

Preparing for Life after High School: The Next Steps

Living with Brain Injury



 **Brain Injury Association of
New Jersey, Inc.**

825 Georges Road, 2nd Floor, North Brunswick, NJ 08902

732-745-0200

E-mail: info@bianj.org

1-800-669-4323

Website: www.bianj.org

This brochure was developed for persons with brain injury, family members, caregivers, and friends to suggest ways to deal with the problems one may face when living with brain injury.

**Preparing for Life After High School:
The Next Steps**

Donald R. Hood
Bonnie Todis, PhD
Ann Glang, PhD

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INTRODUCTION

Deciding what to do after high school is a challenge for any student. The choices are many—continuing education, getting vocational training, finding a job, or juggling part-time work and classes. It's also at this time that many young people first think about moving away from home.

For students with traumatic brain injury (TBI), the basic transition challenges are the same as for any young person, yet they are usually more complex. A student whose injury is longstanding has more time to plan than a student who was injured only recently. For the recently injured student, the transition may be harder. Good planning greatly improves the chances that the move from high school to young adulthood will be a successful one.

This booklet describes the opportunities and resources available to students with brain injuries, their families, and others who care about them. It provides guidance on how to make a successful transition from high school student to young adult. It emphasizes the importance of understanding the student's rights, of exploring options, of collaborative planning, and of flexibility. At the end of the booklet is a list of general resources that will be helpful to all individuals living with traumatic brain injury (TBI). Resources on specific topics are listed at the end of each section.



A FOUR-PART PROCESS

It is helpful to think of the transition process as having four parts. The parts are as follows:

1. **Know your rights.** Our society believes that people with disabilities and their parents have certain rights. Federal and state governments have passed laws to guarantee that Americans with disabilities, including TBI, enjoy these rights.
2. **Consider all the options.** Some students want to attend college after they leave high school. Others want to find a job. Still others choose to work and go to school at the same time. Many students may want to change their living situation.

3. **Make a plan.** No matter what option(s) a student chooses, setting realistic goals and evaluating progress toward those goals is essential. Planning and goal setting should begin as early as possible.

4. **Find an advocate.** An advocate is a person who can help locate resources that a student with TBI needs and who may help to coordinate needed services. The advocate may be a family member, friend, vocational rehabilitation professional, case manager, or another professional. As the student grows more independent and knowledgeable, he or she can become a self-advocate.

1. KNOW YOUR RIGHTS

Students with disabilities, including TBI, have distinct rights. These rights are guaranteed under federal and state laws. To the extent that students, their parents, and others understand these rights, the students will be able to take full advantage of the resulting benefits. If a student's TBI occurred at birth, during childhood or early adolescence, chances are that parents and others are already aware of these laws. If the injury occurred only recently, parents and caregivers may be less familiar with them.

The following federal laws protect the rights of individuals with disabilities:

- Individuals with Disabilities Education Act (IDEA) of 1990, as amended in 1997 and 2004
- Section 504 of the Rehabilitation Act of 1973
- Americans with Disabilities Act (ADA) of 1990

IDEA

The IDEA of 1990 and its amendments provide for a free appropriate public education in the least restrictive environment for students with disabilities who have not received a regular high school diploma up to age 21.

IDEA requires the creation of an individualized education plan, or IEP, for each child who receives special education services. Parents and the student have the right to participate in and approve the IEP.

The first IEP is usually created when a child enters school. IEPs must be updated annually. Students are eligible to continue receiving these services until their 21st birthday or until they receive a regular high school diploma, whichever comes first.

Transition Planning under IDEA

Transition services are supports to help a student move from school to employment, further education, adult services, independent living, or other types of community participation. They are required under federal law for eligible children and youth. The law states that transition services continue even if the student has graduated and has received a regular diploma.

The transition process usually begins when the student is around 14 years old. At this time, the student's IEP team begins to make a transition plan. Members of this team include the student, their family, school representatives and outside agencies, such as vocational rehabilitation.

Transition planning is an important part of IEPs for older students. The first IEP that will be in effect when the student is 16 years of age must contain two things:

- Measurable goals for the student after high school. These goals are based on assessments related to training, education, employment, and where appropriate, independent living skills; and
- A description of the transition services the student needs to reach those goals.



According to the IDEA, transition services are results oriented. They focus on improving a student's academic and functional status. Transition services activities include:

- postsecondary education;
- vocational education;
- integrated employment (that is, in regular settings where they work alongside people without disabilities) including supported employment (integrated employment with continuing support from an agency experienced in finding work for the disabled);
- continuing and adult education;
- adult services (comprehensive social services that help disabled individuals live safely while maintaining as much independence as possible);
- independent living; and
- participation in community life.

Transition services are also based on the student's needs and take into account his or her strengths, preferences, and interests. They may include instruction, related services, community experiences, the development of employment and other adult living objectives, and when appropriate, acquisition of daily living skills and functional vocational evaluation.

Students with disabilities who don't receive special education services in high school may need extra support during the transition period. These students, with the help of their family, advocate, and school staff, can take advantage of many of the services mentioned in this booklet.

SECTION 504 OF THE REHABILITATION ACT AND THE ADA

After high school or at age 21, an individual is no longer eligible for services under IDEA. However, two other federal laws protect students with disabilities from discrimination and provide for transition services: Section 504 of the Rehabilitation Act and the ADA.

The **Rehabilitation Act** protects the civil rights of any student who is enrolled in a college, university, or other entity that receives federal funds. Section 504 requires that the states and the federal government make their programs and buildings accessible to people with disabilities. It provides for reasonable accommodations, defined as changes that enable a person with a disability to have equal opportunities with people who do not have a disability. Examples of reasonable accommodations are: adding a ramp so people using wheelchairs can get into a building, changing work schedules, and providing interpreters. For example, a note-taker or audio recorder is a common accommodation for students with TBI who are enrolled in continuing education. It is the responsibility of the student to let the institution know that he or she has a disability and to request the accommodations needed.

The Rehabilitation Act also states that governments must make sure that people with disabilities have equal access to government jobs. For example, governments must provide devices or extra assistance to help people with disabilities do their jobs or apply for jobs.

The **ADA** extends the protections of Section 504 to public and private education, employment, state and local government offices, accommodations, commercial facilities, transportation, and telecommunications, regardless of whether they receive federal funding. It makes certain types of discrimination against people with disabilities illegal. The law requires that employers, business owners, and the government make reasonable changes to stop discriminating against people with disabilities. As with Section 504, it is the responsibility of the student to inform the institution, employer, or other entity about his or her disability and request the accommodations needed.

States vary in their laws that cover persons with disabilities and the services offered. Students and families should consult their schools for details.

Resources

A Basic Glossary: Legal Terms for People with Brain Injury. Available from the Brain Injury Association of America, www.biausa.org.

Individuals with Disabilities Education Improvement Act of 2004. Accessed at:

http://frwebgate.access.gpo.gov/cgibin/getdoc.cgi?dbname=108_cong_public_laws&docid=f:publ446.108.

A Guide to Disability Rights Laws provides concise descriptions of the laws described in this booklet as well as other laws, including the Fair Housing Act, that apply to individuals with disabilities. It is published by the U.S. Department of Justice. Go to: www.usdoj.gov/crt/ada/cguide.htm#anch or65610.

2. CONSIDER ALL THE OPTIONS

The fundamental choice that students face as they think about life after high school is whether to continue their education, get a job, or balance work and school. Transition planning is centered on that key decision. This section covers what students and families should know about going to college and finding a job.

Although we often think of “finishing school,” we never really stop learning. Lifelong learning is a reality for everyone, whether going to a community or other college or getting a job. There are many formal and informal ways of continuing education. If a student has decided on continuing his/her education, a whole new range of options opens up.



Among the formal educational options are:

- community and other two-year colleges
- technical colleges
- trade schools
- training offered by disability-specific organizations
- adult education programs • other non-degree programs
- four-year public and private colleges and universities

The student may also consider whether to attend part- or full-time, whether to work part-time, and where to live. For a student with disabilities who is exploring these choices, it's important to make sure that support services are available, to plan for coping with the demands of work or continuing education, and to know how to adapt a plan if the situation changes.

CHOOSING AN EDUCATIONAL OPPORTUNITY

The benefits and challenges of each educational choice need to be considered before deciding whether to go to school, and if so, which school to attend.

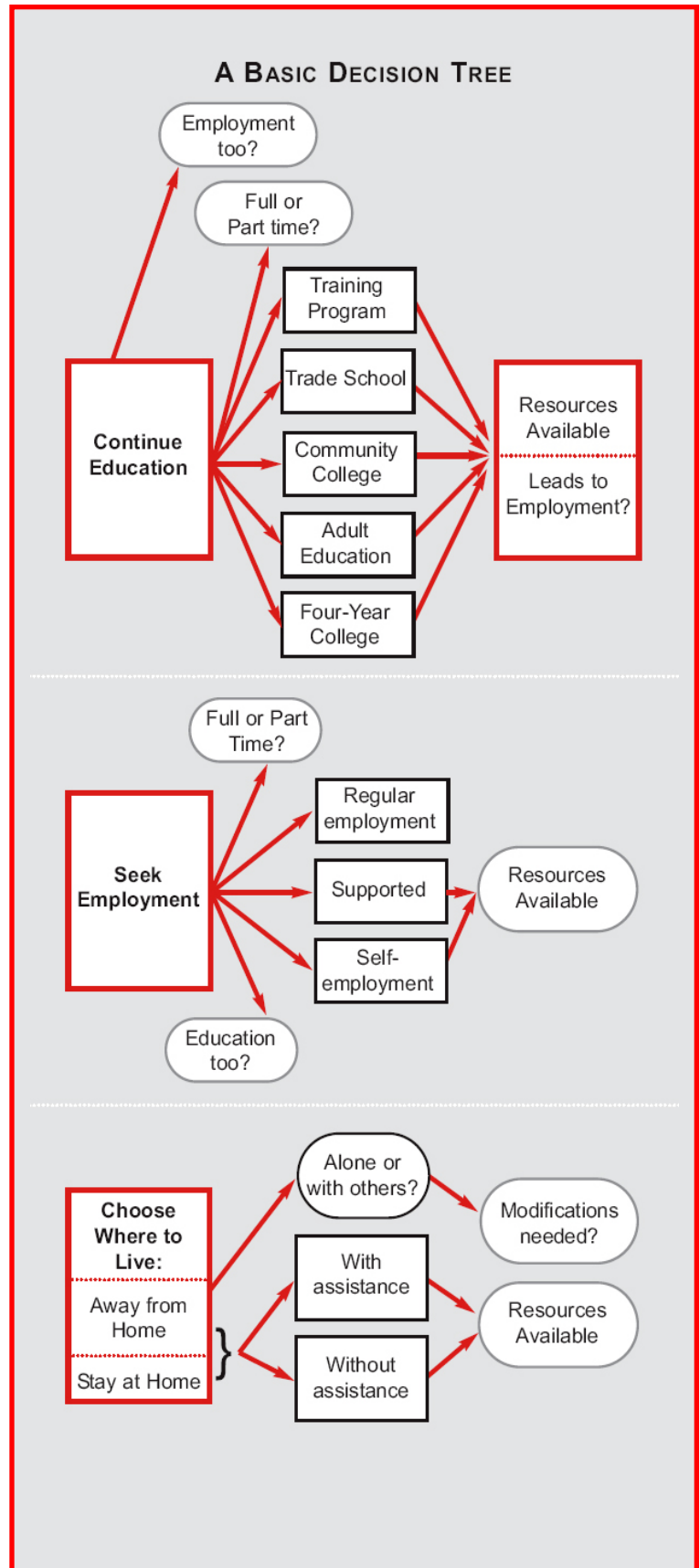
Some things to consider are:

- whether training for a specific job or a more broad education is desired;
- for specific job training, whether a community college or trade school program is best;
- the timing and duration of the program;
- the application and entrance requirements;
- the costs of participation and availability of financial assistance; and
- program location.

Answers to these and other questions are usually available on each school or program's website. In addition, for students who want more information about two- and four-year colleges and universities, a service called College Opportunities On-Line provides the URLs (unique record locators) to thousands of trade and technical schools, as well as, two- and four-year colleges and universities in the United States (see resource list at the end of this section).

Community College

Community colleges often focus on the needs of a community, including training and education for employment. Many community colleges offer excellent disability support services. Community colleges tend to be very flexible and



allow a student to simply take a class or two. Students can complete a trade, certificate, or associate degree programs, or prepare to transfer to a four-year college.

Trade or Technical Schools

Many students find training for a specific job at a trade school or technical college. Training for a wide range of jobs, such as mechanics, dental hygienists, welders, or nurses is generally available. Most trade schools accept federal funds and are required to provide services for students with disabilities.

Colleges and Universities

Four-year colleges and universities generally offer bachelor degree programs in a wide range of specialties or majors. Many also offer adult education classes and some allow students to take just one or two classes a semester.



Special Services to Help Meet the Demands of College

Entering college makes demands on a young student. The adjustment can be difficult. Most colleges and universities have disability support services (DSS) that provide or help arrange for information and referral, registration assistance, auxiliary aids (see Figure 1), and academic accommodation. DSS staff may serve as a student's advocate in some circumstances. The DSS staff may include professionals who provide

crisis intervention and brief supportive counseling. DSS can also help with identifying accessible housing and assistive technology.

Figure 1:

Examples of Auxiliary Aids That May Be Provided under Section 504

- taped texts
- note takers
- interpreters
- readers
- videotext displays
- television enlargers
- talking calculators
- electronic readers
- Braille calculators, printers, or typewriters
- telephone handset amplifiers
- closed caption decoders • open and closed captioning
- voice synthesizers
- specialized gym equipment
- calculators or keyboards with large buttons
- reaching device for library use
- raised-line drawing kits
- assistive listening devices
- assistive listening systems
- telecommunications devices for deaf persons

Students and parents should meet with the DSS staff to discuss needs and arrange for services as early as possible—well before classes start. Schools have limited equipment and funding for free services for students with disabilities. If an institution is not required by law to provide a particular service, such as free tutoring, that service may be in short supply, if available at all. Making arrangements early will give the student the best choices.

If the student has not made arrangements for special accommodations in advance, he or she should meet with each instructor to request accommodations as soon as classes begin. It is the student's responsibility to let instructors know about his/her learning styles and needs. Students should also become aware of a number of simple tips that other students have found useful (see Figure 2).

Some instructors will be unfamiliar with Section 504 and the ADA. They may resist making the necessary accommodations because they don't understand the school's obligations. If this happens, the student should ask DSS for assistance. DSS staff can help make the arrangements. They can also educate the instructors about their responsibilities under the law.

Figure 2:

Useful Strategies, Accommodations, and Modifications for Students with Disabilities Strategies

- Use memory aids such as organizational software, note-taking aids or services, hand-held pocket organizers, notepads, or tape recorders.
- Use index cards to group small bits of information, key concepts, or new vocabulary.
- Practice taking tests, writing term papers, and managing lab assignments.
- Schedule weekly appointments with the campus writing center for help in organizing papers and proofreading drafts.

Accommodations or Modifications

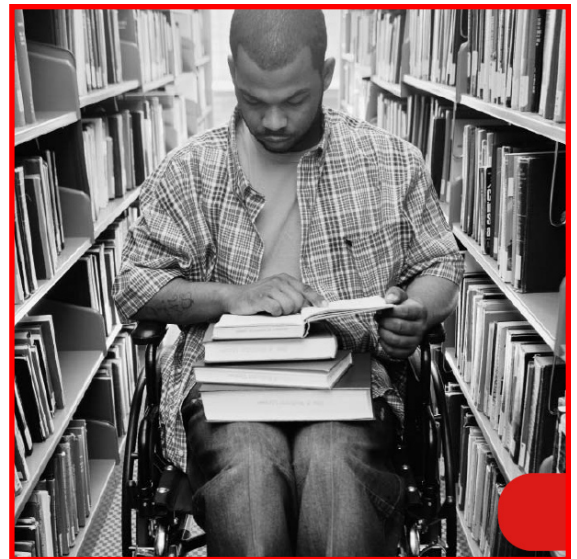
- Request the help of tutors to aid in understanding class material and to keep up with assignments (free tutoring may or may not be available).
- Ask for advance access to course syllabi, including a description of all class requirements.
- Arrange to take more frequent tests that cover smaller amounts of material than the rest of the class. Or take lengthy exams in intervals with short breaks.
- Ask for extra time to prepare for oral presentations, take exams, or complete papers.
- Request frequent feedback from the instructor regarding performance expectations, information to be tested, and course learning objectives.

Adapted from The Student with a TBI: Achieving Goals for Higher Education, Ruoff, J. 2001.

Changing Plans

No matter how well a student has planned the transition to college, and no matter how much support he or she receives, it is not possible to guarantee that they will do well. Many students will succeed; some will shine. Others will fail or run the risk of failure. Failing or having problems in one class does not mean the student cannot succeed in another. However, failure in several classes is usually a sign that it's time to reconsider the student's plan.

The college's DSS and the student's adviser should be included in any discussions about taking fewer classes or leaving college. If a four-year university presented too many challenges, a two-year community college may be a better option for the student, especially if they are just beginning college.



Financing a College Education

Many students need financial assistance to pay for college. The federal government and most states offer scholarships, loans, grants, and other programs. The state office of vocational rehabilitation may also fund tuition, books and supplies, and services for eligible students. (Additional information on services offered through these offices appears below in the section entitled "Entering the Workplace.")



Families and students should also ask the school about tuition waiver and discount programs. Certain professions with workforce shortages, such as nursing, offer incentives for students to consider entering the profession.

Exploring sources of financial aid takes time. A high school guidance counselor, the transition specialist, or the college financial aid office can help point the student and family in the right direction. Public librarians can often suggest good places to look, both in print and online.

Continuing Education Resources

College Opportunities On-Line (COOL) provides links to nearly 7,000 universities, liberal arts colleges, specialized colleges, community colleges, career or technical colleges, and trade schools. COOL is a service of the U.S. Department of Education. Go to: www.nces.ed.gov/ipeds/cool

Information about federal student aid programs at the U.S. Department of Education, including grants, loans, and programs such as Federal Work Study, may be found at the website below. Schools are not required to participate in any of these federal financial aid programs. Be sure to check with each school.

www.ed.gov/offices/OSFAP/Students/student.html

The Free Application for Federal Student Aid, a form that all applicants for federal financial aid must complete, is at: www.fafsa.ed.gov

The Federal Student Aid website offers information about federal, state, and private sources of financial aid. It also offers information about preparing for and selecting colleges. Go to: www.studentaid.ed.gov/PORTALSWebA pp/students/english/index.jsp

The Federal Trade Commission suggests a list of questions to consider in evaluating trade or technical schools. Go to: <http://www.ftc.gov/bcp/conline/pubs/serv ices/votech.htm>

Information about Section 529 College Savings Plans is available from the state department of education or a financial adviser.

See also Vocational Rehabilitation below.

Auxiliary Aids

Information about the auxiliary aids and services that colleges and universities have under Section 504 and the ADA can be found at: www.ed.gov/about/offices/list/ ocr/docs/auxaids.html

The Student with a TBI: Achieving Goals for Higher Education, by Janice Ruoff, Heath Resource Center, 2001. Available free at: www.heath.gwu.edu/PDFs/Brain %20Injury.pdf

ENTERING THE WORKPLACE

Some young people with TBI are able to work full-time or part-time in a regular job. Others will require special training and support from a job coach. Some will do better in jobs that involve a great deal of repetition. Still others will want to open a business or work from home.

A variety of employment options and support services are available to help persons with TBI and other disabilities prepare for and succeed in a job.



The State Vocational Rehabilitation Agency

The state vocational rehabilitation (VR) agency has a key role in helping students find jobs and job training. The VR agency can identify work options and guide the young person in making choices based on his or her interests, abilities, and needs.

Students with TBI who are receiving special education services or whose injury is likely to be a barrier to employment should register with their state VR agency two years before high school graduation or before they turn 21, whichever is earlier. This allows the VR counselor to participate in transition planning meetings and advise the student about vocational assessment, job training, and other services. Because funding is

limited, many states have established priority categories and waiting lists for VR services. Registration may help the eligible student gain access to needed VR services and funding instead of joining the waiting list.

A student who sustains a TBI during the last year or two of high school may not be receiving special education services. If that student has a physical or learning disability that may be a barrier to employment, he or she should register with the VR office as early as possible.

State Vocational Rehabilitation Services

VR agencies offer the following services:

- vocational assessment to help identify skills, abilities, interests, and job goals;
- vocational counseling and guidance;

- physical and mental restoration services related to an employment goal;
- training and education to learn new vocational skills;
- rehabilitation technology, telecommunication aids, and other adaptive devices;
- job placement services;
- services to help students with disabilities get a job after finishing high school;
- supported employment; and
- referral to other services.

Eligibility for VR Services

To receive VR services, the student must:

- 1 have a physical or mental impairment that results in a substantial barrier to employment;
- 2 be able to benefit, in terms of an employment outcome, from VR services; and
- 3 require VR services to prepare for, secure, retain, or regain employment.

Individuals who receive Supplemental Security Income (SSI) or Social Security Disability Income (SSDI) are presumed to be eligible for VR services.

Related Employment Services

One-Stop Career Centers

The U.S. Department of Labor’s Division of Employment and Training has One-Stop Career Centers in every state. Services of these centers are available for anyone who wants to work. The centers offer the following services:

- access to computers for posting resumes and job searching;
- review of job qualifications, experience, readiness, and abilities;
- vocational counseling;
- referral to employers with appropriate job openings, to other agencies for job training, and for supportive services (e.g. health, housing, legal);
- classes in searching for job openings, writing résumés and cover letters, interviewing for a job, networking, and using computers to post résumés and search for jobs; and
- fax, copier, and phones for use during a job search.

Ticket to Work

People over age 18 who receive Social Security assistance may be eligible for a program known as Ticket to Work. The goal of this program is to increase opportunities and choices for Social Security disability beneficiaries to obtain employment, VR, and other support services. This program removes many of the barriers that made it difficult for people to go to work because their earned income would mean a loss of Medicaid benefits.

The Social Security Administration automatically sends eligible students a “ticket” for this program. The ticket is valid at VR agencies, as well as at other service providers.

Local Services

Some community employment agencies specialize in working with people with cognitive impairment. They may offer specialized supports to individuals with TBI.

Vocational Resources

Vocational Rehabilitation

To locate the state vocational rehabilitation office near you, go to: <http://www.jan.wvu.edu/SBSES/VOCREHAB.HTM>.

One-Stop Career Centers

Each state has several career centers that offer services to people looking for work.
Go to: www.careeronestop.org.

Ticket to Work

Go to the Social Security Administration at www.ssa.gov or to the program website at www.yourtickettowork.com.

Other Federal and State Benefits for Young Working Adults

The student's existing sources of income or service eligibility may be affected by earned income. Two major sources of support are usually involved: Supplemental Security Income, or SSI, and Medicaid health benefits.

Supplemental Security Income (SSI)

Once a young person begins to work, SSI may be reduced or eliminated, depending on the student's earnings. The rules for these decisions are complex. It is helpful to consult with the VR agency or Social Security office to discuss the student's specific situation.

Medicaid

States may provide benefits to workers with disabilities who, because of their earnings, no longer qualify for Medicaid. Many states have implemented laws that allow people to purchase Medicaid on the basis of an income-based, sliding scale. This allows people to go to work with less concern about the potential of losing medical benefits.

Income and Medical Benefits Resources

Social Security

Social Security Disability Income (SSDI) and SSI are federal programs that provide financial assistance to people with disabilities. Individuals who have a disability and meet the medical criteria may qualify for benefits under either program. For more information, go to: www.socialsecurity.gov/disability.

Medicaid

For general information about Medicaid, go to: www.cms.hhs.gov/medicaid/consumer.asp

For information about the Medicaid Buy-In Program, which allows people with disabilities who are working to purchase Medicaid benefits, go to: www.socialsecurity.gov/disabilityresearch/wi/buyin.htm.

Medicare

People with disabilities who have been receiving SSDI for 24 months may be eligible for Medicare. For more information, go to: www.medicare.gov.

FINDING A PLACE TO LIVE



Leaving high school often makes young people want to feel more independent. For some, a way to enjoy greater independence is to move away from home. There are some different options depending upon whether the student continues his or her education or decides to work.

At least six months before graduation or at the end of high school, the student who wishes to work should begin meeting with representatives of an independent living center or state and local resources for assistance in determining the options that fit his or her goals and needs.

Students continuing their education may choose to live on-campus, in off-campus housing, or at home. On-campus housing can be more convenient. Section 504 and the ADA require educational institutions offering on-campus housing to accommodate students with disabilities. At some colleges, housing is made

accessible on request. Advance planning will allow time for any renovations that need to be made. Most colleges have a student housing office. Staff of this office can answer questions about on-site and off-site housing.

Regardless of whether a student chooses to work, to continue his or her education, or to combine work and continuing education, some students choose to live with their families, and family members provide all the assistance they need. Some students may need outside assistance, such as a personal care assistant, whether living alone, with family, or with a roommate or group of peers.

Many resources are available that can help students with identifying and paying for housing, supports, and assistance. For example, VR staff can provide guidance to students. In addition, every state offers several independent living centers. Staff of these centers offer peer counseling, skills training, advocacy, and information and referral. Some centers offer housing referrals, communication assistance, support groups, transportation, and health information.

Some states offer home care assistance programs. These programs provide services such as meal preparation, grocery shopping, laundry, and light housekeeping to adults with disabilities.

A student who qualifies for Medicaid may be able to take advantage of the Medicaid Home and Community Services Waiver program if it is available in his or her state. This program offers home health care, personal care, rehabilitation, and other services.

A number of states have established TBI trust funds. These funds provide assistance to persons with TBI who do not have other funding sources for needed services. Eligibility and the types of services offered may vary, not every state has a trust fund. The state affiliate of the Brain Injury Association of America will know whether a trust fund exists and can provide contact information.

Other things to think about when choosing a place to live include: transportation, social and recreational activities, shopping and financial management, health and safety, and behavioral support. For many people, any change or transition can create a multitude of challenges. If change is particularly difficult for the student, it's best to make changes gradually and with advance preparation and practice.

Resources

Medicaid Home and Community Services

Information about Home and Community Services for people eligible for Medicaid and SSI can be found at: www.aspe.hhs.gov/daltcp/reports/primer.htm

Independent Living Centers

Every state has Centers for Independent Living (CILs) that provide services to maximize the independence of individuals with disabilities and the accessibility of the communities in which they live. Core CIL services include: advocacy, independent living skills training, information and referral and peer counseling. Many CILs also help people find housing and personal care assistance.

The Independent Living Resource Utilization program is a national center for information, training, research, and technical assistance in independent living. A list of independent living centers, updated weekly, is included on its website. To find a CIL in your area, go to: <http://www.ilru.org/html/publications/directory/index.html>.

3. MAKE A PLAN

Planning is the third part of the transition process. Because it is a collaborative process, planning takes time. It also often involves compromise. Parents or other supportive people have the student's best interests at heart. They also have a great deal of expertise. The most important factor, however, is that the plan represent the student's ideas and goals. This sometimes means that others may not agree entirely with the plan. They may think the student should do something different. It's important to have wide-ranging discussions of options. But once a plan is firmed up, it is important that everyone support it.

This section provides background information that will help in planning the transition from high school.

The Family's Ongoing Role

As a student nears adulthood, greater independence is often a goal. The need for family involvement may decrease, but it does not end. Family-centered planning is a way to consider the needs of each member of the family when making decisions. The student should have a major role in planning and decision making. However, both the student and family should work together to build support systems (sometimes referred to as "support circles") to ensure the student will have an active family and community life. Support circles foster friendships and networks that enhance a person's life and options.

Assessing the Student's Abilities

The IEP and transition plan are based on a thorough, accurate, and updated assessment of the student's abilities. The IDEA requires that a qualified professional do the testing. The school system pays for the test and provides the personnel (often, a school psychologist), as well as all the materials and equipment necessary to administer the test.

In addition, assessments and other evaluation materials used under IDEA must:

- not discriminate on a racial or cultural basis
- be provided in the language and form most likely to yield accurate information on what the student knows and can do and
- be used for purposes for which the measures are valid and reliable

More than one type of assessment is needed to provide enough information to make good transition decisions. It is important that the student be assessed in all areas of potential disability. The assessment tools and strategies should be chosen to provide information that directly assists in determining that the educational needs of the student are met.

Neuropsychological Assessment

A neuropsychological evaluation is recommended for students with TBI at the time they begin transition planning. This exam should be administered by a neuropsychologist, who is a psychologist with special training in evaluation and treatment of brain functions.

The purpose of the neuropsychological evaluation is to identify strengths and weaknesses in a person's thinking skills. It involves tests that provide a baseline measure of a person's abilities. The test also suggests ways to improve strengths while working around areas of weakness. The school system may need to be convinced to include this as one of the kinds of assessments it provides under IDEA.

Before the test, the parent should be sure that the neuropsychologist knows why the testing is being done. If the student has had previous evaluations, the neuropsychologist should have a copy of the test results. This will enable the neuropsychologist to compare results of the tests. The parent should ask the neuropsychologist to include in the report comments about the types of services or supports that may help the student to have



the best chance of success.

Environmental Assessments

In addition to assessing the student's abilities, it is a good idea to assess the environment. Housing, workplace, and school environments, as well as support facilities in the community must be evaluated. For example, for a student who relies on public transportation, living or working near a bus line or subway can make the difference between success and frustration.

Setting Goals

Once a student's assessment has been done, it is time to set goals for the transition plan. Like planning, goal setting is collaborative. It should include the student, family members, teacher, and other professionals, such as an employment specialist (job coach), vocational rehabilitation counselor, advocate, neuropsychologist, nurse, occupational therapist, psychiatrist, physical therapist, social worker, and speech-language therapist.

The team should explore all possible options before setting goals. Goals should be measurable and attainable. Consider setting goals that address:

- where and with whom the student will live
- what the student will be doing (e.g., working part- or full-time, taking classes, volunteering, going to college)
- financial resources the student will need and how the student will get them

The goals should be consistent with the student's strengths. They should be challenging, but not overwhelming.

The goals should be written down. Each goal should have an action plan that lists the steps necessary to reach the goal and a time-line or deadline. The goal should also foresee any obstacles that need to be overcome and strategies for overcoming them, and each goal should spell out the skills or information needed to reach the goal. Each goal should also designate the person or persons who are responsible for helping the student accomplish each activity, and state how progress will be measured. Finally, it should state how progress will be measured.

Keeping Track of Progress

Many students have trouble following through with plans, even plans they themselves have made. But when goals are written with specific deadlines and an action plan, it is easier to track—and celebrate!--progress. Lack of progress means that it may be time to find other resources to help achieve the goal. In some cases, the best option is to change the goal.

The student should set a time each week to look at the goals, activities, and time lines. Ask the student to determine which tasks are on track and which are slipping. To add structure to this review, the student might ask a school adviser, advocate, or staff from DSS to meet with him or her regularly to do the review.

Troubleshooting Strategies

Even with the best planning, many people find that the goals they set are not attainable. Students with TBI are no exception. For example, a student may wish to graduate from college. But once enrolled, the student may find the demands of higher education are overwhelming.

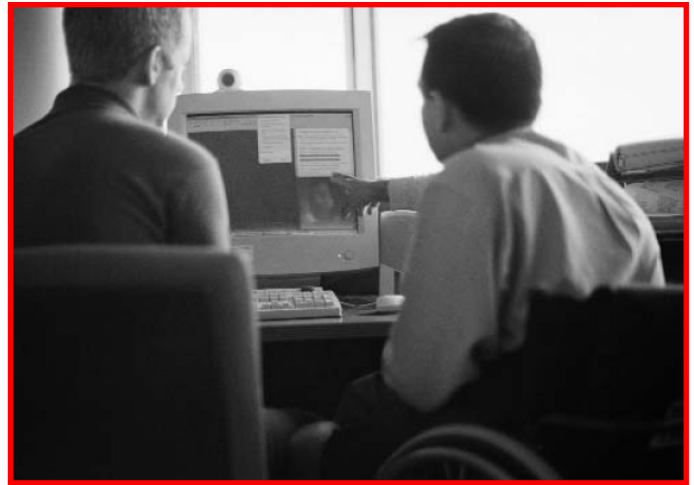
Breaking a goal into parts can help the student to feel successful and move toward a larger goal. For example, a small goal may simply be to pass a test. On the basis of these smaller goals, the student can consider whether the overall goal is realistic. The student should feel free to turn to relatives, his or her advocate, or other people for support when needed.

Reviewing and Revising the Plan

If, despite the student's efforts, something isn't working, the review session is an ideal time to find out what is needed. For example, a goal may have been unrealistic. Or the person assigned to an action step may have met an unexpected obstacle. Extra help, adjustments to the deadline, or just a reminder may help the student get back on track. Flexibility is essential.

The transition plan goals must be reviewed at least once a year. Depending on the type of goals, the services being provided, and the length of time until the transition from high school, it may be helpful to review it more frequently.

Students, parents, and others should consider the time used in setting goals, writing them down, measuring and reviewing progress as an investment. The payoff can be tremendous.



4. FIND AN ADVOCATE

After a student leaves high school, he or she takes on increasing responsibility for securing any needed assistance—whether from a landlord, professor, employer, or agency with which the student is affiliated.

When beginning this move to greater self-reliance, many students find it helpful to have a guide or an advocate. A parent or other family member may have filled this role for many years. As a young person nears adulthood, a new advocate may be more helpful. The student should also learn self-advocacy skills as the transition to adult life proceeds.

Skills of an effective advocate include an ability to:

- find information
- communicate effectively
- solve problems
- make decisions
- negotiate
- stand up for the young person's rights

An advocate can make contacts and represent the student in dealing with agencies and can help the student make phone calls and participate in meetings.

The advocate can also help the student set up and get to appointments, and can make sure the student has enough information to make sound decisions. A good advocate is very familiar with the student's situation, needs, and goals.

Finding an effective advocate can be challenging. Persistence is often the key to finding a good match. School transition specialists may be able to supply the names of potential advocates.

Rather than having just one advocate, a student may develop relationships with several people who will advocate for different services. Some advocates have limited time to share with the student, so it may be helpful to focus on specific problems.

Although they do not take on formal advocacy roles, friends and people involved in working with people with disabilities can also advise a student who is in the transition process. A counselor or staff person from one of the agencies that serves the student is a particularly good possibility for this role.

Transition from high school to college or the workplace is not just a phase. Some people with disabilities will need extended or life-long assistance. The sooner they learn good self-advocacy skills, the more likely they will be able to achieve greater independence. But no matter how independent the student becomes, a trusted

advocate can always help with new issues that arise and provide trusted advice on ongoing issues.

Advocacy Resource

Family Advocacy Skills Training: A Handbook for Family Advocates by Donald Hood, Ann Glang, Marilyn Lash and Bonnie Todis, 2001. Available free at: www.tr.wou.edu/tbi/fast/downloads.htm

GENERAL RESOURCES

Many print and Internet resources provide information and assistance about education, employment, and independent living services. Although the Internet is a wonderful source of information, it must be used with caution. Many websites are not dependable or accurate. Government sites and those supported by national organizations are generally most trustworthy. When using a website, parents and students should never give personal information such as a Social Security number, date and place of birth, or sometimes, even a mailing address or phone number.

General Information

The Brain Injury Association of America (BIAA) is the premier source of information, education, support, and legislative advocacy for persons with brain injury, family members and caregivers, and the professionals and providers who serve them. Through BIAA's network of state and local affiliates and support groups, connections to many of the services described in this booklet may be found. Go to: www.biausa.org.

Disability Info is a federal government website that includes disability-related information and links to hundreds of other organizations and websites. Go to: www.disabilityinfo.gov.

Education

Education Resource Centers

Education Resource Centers offer free information on topics such as accessibility, career development, accommodations, financial aid, independent living, transition resources, training and postsecondary education, vocational education, and rehabilitation.

National Dissemination Center for Children with Disabilities www.nichcy.org

National Clearinghouse on Postsecondary Education for Students with Disabilities (HEATH Resource Center) www.heath.gwu.edu

National Center on Secondary Education and Transition www.ncset.umn.edu

Parent Training and Information Centers and Community Parent Resource Centers

Each state has at least one parent center that serves families of children and young adults from birth to age 22. Center staff members often help families obtain the educational and other services for their children with disabilities. They provide training and information to parents, help resolve problems between families, schools, or other agencies, and connect children with disabilities to community resources. Go to: <http://www.taalliance.org/Centers/index.htm>.

Life Beyond the Classroom: Transition Strategies for Young People with Disabilities, 3rd edition, by Paul Wehman, Paul H. Brookes Publishing Co., 2001. The book discusses planning, supporting, and facilitating transition from high school to work for young adults with disabilities.

Funding

Guide to State Government TBI Policies, Funding and Services, 2nd edition. National Association of State Head Injury Administrators, 2005. Available from: www.nashia.org. The website provides information about state and federal services, as well as names of contact persons.

Resources

There are many sources of information on brain injury, advocacy, special education, and many other topics addressed in this guide. The sources listed below are good places to begin searching when you need information about a specific topic. The Brain Injury Association of New Jersey's Information & Resources Helpline can provide you with additional information on available resources.

Brain Injury Association of New Jersey, Inc.

☎(800) 669-4323 (Family Helpline) ☎(732) 745-0200 Web: www.bianj.org

BIANJ provides a number of services to assist individuals with a brain injury and their families.
(See page 2 for more information)

Brain Injury Association of America (BIA)

☎(800) 444-6443 (Help Support Line) ☎(703) 761-0755 Web: www.biausa.org

BIA provides information about brain injury and resources throughout the United States. The web page provides dozens of links to brain injury information sites.

Statewide Parent Advocacy Network (SPAN)

☎(800) 654-7726 Web: www.spannj.org

SPAN provides information, training, and advocacy for parents of children with disabilities.

New Jersey Protection and Advocacy

☎(800) 922-7233 Web: www.njpanda.org

This program protects and advocates for the rights of citizens with disabilities.

Education Law Center

☎(973) 624-1815 Web: www.edlawcenter.org

This agency provides help for families with issues related to the education system.

Community Health Law Project

☎(609) 392-5553 Web: www.chlp.org

This project advocates for the health care needs of individuals with disabilities.

Association of Schools and Agencies for the Handicapped-New Jersey

☎(877) 287-2724 Web: www.asah.org

This organization provides information about private schools in NJ, which provide specialized services for students with special needs.

Families and Advocates Partnership for Education (FAPE)

☎(952) 838-9000 Toll-free: ☎(888) 248-0822 Web: www.fape.org

The Families and Advocates Partnership for Education (FAPE) project is a partnership that links families, advocates, and self-advocates to information about the Individuals with Disabilities Education Act (IDEA).

HEATH Resource Center

Toll-free: ☎(800) 544-3284 Web: www.heath.gwu.edu

A resource center of the George Washington University, Graduate School of Education and Human Development, and the national clearinghouse on postsecondary education for individuals with disabilities.

Family Support Center of New Jersey

Toll-free: ☎1-800-372-6510 Web: www.fscnj.org

The Family Support Center is a "One-Stop Shop" clearinghouse, offering the most up-to-date information on all types of disabilities as well as national, state and local support programs and services for individuals and families seeking such information.

Lash & Associates Publishing/Training Inc.

708 Young Forest Drive, Wake Forest, NC 27587-9040

☎(919) 562-0015 Web: www.lapublishing.com

This company has a comprehensive array of written materials and resources about brain injury.

National Information Center on Children and Youth with Disabilities

PO Box 1492, Washington, DC 20013-1492

☎(800) 695-0285, ☎(202) 884-8200 Web: www.nichcy.org

Clearinghouse with a large selection of clearly written, free or low-cost information.

National Safe Kids Campaign

1301 Pennsylvania Ave., NW Suite 1000, Washington, D.C. 20004-1707

☎(202) 662-0600 Web: www.safekids.org

SOME NJ GOVERNMENT AGENCIES/PROGRAMS

Office of Special Education Programs

☎(609) 292-0147

Web: www.state.nj.us/njded/specialed

This state office is responsible for providing special education and related services.

Learning Resource Centers

Web: <http://www.nj.gov/njded/lrc/>

The Learning Resource Centers are supported through the New Jersey State Department of Education, Office of Special Education Programs and provide services to parents and educators serving pupils with disabilities ages 3 to 21, including information services, books and videos that can be borrowed, and consultation and training services.

Division of Disability Services

Toll free Information Line ☎(888) 285-3036

Web: www.state.nj.us/health/dds/index.html

The Division of Disability Services is an excellent resource for disability-related information, and also oversees the Traumatic Brain Injury Fund and Traumatic Brain Injury Medicaid Waiver. Call for a free resource guide.

Division of Developmental Disabilities

☎(609) 292-7260

Web: www.state.nj.us/humanservices/ddd/index.html

This organization provides services for households that include an individual with a developmental disability or brain injury sustained before the age of 21.

Division of Child Behavioral Health Services (DCBHS)

24-hour Access Line: ☎1-877-652-7624

Web: www.state.nj.us/humanservices/dcbhs/aboutdcbhs.htm

The Division of Child Behavioral Health Services (DCBHS), serves children and adolescents with emotional and behavioral health care challenges and their families across all child-serving systems.

Division of Vocational Rehabilitation Services

☎(609) 292-2919

Web: www.state.nj.us/labor/dvrs/vrsindex.html

DVRS provides services to individuals with work-related disabilities to help those individuals become employed.

Commission for the Blind and Visually Impaired

☎(973) 648-2324

Web: www.state.nj.us/humanservices/cbvi/index.html

This program provides vocational rehabilitation services for people who are blind or visually impaired.

New Jersey Traumatic Brain Injury (TBI) Medicaid Waiver Program

☎(888) 285-3036

Web: www.state.nj.us/health/dds/index.html

This program provides services in the home and community for those injured after the age of 21 who qualify financially and medically.

New Jersey Traumatic Brain Injury (TBI) Fund

☎(888) 285-3036

Web: www.state.nj.us/health/dds/index.html

The Traumatic Brain Injury Fund, administered by the Division of Disability Services, allows New Jersey residents who have survived an acquired brain injury to obtain the services and supports they need to live in the community.

Special Child, Adult and Early Intervention Services

☎Telephone: 609-777-7778

Web: www.state.nj.us/health/fhs/scdesc.htm

Special Child Health Services provides case management to ensure that children with special health care needs receive quality services that will prevent or reduce the effects of developmental delay, chronic illness or behavioral disorder.

Catastrophic Illness in Children Relief Fund

Toll Free: ☎1-800-335-FUND

Web: www.njcatastrophicfund.org

Financial help is available from this fund if your child is 21 years old or younger when the medical expenses were incurred; your family has lived in New Jersey at least three months prior to application; and in any prior, consecutive, 12 month period, dating back to 1988, eligible expenses must exceed 10% of the family's income, plus 15% of any excess income over \$100,000. Covered expenses include, but are not limited to, special ambulatory care, acute or specialized in- or out-patient hospital care, medical equipment, medically-related home modifications, home health care and medical transportation.

NJ Family Care

Toll Free: ☎(800) 701-0710

Web: www.njfamilycare.org

NJ FamilyCare is a federal and state funded health insurance program created to help New Jersey's uninsured children and certain low-income parents and guardians to have affordable health coverage.

