s transition goals

**9th grade (4 years prior to exit)**
- Review graduation requirements and complete career interest assessments; revise IEP as needed
- Work with the transition coordinator to update the transition plan and work on transition activities
- Ensure that the IEP addresses the acquisition of necessary life skills, especially when the high school offers appropriate courses such as budgeting and money management, technical education, or cooking

**10th grade (3 years prior to exit)**
- Review graduation requirements and update career interest inventories; revise IEP as needed
- Work closely with the transition coordinator to update the transition plan and work on transition activities
- Ensure that the IEP addresses the acquisition of necessary life skills

**11th grade (2 years prior to exit)**
- Review graduation requirements and update career interest inventories; revise the IEP as needed
- Consider placement in a work-based learning program (see below)
- The IEP team or family should make a referral to DORS, and a DORS counselor should attend the IEP meeting
Ensure that the IEP includes anticipated transition services, including Supplemental Security Income (SSI) benefits, higher education or career school support services, and Mental Hygiene Administration (MHA) services, such as supported employment, psychiatric rehabilitation programs and residential rehabilitation programs.

Consider applying for Project Access if you live in central Maryland (see appendix 2).

Visit any continuing education facility the student is considering attending, and talk to staff in the Disability Support Services office.

If a student is not on track to receive a learner’s permit from the Motor Vehicle Administration, they should apply to the MVA for an Identification Card: http://www.mva.maryland.gov/driverserv/apply/id.htm

12th Grade (year of exit)

- Maintain regular contact with the DORS counselor.
- DORS should have examined documentation, performed assessments and determined eligibility status.
- Make sure the DORS counselor is invited to attend the IEP meeting.
- Review the Exit Document.
- Ensure that the IEP includes anticipated transition services.
- DORS counselor should make the outside referral to a supported employment provider and to the MHA as needed.
- Visit any continuing education facility that the student is considering attending, and talk to staff in the Disability Support Services office.
- Visit the DORS Workforce Technology Center if the student is considering receiving any services there.
- Families should fill out the FAFSA (Free Application for Federal Student Aid).

Maryland Seamless Transition Collaborative (STC)

In certain jurisdictions, the Division of Rehabilitation Services has introduced the “Seamless Transition Collaborative” for youth with disabilities who have IEPs. Some of the STC sites serve youth identified with emotional disabilities. Seamless Transition provides enhanced services to youth, including a variety of paid employment options, enhanced family supports, and linkages to adult systems. Contact your school district’s Office of Special Education (Appendix 1) to see if this program is available for students with emotional disabilities in your school.

5 The Maryland Exit Document provides graduating students with IEPs important information that they may use as they transition from school to post secondary activities.
High school course of study options
Youth should work with their guidance counselor/transition coordinator to develop their plans.

Preparatory classes for post-secondary education
Even if a student is planning on pursuing post-secondary higher education, it can be beneficial for them to include a high school work-based learning experience in their schedule (see below). Also, they should consider taking one or more courses at the local community college, if this is a workable option.

Career and Technology Education (CTE) (formerly Vocational Education)

CTE programs are for both career and college bound students.

Career and Technology Education (CTE) programs include a sequence of four or five high school courses taken in addition to the academic core classes

- Courses are offered within a comprehensive high school, a technical high school, or a CTE center
- Course of study includes an internship or work-related experience
- Students have the opportunity to earn career licenses (such as cosmetology) or college credits
- 10 career clusters are offered. Each cluster, however, is not necessarily available in all areas

GED
For a variety of reasons, a traditional high school education is not feasible for some youth. While dropping out of school and pursuing a GED is not the ideal choice, it is an appropriate choice for some students.

Work-based Learning (also called work-study)
Studies indicate that young adults who have had a paid work experience during their high school years are far more likely to be employed in the years following graduation than those who have not. Moreover, a successful work experience can profoundly influence a young adult’s self-esteem and sense of independence. For some youth, a work-study program is an excellent way to get that paid work experience in high school. Work-based learning is a supported program where students work in an independent placement in the

6 They are:
Arts, Media and Communication
Business Management and Finance
Construction and Development
Consumer Services, Hospitality and Tourism
Environmental, Agriculture and Natural Resources
Health and Biosciences
Human Resource Services
Information Technology
Manufacturing, Engineering and Technology
Transportation Technologies
community. The placement may provide training or be a paid position. School staff members provide drop-in support and services.

- Work-based learning is available to all special education students 16 and over who are on an IEP.
- The option to do a work-based learning program is a decision of the IEP team, who will look at:
  -- Behavior and attendance
  -- Availability in a student's schedule
  -- Number of credits still needed for graduation
  -- HSA progress
- Transportation for a work-based learning program may be provided by school

Because of the many benefits a work experience provides, a student's transition coordinator should work to arrange a work-based learning experience for the youth whenever possible.

For all students

The high school guidance counselor should help all students with:

- Registering for academic testing.
- Providing information on colleges and vocational programs.
- Compiling application packets.
- Providing information on applying for financial aid.

Volunteer and work experiences are as helpful for students on IEPs as they are for students who are not. Guidance counselors have information about a wide variety of volunteer opportunities in the local community. While the work-based learning program is not an option for students who do not have an IEP, the Career Technology Education program is an option, and CTE programs include either an internship or a paid work experience.

Students who are considering attending an institution of continuing education should check with their guidance counselor about admission testing requirements. There is a cost for most admission tests, and also for applications, although they may be waived sometimes owing to financial need.

Financial aid

Students who are considering pursuing continuing education after high school should have their families complete the FAFSA (Free Application for Federal Student Aid). A FAFSA is required for almost all forms of financial aid such as grants, loans and scholarships (some scholarships, however, do not require a FAFSA). A FAFSA is also required to be eligible for financial aid through DORS (see chapter 3).
Most students will not be eligible for independent student status (i.e., independent of their family’s income). Students are eligible if they are:

- 24 or older, or
- Married, or
- A graduate student (having completed a bachelor’s degree), or
- Have a dependent other than a spouse (e.g., a child), or
- A veteran, or
- An orphan, or be a ward of the court at age 18

*Maryland law provides that youth, who are in foster care at the time they graduate or complete their GED, receive free tuition at all Maryland state colleges and universities.*
DORS is Maryland’s Vocational Rehabilitation Agency. Federal law requires that every state have a vocational rehabilitation agency, with the mission to promote the employment, independence and self-sufficiency of individuals with significant disabilities. DORS is under the Maryland State Department of Education and serves individuals ages 16-64. DORS serves all disability groups.

**Referrals**

Students with emotional disabilities should be referred to DORS for services if they:

- Have an IEP.
- Have a 504 plan.
- Have a significant mental health disability.
- Have a goal of employment.

**Timeframe and means of referral**

IEP teams should coordinate the referral of students to DORS. This typically occurs at the beginning of a student’s next to last year of high school.

Students with 504 plans will not automatically be referred, so families should contact DORS directly.

In addition, anyone can make a referral to DORS at any time after an individual turns 16 years.

Go to www.dors.state.md.us/dors/referralformpage.aspx or call 1.888.554.0334.
When contacting DORS, families should compile all relevant information such as:

- Educational assessments including cognitive tests or achievement tests.
- Psychological or psychiatric evaluations.
- Speech and language assessments.
- IEPs.
- 504 plans.
- Exit Documents.

This information facilitates the determination of eligibility and the development of the Individualized Plan for Employment (IPE).

**Eligibility**

Consistent with federal law, an individual is eligible for DORS services if they:

- Have a physical or mental impairment which constitutes or results in a substantial impediment to employment.
- Can benefit from services in terms of an employment outcome.
- Require vocational rehabilitation services to achieve employment.

Once a referral is made, DORS will determine a youth's eligibility status by going over existing documentation and perhaps performing some of their own assessments.

DORS uses three eligibility categories: **most significant, significant**, and **non-severe disabilities**. Due to resource limitations, DORS provides services only to individuals who are determined to have most significant and significant disabilities.

Youth who have most significant and significant disabilities are defined as those who:

- Will require multiple services over an extended period of time.
- Have impairments that **seriously limit** one or more functional capacities such as:
  - self direction
  - interpersonal skills
  - work tolerance
  - work skills

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Your right to appeal: If your child is determined to have a **non-severe disability**, you may appeal the decision through the Client Assistance Program. DORS provides information about this program, or call 1.800.638.6343.
Even if a youth is determined eligible for services, they may be placed on a waiting list. DORS may provide some limited services, such as career assessments and counseling, to students on the waiting list.

DORS has transition counselors who are assigned to each high school in Maryland. The transition counselor usually starts interacting with students at the beginning of the student’s next to last year of school. If the student is found to be most significantly or significantly disabled, they develop a plan for employment services, some of which may be provided while the student is still in school.

**Services**

DORS provides a range of services depending on the needs of the youth. These may include:

- career assessment
- career decision-making
- counseling and referral
- vocational training

Services are provided by DORS counselors in the local offices or by community providers. DORS also operates the Workforce and Technology Center in Baltimore.

Many DORS offices are co-located with the “One-stop Job Center.” The One-stop Centers are operated by the Department of Labor, Licensing and Regulation, and are located in each jurisdiction. The One-stop Centers serve all individuals who are searching for jobs. They provide access to various resources, including computers, copiers and fax machines, a library of relevant books, and seminars on diverse job seeking topics. DORS counselors facilitate the connection with the One-stop Centers, which also provide information on topics such as how to:

- use the computers on-site to research job openings
- fill out job applications
- produce a good résumé
- develop networking skills

DORS counselors discuss with the young adult their option of whether or not to disclose their disability to an employer. DORS counselors explain the young adult’s rights under the Americans with Disabilities Act (ADA), and can help to evaluate potential accommodations that might be available to them if they choose to disclose.7

**Payment for services**

DORS pays only for services that have been pre-approved and authorized in writing by a DORS official. DORS has a sliding scale for payment of many services, based on the income of the family. Young adults who receive SSI are not required to contribute to the cost of services. DORS provides a number of services for free, including assessment, counseling/guidance/referral, and supported employment.

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7 Some typical job accommodations are:

- Modified work schedule
- Modified examinations, training, or other programs
- Adjustments to leave policy
DORS is not a primary funder for post-secondary education. Youth who need post-secondary education to reach an approved employment goal are required to apply annually for grants and scholarships. Financial need and other conditions apply in order to become eligible for financial aid through DORS.

**Workforce and Technology Center (WTC) programs and services**

The Workforce and Technology Center in Baltimore is the main campus of DORS. It offers a diverse variety of services and programs for individuals with disabilities, including intensive career and ability assessments, life-skills classes, driver’s education courses, classes on using assistive technology, classes on reading Braille, and a variety of vocational training programs. Dormitory services are available Sunday night–Thursday night. It is important to note that the WTC serves individuals of all ages and all disabilities.

Two programs that might be of interest to youth of transition age with mental health needs are Pre-vocational Services and Occupational Training.

- Pre-vocational services focus on developing work readiness, household skills, and personal organization.
- Occupational training is offered in nine program areas for individuals who have a determined career goal.8

It is highly recommended that interested individuals and their families arrange for a tour of the WTC.

*For more information on DORS, including the phone numbers and locations of the local DORS offices, see the DORS website www.dors.state.md.us, or contact the DORS Transition Specialist at 410.554.9109 (toll free: 1.888.554.0334).*

**Supported Employment—a partnership between DORS and the Mental Hygiene Administration**

Supported Employment provides a job coach to help people with disabilities find and keep competitive employment in their communities. It has been found to be a successful program for youth with mental health disabilities. The goals of Supported Employment are to help individuals secure:

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8 They are:

- Automotive detailing
- Automotive mechanics
- Tire, oil and lube services
- Computer-aided drafting and design
- Environmental services
- Food service
- Office technology—customer service
- Office technology—administrative professional
- Security guard
- A mainstream job in the community that pays at least minimum wage
- A work setting that includes people who are not disabled
- A job coach who provides ongoing, proactive support

The approach is based on the principles that:

- An individual's preferences are important
- A person should choose as much or as little support as they want from their job coach
- An individual should make the decision on whether or not to disclose their disability to employers
- Follow-along supports must be continuous

Supportive Employment is responsive to the fact that many young adults with mental health needs want to both work and attend school. If that is a youth's preference, their job coach will work to help them search for a part-time job that will fit in with their school schedule.

Although a fundamental principal of Supported Employment is to achieve a job that pays at least minimum wage, if paid employment is not possible, job-shadowing or unpaid internships in the area of interest to the youth may be a possible option. Supported Employment specialists will work with the young adult in whatever their job interest may be, and will continue working with the young adult as long as they want the help.

Transition-age youth who are found to be most significantly or significantly disabled meet the criteria for receiving Supported Employment services through the Mental Hygiene Administration.

To access Supported Employment, it is important that all of the referrals are made to the appropriate agencies. The chart in Appendix 3 shows the various paths for accessing Supported Employment services for youth of transition age.

**Other employment options**

In the current economic climate, there are no guarantees of landing a job. Families and youth should always try to develop their own opportunities. Parents and students should explore the network of adults they know to find out if they are aware of any job openings, or if they have other connections that might be helpful in locating a job.
Chapter 4  Post-secondary Education

Post-secondary education options
Students have a broad range of options for continuing education.

College

4-year selective-admission colleges seek students who have:
- Good grade point averages
- College preparatory courses in high school
- Good scores on standardized college admissions tests (e.g., SATs)
- Extra-curricular activities

2-year open-admission community colleges admit all applicants that meet the requirements for a specific program.
- Community Colleges options include:
  -- Taking a few selected courses in an area of interest
  -- Taking vocational courses to train for specific jobs or certifications
  -- Pursuing an Associate Degree
  -- Preparing for a four-year college
- Standardized college admission testing (e.g., SATs) and specific high school courses are not required.
- High school grades are not relevant to admission.
- Schools usually require placement tests in reading, writing and math to determine the level at which to begin course work. If students do not meet the minimum proficiency levels, they are required to take remedial courses.

Credits earned in Maryland community colleges usually transfer to Maryland four-year colleges, if the credits are for college-level courses
Vocational and technical schools

Vocational schools are many and varied. They teach job-specific skills and are devoted to practical training rather than academics. Examples include:

- Technical Institutes
- School of Dog Grooming
- Welding School
- School of Cooking
- Bartender School
- Barber School
- Travel Academy
- Academy of Hair Design

Let the buyer beware. Try to get references about vocational schools of interest from the high school guidance counselor, alumni, friends, or career resource centers.

Apprenticeships

The Maryland Apprenticeship and Training Program oversees state-approved apprenticeship programs and provides information on the numerous apprenticeship programs in Maryland. Some of the more common apprenticeship programs are:

- Automobile Mechanic
- Cabinet Maker
- Electrician
- Plumber
- Tool and Die Maker
- Bricklayer
- Carpenter
- HVAC/R Technician
- Sheet Metal Worker
- Welder

Apprentices work full time, and are paid depending on level of tenure. Most programs take three to six years to complete, and lead to a nationally recognized certificate of completion. Many apprenticeships are very competitive.

A student’s guidance counselor or transition coordinator can explain the apprenticeship application process and make the appropriate referrals. Also, you can go to www.dllr.state.md.us/labor/appr/ for more information.

The Americans with Disabilities Act (ADA) and Section 504 accommodations

If a student has an IEP in High School, it will not carry over to a program of continuing education. Instead, students must prove with supporting documentation that they have a disability that entitles them to accommodations under ADA and Section 504.

The Americans with Disabilities Act (ADA)

The American with Disabilities Act is a federal law that guarantees equal opportunity for people with disabilities in public accommodations, employment, and other arenas. Unlike the Individuals with Disabilities Educational Act (IDEA), persons with disabilities are not entitled to services but can request “reasonable accommodations.”
Section 504 of the Federal Rehabilitation Act

Section 504 of the Federal Rehabilitation Act prohibits discrimination on the basis of a disability in programs conducted or funded by federal agencies. Unlike IEP accommodations, which are intended to make available to students with disabilities "a free appropriate public education that emphasizes special education and related services designed to meet their unique needs," Section 504 requires that "reasonable accommodations" be provided to students with disabilities.

Typical continuing education accommodations for youth with mental health disabilities include:
- Allowance for excused absences
- Tutoring
- Extended time on tests
- Freedom from distractions when testing

Schools will not provide accommodations that require a fundamental alteration of the coursework.

Schools and professors vary tremendously in their willingness to develop and implement ADA and Section 504 accommodations. For this reason, it is very important for students to visit the Disability Support Services Office before deciding to attend a particular institution. Ask questions and you will get a sense of how willing they will be to work with you.

Accessing accommodations

At least one month before starting classes, a student (not the parent) should register with the Disability Support Services office. The name of this office varies by institution. The student will meet with a DSS counselor and should bring supporting documentation of their disability, as well as suggestions for accommodations that may be helpful.

A student must meet with a counselor before receiving accommodations. Accommodations will not be provided retroactively for a student who is doing poorly.

Supporting documentation

The documentation required to be eligible for accommodations differs from one school to another. As a rule, however, schools require documentation prepared by a qualified professional that includes:
- Diagnosis
- Methodology used to determine diagnosis
- Functional limitations
- A medical history, including past treatments and medications

Other documentation might include a letter from a doctor, documentation from high school, or testing results from a professional. In addition, it can be useful if a professional recommends specific accommodations that might be helpful to the student.

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Chapter 5  Supplemental Security Income

About SSI

Supplemental Security Income (SSI) is a federal program that provides a monthly payment to qualifying individuals with disabilities and limited income and resources. Benefits are based on financial need and adjusted to the individual’s income and living situation. Currently, the maximum monthly payment is $674. In addition to a monthly payment, the benefits of SSI eligibility include:

- Automatic eligibility for Medicaid – a comprehensive public health care plan.
- Automatic DORS eligibility and all of DORS services free of charge.
- Tuition waivers at many Maryland Community Colleges.

SSI should not be confused with SSDI (Social Security Disability Income); they are different programs. People who have worked a certain amount of time and paid into Social Security, who then become disabled, are eligible for SSDI. SSI is for people with disabilities who either have not worked or have not worked long enough to qualify for SSDI. What follows is a discussion about SSI since, in most circumstances, it is the program that youth of transition age might qualify for.10

A Decision

Many families struggle with the decision of whether or not to have their child apply for SSI. While the advantages of a secure income are clear, there may be disadvantages as well. Studies show that only 1 out of 1,000 people who go onto SSI ever come off of SSI. Thus, there is a fear that being on SSI might promote dependence. Also, some families believe there is a stigma associated with receiving public benefits. Ultimately, the decision to apply for SSI should be your young adult’s, with you providing the best information and support that you can.

Eligibility Requirements

An individual age 18 and older is considered disabled if he/she:

- Has a medically determinable physical or mental impairment which:
  - Results in the inability to do any substantial gainful activity
  - Has lasted or can be expected to last for a continuous period of not less than 12 months

10 If your young adult has a substantial work history, they may qualify for SSDI rather than SSI. The application process for the two programs is identical. The Social Security Administration will make the determination on whether your application is for SSI or SSDI.
To be eligible for SSI, an individual must have “limited” income and resources. Currently, the income limit is $980/month and the resource limit is $2,000. Not all sources of income or resources are counted towards the limits. On the SSI web-site [www.ssa.gov/ssi/text-eligibility-ussi.htm](http://www.ssa.gov/ssi/text-eligibility-ussi.htm), there are lists of income and resource exemptions.

**The Application process**

The application process for SSI can be difficult, in terms of both paperwork and emotional impact. You and your child will have to document all of their past illness, which can be rather traumatic. In addition, you will be trying to show why your child's illness will prevent them from engaging in any gainful activity. This experience can be demoralizing for your child. The potential benefit of being determined eligible, however, for SSI may outweigh these drawbacks.

A youth may apply for adult SSI after they turn 18. At age 18, the youth will be evaluated on their own income and assets, not the family's. For a child under age 18 to be eligible for Medicaid, there is a very low family income limit. While ideally your child should do as much of the application as they can, realistically you will be much better able to tackle the fairly daunting application process.

To apply for SSI, call **1.800.772.1213**. Representatives are available Monday through Friday from 7 a.m. to 7 p.m. For shorter call-waiting times, it is best to call at the end of the month, at the end of the week, and early in the morning. You will eventually speak with a representative who will gather some basic information about your child. The representative will also set up an appointment for you at your local Social Security Office. A face-to-face meeting with a representative of the Social Security Administration at your local SSA office is a required part of the application process. Your child must be present at the meeting.

Before the meeting, you must complete an Adult Disability Report. You can either fill it out on-line (go to [www.ssa.gov](http://www.ssa.gov), click on “Supplemental Security Income,” click on “How do I apply for SSI?” then click on “Adult Disability Report”) or have a packet sent to you. Either way, you must have the Adult Disability Report forms completed before your appointment with the Social Security Office. **You can not apply for SSI on-line.**

Filling out the Adult Disability Report potentially can be an overwhelming process. It helps if you are well prepared before you start to fill out the forms. In order to fill out the report, you will need to gather a list of all services provided to your child, including:

- Emergency Room visits
- Hospitalizations
- Day hospitalizations
- Treating psychiatrists
- Treating therapists and/or counselors
- School services—IEPs or 504 plans
- Neuropsychological or other testing
- Medications

Start with the most recent services and providers and go back in time for the history.

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11 If you go to the Social Security website, it will appear as if you can apply on-line.
Then you will need to locate:

- The name, address and phone number of each provider/hospital that provided the service.
- The dates that your child received services from the provider/hospital.

The second part of the Adult Disability Report is employment history. To complete this report, you will need to provide a list of all the jobs your child has held along with the names, addresses and phone numbers of their employers, along with the dates that they worked. Once you have gathered this information, you will be able to fill out the report.

If you did not file the Adult Disability Report on-line, you will need to bring a copy of it to your appointment. In addition, everyone must bring:

- Social Security Card or number
- Original birth certificate
- Copies of bank statements for checking and savings accounts
- Copies of other assets such as savings bonds
- W-2 form from last year (if your child worked)
- If your child is living with you, you will need a written agreement from your child to pay fair market value for housing and food (in the amount of at least $250 per month).12 If you do not have a lease agreement with your child, the free room and board that you are providing to them will be counted as a source of income.

You do not need to bring medical records. The Disability Determination Service will send letters to your child’s medical providers (including hospitals) to request medical records. The Disability Determination Service may also require that your child has a psychiatric evaluation with their own psychiatrist, at no cost to you.

SSI determinations usually take about six months. It is not unusual for young adults with mental health needs to be turned down on the first application. Therefore, plan to appeal any denial. Many applicants who are turned down initially are determined eligible on appeal. In a denial letter, Social Security provides detailed information about how to file an appeal. Follow this process.

> Once Social Security makes a favorable disability determination, the claimant is eligible for SSI benefits going back to the date on which they initially applied for the benefits. Since six months or more may have passed, this usually means that a large back payment is owed to the individual by SSA, which SSA will pay in three installments.

12 It should say, “I am receiving food and shelter from (caregivers’ names) in the amount of $250 and I agree to repay them.”

Signed by (child’s signature) and date
Managing SSI benefits

Monthly SSI checks may be sent directly to your child or, if Social Security determines that your child will not be able to manage their monthly checks, they may require a “Designated Payee” for the youth. You can apply to be named your child’s designated payee (see chapter 9).

- If you wish to ensure that your child receive the full SSI benefit ($674/month), and if your child is living with you, you must draw up a rental agreement charging your child a minimum of $250 for room and board and continue to charge them that amount.
- All income the youth earns must be reported to SSA. As an SSI recipient earns wages, the benefit check is reduced according to a formula that provides continued incentives to work. SSI recipients will always make more money by working than by not working.
- If your child is under the age of 22 and regularly attending school, they may earn up to $1,640/month (up to $6,600/year) and not have it affect the amount of their SSI benefit. Certain stipulations apply. Contact SSA for more information (www.ssa.gov/ or 1.800.772.1213).

Employed Individuals with Disabilities Program

The Employed Individuals with Disabilities Program (EID) allows individuals with disabilities who lose SSI due to their income to retain full Medicaid coverage. The impetus for the EID program is to encourage SSI recipients to work, and work at higher salaried positions, without having to worry about losing their Medicaid.

The EID program is for Marylanders who:

- Have disabilities that meet Social Security’s medical criteria
- Work for pay
- Are 18–64 years old
- Meet the income limit (as high as $66,000/year for individuals and $88,440/year for married couples)
- Meet the resource limit ($10,000, which does not count the home in which the applicant lives, any vehicles, and many types of retirement accounts)

EID enrollees pay a monthly premium based on their level of countable income. The monthly premium may be $0, $25, $40, or $55. EID beneficiaries receive the full Medicaid package of coverage, and can also have private insurance.

Contact: Maryland Department of Disabilities 1.800.637.4113
Chapter 6  Health Care

Health care reform
This is a time of rapid changes in health care law. On July 1, 2010, the Mental Health Parity Act went into place, requiring that health care insurers provide the same coverage for mental health care as they pay for somatic (physical) care. At the same time, new federal health care legislation is in the process of radically altering both private health insurance and Medicaid, with changes scheduled to go into effect between now and 2014.

Mental Health Parity Act
While the full ramifications of the Mental Health Parity Act are still unknown, certain points are clear. As of July 1, 2010:
- Insurers may not charge separate deductibles for mental health care and somatic health care.
- Insurers may not impose different limits on the number of visits allowed for mental health care and the number of visits allowed for somatic health care.
- Insurers may not charge greater co-payments for mental health care than for somatic health care.
Some of the finer points of these changes will be complicated, and some may need to be challenged through appeals. In general, if your insurer treats your mental health coverage differently that your somatic health coverage, complain to the insurance company and complain to the Maryland Insurance Administration. To file a complaint with the Maryland Insurance Administration, go on-line and click on “file a complaint,” or call 1.800.492.6116.

Patient Protection and Affordable Care Act
The Patient Protection and Affordable Care Act is the landmark change in health care in the United States that was enacted in 2010. Some provisions of the legislation have already taken effect; others will not take effect until 2014. The two provisions that will have the greatest impact on youth of transition age and their families are the age extension for health care coverage for dependents, and the expansion of Medicaid to childless adults.

New federal health insurance law
Beginning September 23, 2010, federal law requires health insurers to allow families to maintain dependent children on their health insurance policy until a young adult’s 26th birthday, regardless of the youth’s student status. This law will take effect during an employer’s first open enrollment period after September 23, 2010. At that time, a family will be able to re-enroll any dependent child under the age of 26 who previously had lost coverage because of age and/or student status.
**No change**

It was true and remains true that a parent can maintain a dependent child on their health insurance policy indefinitely if the youth:

- Is dependent for support on the parent/guardian.
- Is unmarried.
- Is incapable of self-support because of mental or physical incapacity (in this event, a youth may also be eligible for SSI/Medicaid).

*An individual may have both private health insurance coverage and Medicaid.*

**Medicaid**

Medicaid (also called Medical Assistance) is a joint federal-state program that pays for the health care of people with disabilities and of certain people who have low income. Medicaid is not the same as Medicare—they are different public health insurance programs.

**Medicaid eligibility requirements**

Currently, youth of transition age are eligible for Medicaid under the following conditions:

- If they are enrolled in the Maryland Children’s Health Insurance Program (MCHIP), they are Medicaid eligible until age 19.
- If they were in foster care when they turned 18, they are Medicaid eligible until age 21; in 2014 the age will be raised to 26.
- If they receive a disability determination and are eligible for SSI, they are automatically Medicaid eligible.
- If they have a dependent child and have a low income ($21,200 for a family of three), they are Medicaid eligible.
- If they fall under one of Medicaid’s other categories (such as low-income pregnant women), they are Medicaid eligible.

To find out if you are eligible for Medicaid, you must file an application with the Local Department of Social Services (LDSS) in the city or county where you live. Go to [www.dhr.maryland.gov/county.php](http://www.dhr.maryland.gov/county.php) or call 1.800.332.6347 for a list of offices.

**New federal Medicaid eligibility expansion**

Federal law requires that by 2014, all individuals, including childless adults, with limited assets and an income at or below the Federal Poverty Level (currently $10,825 for an individual) will qualify for Medicaid.

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13 Low income is defined differently for different categories of eligibility. Some Medicaid eligibility criteria have asset limits, some do not.
The expansion of Medicaid will help many young adults.
Maryland may phase in Medicaid eligibility expansion before 2014. If the State's fiscal condition improves, watch for earlier changes to Medicaid expansion.

The public mental health system

If your young adult qualifies for SSI, they will receive Medicaid. If they receive Medicaid, they will be eligible to obtain mental health services through the public mental health system (PMHS). In Maryland, the PMHS is managed by the Mental Hygiene Administration (a state agency) through local mental health authorities—the Core Service Agencies (for a list of Core Service Agencies and their contact information see appendix 1). The PMHS provides mental health services to those individuals who are on Medicaid or, in very specific cases, to those who are found exceptionally needy. The PMHS offers a spectrum of mental health services, a number of which are not available through private insurance. For those who are eligible, most services are low-cost or no-cost.

PMHS eligibility criteria

- Must be eligible for Medicaid

OR

- Must meet the strict eligibility criteria for exceptional circumstances

The criteria for exceptional circumstances are very narrow, applying to such cases as homeless individuals, youth coming out of residential treatment centers, or individuals coming out of jail. A number of conditions apply in these circumstances. Contact the local Core Service Agency for help determining an individual's eligibility for services in the PMHS.

Services provided in the Public Mental Health System

The following list is not exhaustive, but includes the more commonly utilized services:

- Psychiatric inpatient care (hospitalization)

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14 The criteria to receive services from the PMHS for those who are not on Medicaid are:

- Must need treatment for a covered mental health diagnosis
- Must have a verifiable Social Security Number
- Must have applied for Medicaid, SSI or SSDI
- Must meet citizenship requirements
- Must meet Maryland residency requirements
- Must meet the financial criteria established by the MHA

In addition, an individual must meet one of the following requirements:

- Received services from the PMHS within the past two years
- Received SSDI for mental health reasons
- Is homeless
- Has been released from prison, jail or a correctional facility with a mental health diagnosis in the last three months
- Has been discharged from a Maryland psychiatric hospital within the last three months
- Mental health services are required as part of a conditional release
- Psychiatric day treatment (partial hospitalization)
- Residential Treatment
- Respite
- Individual mental health practitioner services (sessions with counselors, psychologists and psychiatrists)
- Medications
- Psychiatric Rehabilitation Programs (a day program, for 5-6 hours/day, 5 days a week; usually more appropriate for older adults who have a severe mental illness)
- Residential Rehabilitation Programs (RRP) - the most intensive level of housing service provided
- Supported Living Services (provides less intensive services than an RRP)
- Supported Employment and vocational services
- Case Management Services (A case manager is assigned to coordinate care across all providers and agencies and to help with benefits.)

**PMHS programs for youth of transition age**

The Mental Hygiene Administration has introduced several pilot programs geared toward serving only youth of transition-age. These programs are designed to move youth into adulthood – not into the adult-serving mental health system. The underlying philosophy of transition-age programs is that with the proper supports in place, and given time to mature, many of these youth will not require long-term services in the adult system.

Appendix 4 provides brief descriptions of the Mental Hygiene Administration's programs for youth of transition age. The programs are widely diverse—from a summer camp to Residential Rehabilitation Programs (RRP). Typically, a youth must be a resident of the county in which the program is located in order to receive services, but exceptions may be made in certain circumstances.

Appendix 4 also lists a program for transition-age youth for which youth do not need to be eligible for the PMHS in order to receive services—the St. Luke's program in Montgomery County.

**Maryland Primary Adult Care (MPAC)**

Maryland Primary Adult Care was introduced in 2006 to provide health care services to people with limited incomes aged 19 and over. It does not offer the broad array of services that Medicaid provides, but it has much less stringent eligibility requirements.

**MPAC eligibility requirements**

- Be age 19 or older
- Not be eligible for Medicare
As an individual, have an income under $12,550 a year and assets less than $4,000. Certain types of income and resources are not counted; for example, income from supported employment programs. Check the MPAC web site for information on exemptions.

Children who live with their parents are eligible for the program. Their parent’s income is not included in eligibility calculations, provided that their family does not claim them as an exemption for income tax purposes.

**MPAC provides:**

- Free visits to a Primary Care Provider
- Free outpatient visits to a psychiatrist
- Free outpatient visits to mental health professionals, including occupational therapists, social workers, psychologists, and professional counselors
- Substance abuse treatment
- Mobile treatment services
- Psychiatric rehabilitation programs
- Low-priced prescription drugs
- Mental health related medical laboratory services

PAC does not pay for hospital stays or emergency room visits.

Designated providers serve PAC clients. For more information, an application, or a list of participating providers, go [www.dhmh.state.md.us/mma/pac/index.htm](http://www.dhmh.state.md.us/mma/pac/index.htm) or call toll-free at 1.800.226.2142.
Chapter 7  Housing Options

Housing realities
Most families of young adults will find their youth continuing to live with them, if not on a permanent basis, then on a revolving door trajectory—moving out for a time and then moving back in. Youth with mental health disabilities may well need to live in the family home longer than average, since it can be more difficult for them to attain a well-paying job. In some cases, however, the severity of a young adult’s emotional disability makes it difficult for them to live at home. In other cases, even though it may be a financial strain, it is desirable for youth to get the experience of having some independence from their family. Outside of the major option of living in the family home, there are both subsidized and private-pay housing possibilities.

Subsidized housing
The Mental Hygiene Administration operates a number of Residential Rehabilitation Programs. RRPs provide the most intensive level of housing service. Typically two to three adults live in a furnished apartment or townhouse, with varying level of staff support as needed per unit.

Transition-age youth (TAY) Residential Rehabilitation Programs
- Must be eligible for the Public Mental Health System
- For youth of transition age only
- Very limited number of beds
- Waiting lists usually exist—but can fluctuate rapidly
- County residents have priority
- Intensity of need takes priority—If a young adult is homeless or coming out of an RTC, they will go to the top of a waiting list.
- For information about the TAY residential programs, see Appendix 3. For information about a particular program, contact the CSA in that county (see Appendix 1).

Adult Residential Rehabilitation Programs are for adults with mental health disabilities.
- Must be Public Mental Health System eligible
- May be appropriate for young adults who will need RRP services beyond 24 years of age
- Limited number of beds
Waiting lists exist
County residents have priority
Intensity of need takes priority
For information, contact the local CSA (see Appendix 1)

Other subsidized housing programs

Department of Human Resources Supported Housing Programs
- For young adults 18-21 who are coming out of foster care
- For information, contact your local Department of Social Services, which can be found at www.dhr.maryland.gov/county.php or call 1.800.332.6347

Main Street Housing
Main Street Housing is a non-profit organization that offers quality affordable rental housing to individuals with mental health disabilities. The organization owns 17 properties throughout Maryland and is continually expanding its number of rental units.
- Two or three tenants per house
- Rent set at affordable levels
- For information: www.onourownmd.org/msh.html or call 410.646.0262

Section 811
Section 811 is a federal program that provides affordable rental housing for people with disabilities and low incomes.
- Rent set at affordable levels
- Not available in all jurisdictions
- Waiting lists exist
- For information: local Public Housing Authority office (see Appendix 5)

Section 8 housing
Section 8 is a federal program that provides rent subsidies to families and individuals with low incomes.
- Section 8 voucher recipients typically pay about 30% of their income toward rent.
- Waiting lists vary by jurisdiction, but typically are very long and sometimes are closed.
- For information, contact your local Public Housing Authority office (see Appendix 5).
Private-pay housing options

- College/university dormitories: the “room” part of “tuition, room and board”
- College and Community College message boards seeking roommates
- Craig’s List—a popular computer message board - be savvy about meeting up with strangers
- Private transition-age youth/adult programs: out-of-state group homes exist for TAY, but are very expensive.
Chapter 8  Legal Matters

This information is meant as a guide. In all legal decisions, it is important to consult with a lawyer who is knowledgeable about issues pertaining to individuals with disabilities.

Age of Majority

When your child turns 18, they become a legal adult, regardless of whether or not you feel they are ready for this status. Men must register for the selective service. Your young adult must act for themselves in all legal matters. They have the right to exclude you from receiving medical or financial information about them, and the right to exclude you from participating in any decision-making process.\(^ {15} \) This can be a scary prospect for parents of young adults with a mental health disability. Their young adult may seem especially vulnerable.

There are many ways for young adults to consent to the disclosure of confidential information and include parents in decision making. Some are voluntary at the discretion of your child; others are involuntary. As your youth transitions to adulthood, it is important to always begin with choosing the least restrictive option in matters of decision making. The ultimate goal is for your youth to feel as empowered as possible.

Consent to share information

If your child agrees to allow their doctor or therapist to share information with you, your child can simply write a statement to this effect. They may revoke the statement at any time.

Decision-Making Spectrum of Options

Beyond sharing information, there is a spectrum of options for sharing decision making with your child.

Medical decision-making

Advance directives

An advance directive allows a person to decide who they want to make health care decisions for them, especially in the event that they are unable to do so themselves. It can also be used to state what kinds of treatment a person wants or does not want. An advance directive can either name a health care agent, or provide health care instructions, or do both. It is voluntary and empowering to the individual.

\(^ {15} \) Education is an exception. As long as your child is in high school, you are entitled to receive information about their educational progress and to participate in any planning process. Once your child advances to post-secondary education, however, you lose these entitlements.
Health care agent
A health care agent is someone named to make decisions about another’s health care. (This sometimes is also called a “durable power of attorney for health care,” but, unlike other powers of attorney, this is not about money.) A health care agent has the authority to see that doctors and other health care providers give a person the type of care they want, and that they do not give an individual treatment against their wishes. This person has full power to receive and provide information about the individual.

Health care instructions for treatment
An individual can let providers know what treatments they want or do not want, in the event that they are unable to make their wishes known themselves.

Preparing an advance directive
Advance directives do not need to be drawn up by an attorney. You can get sample forms from the web site of the Maryland Attorney General, which also contains links to other sample forms. There is no one form that must be used. To make the advance directive valid, it must be signed in the presence of two witnesses, who will also sign. If a health care agent is named, they may not be a witness. Maryland law does not require the document to be notarized. Copies of the advance directive should be given to doctors and hospitals. If a health care agent is named, that person should also be given a copy of the advance directive. For a sample advance directive form and instructions, go to: www.oag.state.md.us/healthpol/advancedirectives.htm.

Implementation of an advance directive
If an individual names a health care agent, he/she should make clear in the advance directive when he/she wants the agent to be able to act for you. This can be at any time (including the present). An advance directive typically takes effect, however, when a doctor certifies in writing that a person is not capable of making a decision about their care. An individual can change or rescind his/her advance directive at any time.

Advance directives for mental health treatments
Advance directives for mental health treatment are identical to medical advance directives, except they are used for psychiatric decision making. An advance directive for mental health treatment is an empowering and proactive step for a person with a mental health disability, for they retain the say of their preferences. All of the regulations that apply to advance directives, including their preparation and implementation, apply to advance directives for mental health treatment. For a sample advance directive for mental health treatment, go to www.dhmh.state.md.us/mha/forms.html and click on “Advance Directive for Mental health Treatment.”

As in medical advance directives, a person may do one or both of the following in an advance directive for mental health treatment.

Health care agent
An individual can appoint a health care agent to receive and share medical information about them, and/or to make treatment decisions for them. It can go into effect whenever the individual chooses – either immediately after being witnessed, or when the person is declared medically incompetent by a treating physician.
**Treatment directive**

In a treatment directive, an individual states their wishes regarding treatments or medications they do or do not want, providers they do or do not want, visitors they do or do not want, and who providers have permission to speak with. A treatment directive goes into effect when a treating physician determines that the individual is mentally incompetent.

You should know, however, that an individual may revoke their psychiatric advance directive at any time—even in the event that they are found incompetent to make decisions. Also, Maryland law does not allow a person to sign another adult into a psychiatric hospital. This power can not be exercised by a health care agent. If your child finds it difficult to complete a formal advance directive, they can simply write down their own wishes in their own hand.

**Financial decision-making**

**Financial power of attorney**

There are different kinds of financial powers of attorney: general and limited. Like advance directives, financial powers of attorney are voluntary.

- A general power of attorney conveys to an agent full power and authority to act on behalf of the grantee in business and personal situations involving bank accounts, real estate, stocks, contracts, and anything else that may arise.

- A limited power of attorney is used for a limited duration or circumstance, to give the agent the authority to perform a specific action or transaction, or series of transactions, on behalf of the grantee. This action is clearly stated in the document (such as selling a car).

Financial powers of attorney do not need to be drafted by an attorney. There are sample forms on websites that can be used as guides. Some financial institutions have their own forms that they require be used. Power of Attorney documents should be signed and notarized.

**Representative Payee**

When the Social Security Administration (SSA) makes a disability determination, it may also determine that the beneficiary cannot manage their own money. In this event they will seek to appoint a representative payee—preferably someone who lives with the beneficiary and has their best interest in mind. Parents are frequently named the representative payee for their child.

A representative payee must see to it that the payee's benefit checks are used for the beneficiary's needs. They must file an annual report that states how the beneficiary's money was spent.

If the SSA did not find that your child needs a representative payee, but you have come to believe that your child is unable to manage their own money for their care, you can apply to become their representative payee. Contact the SSA office nearest you to apply (to locate the nearest office, go to www.ssa.gov). You must submit:

- An application form. SSA requires that you complete the form in a face-to-face interview with a representative.

- Documents to prove your identity

- Your social security number
After you apply to be your child’s payee, SSI will investigate and make a determination as to whether or not your child is capable of managing their money. If you are designated your child’s representative payee, you can use this as an opportunity to empower your child by having them decide how and when money realistically should be spent.

**Guardianship**

Guardianship is the most restrictive way to assist a person with decision making. It is a drastic measure, and the law requires that it only be considered when less restrictive alternatives have failed.

- Deprives the person of the right to make virtually all personal and/or financial decisions.
- Must be determined in a court by a judge. Laws differ by state and Maryland has very restrictive laws; it is quite difficult to be granted guardianship.
- Is costly and time consuming.
- Potentially sets up an adversarial relationship with your child, who will have a court-appointed attorney represent them.

There are three types of guardianship:

- Guardianship of Person: makes decisions about the person's medical care, residence, food, clothing, shelter, etc.
- Guardianship off Property: makes decisions only about the person's money, income, property, and other assets
- Guardianship of both

If less restrictive measures have failed, it is preferable to have limited guardianship, such as just guardianship of property, rather than full guardianship. This limitation allows your child to maintain some control of their own life.

It is important to consult a lawyer if you are considering guardianship.

**Estate Planning**

Families have important issues to consider when planning how to leave money or assets to a child with mental health disabilities. First, an inheritance over $2000 will cause their child to lose their SSI and possibly their Medicaid. Second, the family must consider whether the child is mature enough to manage a bequest responsibly, and how will the child support themselves in their later years.

Due to the complexities that these questions involve, it is wise to hire an attorney who specializes in disability estate planning. An attorney who is knowledgeable about government benefits and sensitive to the needs of people with disabilities can guide you through the issues and help you consider alternatives on how best to structure your estate.

It may also be appropriate to discuss potential inheritances with grandparents or anyone else that might leave a bequest to your child. Again, an attorney with expertise in special-needs estate planning can recommend options that will preserve your child's eligibility for public benefits.
Chapter 9 Conclusion

While navigating the transition years can feel like travelling through treacherous waters at times, there is ample reason for hope. Studies have shown that continued family support and commitment to a young adult vastly improves the odds of achieving a successful outcome. Your very act of reading this handbook shows that you possess this commitment to helping your young adult. We hope that it will provide you with some information and tools to assist your young adult to achieve their dreams.
# Appendix 1

## Department of Special Education, Core Service Agency Phone Numbers

<table>
<thead>
<tr>
<th>JURISDICTION</th>
<th>OFFICE OF SPECIAL EDUCATION</th>
<th>CORE SERVICE AGENCY</th>
</tr>
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<tbody>
<tr>
<td>Allegany County</td>
<td>301.759.2064</td>
<td>301.759.5070</td>
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<tr>
<td>Anne Arundel County</td>
<td>410.222.5410</td>
<td>410.222.7858</td>
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<td>Baltimore City</td>
<td>410.396.8901</td>
<td>410.837.2647</td>
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<td>Baltimore County</td>
<td>410.887.3660</td>
<td>410.887.2731</td>
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<td>Calvert County</td>
<td>410.535.7422</td>
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<td>Caroline County</td>
<td>410.479.3246</td>
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<td>Carroll County</td>
<td>410.751.3033</td>
<td>410.876.4440</td>
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<td>Cecil County</td>
<td>410.996.5449</td>
<td>410.996.5112</td>
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<tr>
<td>Charles County</td>
<td>301.934.7389</td>
<td>301.396.5238</td>
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<td>Dorchester County</td>
<td>410.221.1111 x1022</td>
<td>410.770.4801</td>
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<td>Frederick County</td>
<td>301.644.5281</td>
<td>301.682.6017</td>
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<td>Garrett County</td>
<td>301.334.7655</td>
<td>301.334.7440</td>
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<td>Harford County</td>
<td>410.588.5246</td>
<td>410.803.8726</td>
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<td>Howard County</td>
<td>410.313.6655</td>
<td>410.313.7350</td>
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<td>Kent County</td>
<td>410.778.6422</td>
<td>410.770.4801</td>
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<td>Montgomery County</td>
<td>301.279.3135</td>
<td>240.777.1400</td>
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<tr>
<td>Prince George’s County</td>
<td>301.618.8300</td>
<td>301.985.3890</td>
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<tr>
<td>Queen Anne’s County</td>
<td>410.758.2403 x128</td>
<td>410.770.4801</td>
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<td>St. Mary’s County</td>
<td>301.475.5511 x220</td>
<td>301.475.4288</td>
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<td>Somerset County</td>
<td>410.651.1616</td>
<td>443.523.1810</td>
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<td>Talbot County</td>
<td>410.822.0330</td>
<td>410.770.4801</td>
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<td>Washington County</td>
<td>301.766.8605</td>
<td>301.739.2490</td>
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<td>Wicomico County</td>
<td>410.677.4507</td>
<td>410.543.6981</td>
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<tr>
<td>Worcester County</td>
<td>410.632.5034</td>
<td>410.632.3366</td>
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</table>
Appendix 2  Project Access

What:
The Project Access Summer Institute is a transition program located on the Howard Community College campus in Columbia, Maryland. Its goal is to help high school students with disabilities get into college and succeed there.

The four-week program offers instruction in reading, writing, math, study skills, college survival skills and drama. Career counselors with backgrounds in special education will be available to help students identify appropriate career goals and learn strategies to achieve them. Successful college students with disabilities will help as tutors, mentors, and role models to show the students ways to achieve success.

Who:
- Project Access accepts students coming out of 10th, 11th, and 12th grades. Students must be on a diploma track and recognized by their high schools as having the ability to do college-level work.
- The Institute serves students in the following counties:
  -- Anne Arundel
  -- Baltimore
  -- Carroll
  -- Howard
  -- Montgomery
  -- Prince George's

Transportation is provided for students in Howard County, and the college helps students in other counties arrange car pools.

When:
- The Institute typically is held for four weeks in July from 9:00 a.m.–3:00 p.m.
- The application process begins in early January and continues until the middle of April.

Cost:
- The cost for the 2010 Summer Institute was $550 for Howard County residents and $560 for out-of-county residents. Financial aid is available.

If interested, call Dr. Linda Schnapp at 410.772.4625 or email at lschnapp@howardcc.edu and your name will be added to the mailing list.
Appendix 3
Process for Referrals to Supported Employment

Transitioning Youth with a Mental Health Disability

IEP Team makes referral to DORS

Family makes referral to DORS

DORS
Department of Vocational Rehabilitation makes referral to Core Service Agency

CSA
Core Service Agency makes referral to supported employment provider

Supported employment provider
Appendix 4

Mental Hygiene Administration

Transition-age Youth Programs

The Mental Hygiene Administration made available grant money for Core Service Agencies throughout the state, to provide services for transition-age youth with significant mental health needs. The following Core Service Agencies received grant funding to provide specified services:

Area Served: Anne Arundel County
Ages Served: 16–22
# of Youth: 11 TAY
Services: Intensive educational, case-management, and vocational supports. Concentration on skill development and activities related to employment, recreation and leisure. Provide funds for health, vocational, educational, recreational, and other services.
Contact: Anne Arundel Mental Health Authority, Inc.

Area Served: Baltimore City
Ages Served: 18–23
# of Youth: 26 TAY—14 in Residential Rehabilitation Program
Services: Residential Rehabilitation Program, intensive case management, and wrap-around supports. Services include coordination and linkages to housing, vocational training, social and recreational activities, transportation, and in-home and school supports.
Contact: Baltimore Mental Health Systems, Inc.

Area Served: Baltimore County
Ages Served: 18–22
# of Youth: 10 TAY—6 in Residential Rehabilitation Program
Services: Residential Rehabilitation Program. Individuals are coached on independent living skills and provided with case management. Clients participate in community-based school, training, or employment. Case management is provided for non-residential clients.
Contact: Baltimore County Bureau of Mental Health
Area Served: Charles, Calvert, and St. Mary’s Counties
Ages Served: 17–22
# of Youth 10–25 TAY
Services: Assistance with supported housing, obtaining a high school diploma or GED, participation in support groups, employment, and establishing savings accounts. Provides housing and independent living supports to youth who are stepping down from RTCs, therapeutic group homes, or other intensive placements. Services include outpatient psychiatric treatment, Psychiatric Rehabilitation Services, special education, case management, and residential support.
Contact: Charles County Core Services Agency

Area Served: Howard County
Ages Served: 17–25
# of Youth 12 TAY
Services: Provides Residential Rehabilitation Program, supported employment, and supported living to enable individuals to achieve independent living. Funds dental services, tuition and training, transportation, and rental deposits.
Contact: Howard County Mental Health Authority

Area Served: Kent, Queen Anne’s, Talbot, Caroline, and Dorchester Counties
Ages Served: 16–22
# of Youth 3 TAY
Services: Provide funds for transportation, utility payments, grocery assistance, and educational expenses such as tuition and books. Provide 40 hours of psychological consultation and travel expenses.
Contact: Mid-Shore Mental Health Systems
Area Served: **Montgomery County**
Ages Served: Undefined
# of Youth 117 TAY
Services: Offers 3 programs
1. 22 TAY: Intensive Residential Rehabilitation Program and supported employment. Includes 24/7 on-site awake staff coverage. Also provides stipends for medicine, food, and social and recreational activities.
2. 65 TAY: Provides ongoing support services to youth placed in jobs, including job coaching and transportation.
3. 30 TAY: Provides supported education services.
Contact: Montgomery County Core Service Agency

Area Served: **Prince George's County**
Ages Served: Ages 16–23 who are parents
# of Youth 6 TAY
Services: Provide housing, vocational training, career development, and GED or college-level education assistance to transition-age youth that have children. Services include parenting and family supports, transportation, childcare, and mentoring.
Contact: Prince George's County Mental Health Authority

Area Served: **Washington County**
Ages Served: 17–21
# of Youth 12 TAY
Services: Provides assistance with housing, education and employment. Provides discretionary funds to pay for tuition, vocational training, transportation, educational and vocational supplies, and rental deposits

Area Served: **Worcester, Wicomico, and Somerset Counties**
Ages Served: 17–24
# of Youth 15 TAY
Services: Assistance with educational activities, vocational training, volunteer activities, and employment. Provides transportation, dental services, tuition, recreational activities, and rental deposits.
Contact: Worcester County Core Service Agency
Other transition-age youth programs

Healthy Transitions Initiative—Frederick and Washington Counties
In addition to the above programs, the MHA received a grant in 2009 to expand programming for transition-age youth. The MHA is implementing two programs—one in Washington and one in Frederick counties. These programs provide transition facilitators to work with youth aged 16–24 who have a serious mental health disability. The program offers an intensive form of transition facilitation, providing access to supported employment, community treatment, and other individualized supports exiting within the communities.
For more information, contact the Frederick or Washington County Core Service Agencies (see Appendix 3).

St. Luke's Career Transition Program (CTP)—Montgomery County
The St. Luke's Career Transition Program helps high school juniors and seniors with mental health needs make a successful transition to college, vocational training, the workforce, or other post-secondary goals. It offers a unique combination of mental health and career/vocational resources to assist students and their families in identifying and obtaining necessary resources to achieve a successful transition. Services include:
- Finding a job that matches skills and interests
- Defining career and educational goals
- Applying for college or further training
- Learning about public benefits for which a youth may be eligible to receive
- Connecting with support services in the community
St. Luke's House has a history of successfully engaging youth with mental health needs, providing significant support and resources, and enabling them to experience a successful transition to adulthood.
For more information, call 302.493.4200 ext. 303.
Notes