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Dear Families,

This "manual" has been compiled with the intent of providing you with enough general information for you to build a framework for creating and achieving goals. There will be sections of this manual that may not apply to your particular situation. All the information enclosed is purely for your reference in the event you may need it at some point. This is not a step-by-step guide, but rather a point of reference with which you can fashion your own plan. It will hopefully give you some direction and spark questions you may have.

The transition process is highly individualized, and must be coordinated primarily by the family in order to be successful and provide helpful outcomes. There are many service agencies referred to in this manual, some of which you may find helpful in assisting you in your endeavors. Remember, there is no magic solution or instructions, and no agency is "the answer" to all your needs. All the agencies strive to assist families in achieving their goals, but none is able to just do it on their own.

By joining in partnerships with the agencies in your community, you will be able to create more opportunities for a fulfilling, safe life for your young adult. It is certainly not easy, but it is definitely worth the effort!

Yours,
How to Use This Manual

As you read this manual, you may have questions on the information presented. You may want to write your questions down as you think of them. Answers may be found elsewhere in this manual.

However, if you don’t find the answers you need, consider contacting your child’s school case manager or your primary contact person at the Area Agency. They can assist you in finding the answers.

Transition Timeline

Questions to ask:
What about:
• Medicaid
• Social Security
• Guardianship
• Vocational Rehabilitation
• Mental Health Services
• Community Housing
• Post-Secondary Education
....for my child?

Age 21
Adult Services or Wait List or Natural Supports

Age 18
SS, Medicaid, Guardianship, Post-Secondary Education
Guardianship decree provided to team
New releases signed

Age 17
Discussion: Social Security, Medicaid
Guardianship, Post-Secondary Education

Age 16
Transition plan in place and implemented
Preliminary graduation plan in place

Age 14
Transition information shared through school
Graduation plans discussed
Checklist

The following is a checklist by ages you may find helpful in assisting you in addressing some of the most important areas in transition. This is only a basic guide.

**At age 14:**

- Talk with your family about your hopes, dreams, and fears for your child.
- Create a beginning “picture” of who your child is and wants to be (or you hope to see) as an adult.
- Connect with your local Area Agency, if you have not done this yet.
- Request transition information from your school and Area Agency.
- Discuss change from middle to high school, and how to prepare your child for this transition.
- Discuss your ideas around graduation and request your school’s policy on graduation.
- Assist your child in securing a job (paid or volunteer, even if only for 1 hour per week) to begin exposure to the work community, if possible.

**At age 15:**

- Facilitate discussions with your school team around new opportunities for growth for your child, in and out of school.
- Discuss graduation options with your school, family, and others who have knowledge about graduation practices.
- Continue summer/after school job opportunities with your child.

**At age 16:**

- Assist your child in participating in his/her IEP meetings from now on.
- Review your child’s transition plan and insure it includes all areas of your child’s life.
- Select a graduation plan (you can always change your mind) that is best for your child and talk with your school team about it.
- Apply to Voc. Rehab. for assistance with vocational support and planning.
- Continue summer/after school job opportunities with your child.
- Discuss driver’s education with your team, if appropriate.

**At age 17:**

- Discuss Social Security and Medicaid benefits with your Area Agency.
- Discuss guardianship options with your Area Agency.
- Discuss Post Secondary education options with your family and school team.
- Secure any financial resources your child may have that exceed $2,000.
- Continue to advocate for a comprehensive transition plan that can be implemented, and to insure your child’s graduation plan is still in place.
- Continue summer/after school job opportunities.
At age 18:

_____ Register for selective service (for males).
_____ Apply for Social Security and Medicaid benefits.
_____ Complete guardianship process, if appropriate.
_____ Establish contact with Post Secondary education representative, if appropriate.
_____ Discuss with your family and school team how to address the financial needs of your child’s Post Secondary education.
_____ Hand out guardianship decree to team.
_____ Sign new releases if you are not the guardian.
_____ Begin to discuss the support needs of your child as they enter into adulthood.
_____ Continue job.

At age 19:

_____ Inform Area Agency of specific support needs for your child when he/she turns 21.
_____ Advocate for legislation to have waiting list money released to serve adults in the Area Agency (your child will be one very soon).
_____ Work on future/estate planning for your child for when you are gone.
_____ Continue to adapt your child’s transition plan as his/her needs change.
_____ Continue job.

At age 20:

_____ Work closely with your Area Agency to develop several support plans in the event funds are not available for your first choice option.
_____ Discuss with your Area Agency the role of consumer directed supports and choosing your own service coordinator for adult services for your child.
_____ Complete future planning if possible.
_____ Insure your child’s last transition plan (if he/she is still involved with the school) covers all it needs to cover.
_____ Facilitate participation in all senior activities, if desired.
_____ Complete any applications for Post Secondary education programs.
_____ Work with Voc. Rehab. to find paid job if needed, or assist with vocational training needs.
**Things to Consider**

Things to consider during your child's high school years certainly vary from student to student. Some fairly generic (but just as important!) ones are mentioned here:

- Special Education students are eligible for individualized services up to age 21. Schools have the flexibility of extending this support after graduation at 18, or terminating it at graduation. Find out what your school's policy is and decide if it fits what makes sense for the support needs of your child.

- Establish the link between your child's IEP/transition goals and the required curriculum needed for graduation.

- Set priorities of what you want your child to learn.

- Maximize your education potential - What can be taught/reinforced/practiced at home?

- Simplify goals - Only write as many as can be consistently worked on and measured.

- Choose what school goals you will carry over at home, and what home goals can be carried over at school.

- Be sure to address all areas:
  
  ACADEMIC     VOCATIONAL
  
  INDEPENDENT LIVING     SOCIAL
Academic
Although free education ends at age 21 (or graduation), the concept of being "Learners for Life" applies to all people, regardless of disability. Identifying the most important skills and generalizing them into all aspects of life will increase your chances of success.

Independent Living
These are things most of us primarily learned at home and had reinforced at school and in the community. Beginning with this truism, identify skills that are most important and focus on them at school as well as at home. Again, don't try to focus on too many at once. Slow, careful learning will help more in the long run.

Vocational
Some say work as soon as possible, others say you have the rest of your life after high school to work. Often a balance of the two has proven successful. Work ethics are essential. Employers are looking for skilled workers that can be trusted and have earned respect. These ethics are taught from first grade: Finish projects/homework on time, Work cooperatively, Be neat and clean, Be honest and prompt, and Always try your best. You do not need to be at a worksite to learn these skills. In your last couple of years in school, focusing on interests and required skills is a great way to transfer and reinforce work ethics.

Social Activities
This is often looked at as trivial & of little worth as an educational goal, but your ability to present yourself affects opportunities and other people's perceptions of you. Many people make friends or secure jobs or assistance because of their positive social skills, often not initially because of any other skill they may possess. Immersing students in social opportunities and providing assistance when teachable moments arise can often be one of the most important skills we can give a young person. It cannot be done in isolation, but must be experienced through typical events. Again, there are a variety of environments this can and should occur in, in order to assure a well-rounded background.
The 1997 IDEA Amendments: How They Affect Transition Planning

The IDEA amendments of 1997 bring many key changes to the law that was originally passed in 1975. This law was known as P.L. 94-142 or the Education for All Handicapped Children Act. Over the years this law has been amended. The reauthorized law is now known as the Individuals with Disabilities Education Act and on June 4, 1997, President Clinton signed the 1997 IDEA Amendments into law. There are two key amendments that directly affect transition services. These changes will take effect on July 1, 1998. These changes are as follows:

• When a student has reached the age of 14 and annually thereafter, the student’s IEP must contain a statement of his/her transition service needs under the various components of the IEP. These components must focus on the student’s courses of study, as identified in the student's IEP. While the new law maintains 16 as the age when a student’s IEP must contain statements of needed transition services, the purpose of including the age 14 requirement was to focus attention on how the student’s education can be planned. The provision is designed to enhance, not replace, the separate transition services requirement.

• Beginning at least one year before the student reaches legal age (18), the IEP must contain a statement acknowledging that the student has been informed of the rights that he/she will have under law when he/she reaches legal age.

If you have any questions with how these changes will affect your child’s education, please feel free to contact:

• Your local area agency (a list of these on back of the manual)
• Disability Rights Center 228-0432
• Parent Information Center 1-800-232-0986

GETTING A COPY OF THE CURRENT IDEA

There are several resources where you may obtain a copy of the current legislation. The quickest of these is the Internet sites that have the new law posted on their sites. If you have access to the Internet, try the following Web sites:


You can also obtain a copy of the new law by contacting your U.S. Senator or U.S. Representative and request a copy of the law. Ask for S.717/H.R.S. The P.I.C. (Parent Information Center) or the State Department of Education.
Vision for the Future

The creation of an IEP begins with your child’s strengths and weaknesses. From there a list of needs is frequently determined. From that list of needs, goals are developed. In the process, your end result is often a list of solutions to problems. Focus on solutions that will enrich your child’s life, rather than seeing them as problems to be fixed.

Some thoughts to keep in mind while creating the Transition Plan:

**Personal Profile**

Describe your child
- What does your child like to do?
- What is your child’s personality like?
- Where does your child like to go?
- What are your child’s strengths & positive contributions to your family and community?

**Relationship Map**

A Relationship Map gives a clear picture of who spends time with your child. Place your child’s name in the center circle and then, working outward, place the names of the individuals who are closest to your child in the next circle. In the next circle, place the names of those individuals who spend less time, and continue the process, until the circles are filled.

Who spends the most time with your child? Family? Friends? Professionals? Do you want to change this?

**Prioritize Your Options and Resources**

The information you have identified in the Personal Profile and Relationship Map are resources to your child:

- Which resources look most promising?
- Which ones would be easiest to mobilize?
- Which ones will give you the most results with the least effort?
- Which ones should you start with first?
Transition Plan Basics

The purpose of a transition plan is to insure that students with disabilities graduate with the skills they will need to live and work in their communities.

- Beginning at age 14, all IEP's must document a decision of whether or not a transition plan should be formulated.

- All IEP's must include a transition plan from age 16 until graduation.

- The plan should include all areas of a student’s life: academic, vocational, independent living, social/recreational, and residential.

- The plan should include responsibilities for all team members, not just the teachers. If the school will not agree to this, request an informal plan be created to capture all members' responsibilities.

- The plan is best done as a separate component. If they are done at the same meeting, you will likely need over one hour to effectively complete the brainstorming and participation process. If you run out of time, reschedule rather than rush through it to finish.

- The plan should include researching options, accessing benefits and counseling/mentoring (when appropriate) as well as purely educational goals.

The following pages includes a SAMPLE TRANSITION PLAN that allows for a thorough discussion and plan to be developed. You may choose to use this as a guide when working on your own transition plan with your team. It is a good idea to create a draft before the meeting with someone you are comfortable with. This will insure you cover all areas you want to.

REMEMBER!

This is your child's future - do not be intimidated or rushed by professionals with tight schedules. You have the right to request a meeting and the duration of that meeting at any time you feel it necessary.
Individual Transition Plan (ITP)

STUDENT’S NAME______________________________________________________________ITP DATE _______________________

REVIEW DATES_________________________________________

ADDRESS_______________________________________________________________________________________________________

SOCIAL SECURITY # ______________________________________PHONE_____________________________DOB______________

CONTACT PERSON_______________________________________________RELATIONSHIP________________________________

PRIMARY DISABILITY__________________________________SECONDARY DISABILITY__________________________________

DATE OF EXPECTED SPED TERMINATION_________________________________________

H.S. DIPLOMA__________ 21ST BIRTHDAY__________ OTHER______________________

CASE MANAGER (S)_____________________________________________________________________________________________

TRANSITIONAL AGENCY/ CONTACT PERSON_________________________________________

ADDRESS______________________________________________________________PHONE __________________________________

Team Members Who Participated in ITP Meeting Sign In Sheet:

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1. POST SECONDARY EMPLOYMENT AND/OR EDUCATION

Long term goal statement: ____________________________________________________________
__________________________________________________________________________________

______ Competitive Employment
______ Transitional Employment
______ Supported Employment
______ Community College/University
______ Technical College
______ With Support  ______ Without Support
______ Other

Objective: ___________________________________________
__________________________________________________________________________________
Evaluation Criteria: __________________________________
__________________________________________________________________________________
Person/ Agency Responsible: __________________________
__________________________________________________________________________________
Expected Completion Date: ___________________________

Objective: ___________________________________________
__________________________________________________________________________________
Evaluation Criteria: __________________________________
__________________________________________________________________________________
Person/ Agency Responsible: __________________________
__________________________________________________________________________________
Expected Completion Date: ___________________________

Objective: ___________________________________________
__________________________________________________________________________________
Evaluation Criteria: __________________________________
__________________________________________________________________________________
Person/ Agency Responsible: __________________________
__________________________________________________________________________________
Expected Completion Date: ___________________________

2. POST SECONDARY LIVING ARRANGEMENTS

Long term goal statement: ____________________________________________________________
__________________________________________________________________________________

______ Independent Living
______ With Family or Relative
______ Supervised Apartment
______ Enhanced Family Care
______ Individual Service Option
______ Activities of Daily Living Skills
______ Sect. 8 Housing/Public Housing
______ College Dormitory
______ With Support  ______ Without Support

Objective: ___________________________________________
__________________________________________________________________________________
Evaluation Criteria: __________________________________
__________________________________________________________________________________
Person/ Agency Responsible: __________________________
__________________________________________________________________________________
Expected Completion Date: ___________________________

Objective: ___________________________________________
__________________________________________________________________________________
Evaluation Criteria: __________________________________
__________________________________________________________________________________
Person/ Agency Responsible: __________________________
__________________________________________________________________________________
Expected Completion Date: ___________________________

Objective: ___________________________________________
__________________________________________________________________________________
Evaluation Criteria: __________________________________
__________________________________________________________________________________
Person/ Agency Responsible: __________________________
__________________________________________________________________________________
Expected Completion Date: ___________________________
3. MEDICAL NEEDS

Long term goal statement: ________________________________________________________________

____ Independent - No Services Recommended
____ Requires Assistance
____ Adaptive Equipment/Prosthetic Devices

List Equipment: _____________________________________

________________________________________________

________________________________________________

________________________________________________

________________________________________________

Other: ______________________________________________

Objective: ___________________________________________

________________________________________________

________________________________________________

Evaluation Criteria: __________________________________

________________________________________________

Person/ Agency Responsible: __________________________

________________________________________________

Expected Completion Date: ___________________________


Objective: ___________________________________________

________________________________________________

________________________________________________

Evaluation Criteria: __________________________________

________________________________________________

Person/ Agency Responsible: __________________________

________________________________________________

Expected Completion Date: ___________________________


Objective: ___________________________________________

________________________________________________

________________________________________________

Evaluation Criteria: __________________________________

________________________________________________

Person/ Agency Responsible: __________________________

________________________________________________

Expected Completion Date: ___________________________


4. RECREATION/LEISURE NEEDS

Long term goal statement: ________________________________________________________________

____ Independent
____ Family Supported
____ Church Groups
____ Other

____ Independent
____ Family Supported
____ Church Groups
____ Other

Objective: ___________________________________________

________________________________________________

________________________________________________

Evaluation Criteria: __________________________________

________________________________________________

Person/ Agency Responsible: __________________________

________________________________________________

Expected Completion Date: ___________________________


Objective: ___________________________________________

________________________________________________

________________________________________________

Evaluation Criteria: __________________________________

________________________________________________

Person/ Agency Responsible: __________________________

________________________________________________

Expected Completion Date: ___________________________


Objective: ___________________________________________

________________________________________________

________________________________________________

Evaluation Criteria: __________________________________

________________________________________________

Person/ Agency Responsible: __________________________

________________________________________________

Expected Completion Date: ___________________________
5. **FINANCIAL/INCOME NEEDS (MAY BE COMBINATION OF SOURCES)**

Long term goal statement: ____________________________________________________________

________________________________________________________________________________

- Earned wages
- Social Security Disability
- Insurance (SSDI)
- Supplemental Security Income (SSI only)
- SSI and earned wages
- Unearned income (gifts, family support)
- Trust/will stamps
- Food
- Medicare
- Group insurance available (e.g. Medicaid, Champus, Blue Cross, etc.)
- Section 8/Housing, Public housing
- Other

Objective: ____________________________________________________________

________________________________________________________________________________

Evaluation Criteria: ________________________________________________________

________________________________________________________________________________

Person/ Agency Responsible: ____________________________________________

Expected Completion Date: _________________________________
6. COMMUNITY NEEDS

Long term goal statement: ____________________________________________________________
________________________________________________________________________________

_____Independent - No services recommended
_____Needs family planning services
_____Needs support group
_____Needs respite care/family support
_____Other ________________________________________

Objective: ___________________________________________
________________________________________________________________________________
________________________________________________________________________________
Evaluation Criteria: __________________________________
________________________________________________________________________________
Person/ Agency Responsible: __________________________
________________________________________________________________________________
Expected Completion Date: ___________________________

Objective: ___________________________________________
________________________________________________________________________________
________________________________________________________________________________
Evaluation Criteria: __________________________________
________________________________________________________________________________
Person/ Agency Responsible: __________________________
________________________________________________________________________________
Expected Completion Date: ___________________________

Objective: ___________________________________________
________________________________________________________________________________
________________________________________________________________________________
Evaluation Criteria: __________________________________
________________________________________________________________________________
Person/ Agency Responsible: __________________________
________________________________________________________________________________
Expected Completion Date: ___________________________

7. PRIMARY TRANSPORTATION

Long term goal statement: ____________________________________________________________
________________________________________________________________________________

_____Independent - No services recommended
_____Public transportation
_____Specialized transportation
_____Family transports
_____Car pools
_____Drivers license assistance
_____Other ________________________________________

Objective: ___________________________________________
________________________________________________________________________________
________________________________________________________________________________
Evaluation Criteria: __________________________________
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Person/ Agency Responsible: __________________________
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Expected Completion Date: ___________________________

Objective: ___________________________________________
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Evaluation Criteria: __________________________________
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Person/ Agency Responsible: __________________________
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Expected Completion Date: ___________________________

Objective: ___________________________________________
________________________________________________________________________________
________________________________________________________________________________
Evaluation Criteria: __________________________________
________________________________________________________________________________
Person/ Agency Responsible: __________________________
________________________________________________________________________________
Expected Completion Date: ___________________________
8. **ADVOCACY/LEGAL NEEDS**

Long term goal statement: ______________________________________________________________________________________

______________________________________________________________________________________________________________

- Independent - No services recommended
- Care management (Dept. of Mental Health and Developmental Services DMH/DS)
- Guardianship (sought/acquired/needed)
- Other ________________________________________

Objective: ___________________________________________

________________________________________________

________________________________________________

Evaluation Criteria: __________________________________

________________________________________________

Person/ Agency Responsible: __________________________

________________________________________________

Expected Completion Date: ___________________________

Objective: ___________________________________________

________________________________________________

________________________________________________

Evaluation Criteria: __________________________________

________________________________________________

Person/ Agency Responsible: __________________________

________________________________________________

Expected Completion Date: ___________________________

Objective: ___________________________________________

________________________________________________

________________________________________________

Evaluation Criteria: __________________________________

________________________________________________

Person/ Agency Responsible: __________________________

________________________________________________

Expected Completion Date: ___________________________

9. **ADULT DAILY LIVING (ADL) SKILLS**

Long term goal statement: ______________________________________________________________________________________

______________________________________________________________________________________________________________

- Independent - No services recommended
- Needs self-care skills
- Needs money management skills
- Needs assistance in community resource use
- Needs housekeeping skills
- Needs meal preparation skills
- Other

Objective: ___________________________________________

________________________________________________

________________________________________________

Evaluation Criteria: __________________________________

________________________________________________

Person/ Agency Responsible: __________________________

________________________________________________

Expected Completion Date: ___________________________

Objective: ___________________________________________

________________________________________________

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Evaluation Criteria: __________________________________

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Person/ Agency Responsible: __________________________

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Expected Completion Date: ___________________________

Objective: ___________________________________________

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Evaluation Criteria: __________________________________

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Person/ Agency Responsible: __________________________

________________________________________________

Expected Completion Date: ___________________________
Graduation & Diploma Issues

This topic is an important one to think about early on in your child's high school career. Will your child simply graduate at age 18 with his/her diploma and be done with school services? Will he/she stay until 21 and continue to receive services from school? What is the current school policy on graduation in your district?

Every school has a different policy. Find out early what yours is and how it fits with your plans. If it doesn't, you may need several years to work with the school to find a solution that meets your child's needs.

Some ideas may work with one school but not another. Look at all your options and then tailor one to fit your child's needs.

Some options include, but are not limited to:

- Getting a diploma when all credits are acquired (could be at age 18, 19, 20, or 21).
- Stay in school until 21 regardless of credits to continue learning.
- Combine academic and vocational activities until age 21.
- Complete academic courses at age 18 or 19 and participate in graduation ceremony, and then receive vocational training in the community with school support until 21.

Some schools will educate a student until:

- Their 21st birthday
- The end of the semester in which they turn 21
- The student participates in the graduation ceremony

Check with your school early so you don't have any surprises!
Defining Roles and Responsibilities for Transition Service Teams

The goal of transition is meaningful, paid employment and successful community participation for young adults with disabilities. This goal requires a restructuring and rethinking of agency roles and local responsibilities to ensure appropriate, non-duplicative service delivery.

• Participates in developing vision for future
• Informs others re: preferences and interests
• Participates in IEP development
• Follows through with EIP
• Self-advocacy

• Provide input on business needs & local job trends
• Provide funding for job related services
• Provide vocational evaluation information
• Facilitate job placement and training services

• Provide input on local support services
• Provide information on medical & Social Security benefits
• Provide inservice & community education
• Provide resources for counseling, advocacy & follow-along support service

• Locate vocational training sites
• Provide specific vocational skill training
• Assist in collection and analysis of vocational evaluation data

• Provide information on family & community job opportunities
• Actively participate in selection of EIP goals
• Advocate for full community integration
• Access other support systems (e.g. benefits, guardianship, etc.)
• Provides & supports opportunities for child to develop work, independent living, recreational & leisure skills

Remember, your team could also include an employer or other community member
Helping Parents Prepare Students for Employment

Preparation for the world of work begins at birth for everyone. By gradually learning independence, all people are exposed to skills that will be needed in adulthood. Obviously, some need more exposure than others in order to master certain skills, and some need additional supports to insure success in a job. It is very important to continually work on gaining new skills that will lead to increased independence.

Listed below are some ways parents can help to prepare their high school children for the world of work:

- Develop a long-term plan covering educational, vocational, social, and independent living skills that will be needed upon graduation.
- Be sure the IEP addresses employment and training activities in real situations.
- Discuss adult living options available and develop a plan for increasing your child's independence. A plan for support should be started as well.
- Make sure your child's IEP has a transition plan starting at age 16 at least. It would be helpful to invite your Vocational Rehabilitation Counselor and your Area Agency representative to assist in this plan.
- Encourage your child's participation in a variety of community activities to increase their circle of friends and acquaintances.
- Talk to your friends and neighbors about your child's plans, especially around work. Often our first jobs are found through someone we know.
- Work with your school to find your child work opportunities during the summer, on weekends, or after school. Keep track of the supports needed for success.
- Begin financial planning for adulthood. Apply for SSI, guardianship, and Medicaid. Speak with a reliable professional regarding estate planning, even if you do not have many assets.
Post-Secondary Education Options

In keeping with the concept of being “Learners for Life”, this is an area an individual may choose to consider; whether it be traditional college, tech school, internship, on the job training, or independent living skills training.

It has been said that the best preparation for a successful adult life is a supportive and inclusive high school experience. Many of the barriers to college, such as the lack of a standard high school diploma, low academic achievement expectations, or insufficient exposure to assistive technology, can be overcome while a student is still in high school. Consistent advocacy on the parent’s and the student’s part is essential for this to occur. Encourage your child to take as active a role as he/she can in all planning meetings. Learning to advocate for oneself in this way is a very important lifelong skill.

Post-secondary schools (and work places) are not mandated by law to automatically provide any supports necessary for a person to be successful. In college, no services are provided to any student until a request from the student is made to the Support Services office. It is up to the student to assure that the supports are in place and working properly. There is no “case manager” assigned to check up on things for you. Requesting a service does not mean it has to be provided. Both the service and its cost must be considered reasonable by the college. Colleges will make accommodations, not modifications, as modifications change the actual content of the course.

When any young adult thinks about going to college, there are many factors to consider: location, courses, living needs, size, costs, and available supports. Some of the resources to explore in creating your supports include: high school, area agency, voc rehab, natural supports, the college, and, of course, your family.

Planning for the future can help a student articulate what he/she wants out of life and begin to formulate how to get it. Whether it is a career goal, social connections, or learning for its own sake, planning helps students make informed decisions and set goals. Students who are successful have collaborated with others, and coordinated necessary supports between and among the services available to them.
Benefit Information

Social Security, Supplemental Security Income, Medicare and Medicaid are just a few of the many words you may hear which may help your son or daughter obtain needed financial and medical resources. What do these words mean? How does one obtain that benefit? Where does a person apply for them?

The following pages are reprinted from the New Hampshire Challenge from spring, 1997. There is a brief summary of each benefit as well as information telling who qualifies and when. Please keep in mind that some of the financial numbers may have changed as adjustments are made on an annual basis.

For more information related to these benefits, contact your local Social Security Office or your Health and Human Services District Office. These numbers can be found at the back of this manual.

Your Area Agency is also available to help explain any of this information as well as assist you to apply for the benefit for which your son or daughter may qualify.
Cash Benefits

Social Security Disability Insurance (SSDI)

Social Security is a federal insurance program. You pay taxes into a trust fund during your work years, and you and members of your family receive monthly benefits when you retire or become disabled. Social Security, then, is based on a worker paying into the system before benefits can be received.

There are three categories of Social Security Benefits; Retirement, Survivor, and Disability. Each of these categories has family benefits, which are available to spouses and/or children. We will be concentrating on the Disability category, which is know as Social Security Disability Insurance, or SSDI.

Once a worker becomes eligible for SSDI benefits, then his or her family members may also be eligible, based on the record of the former wage-earner. For instance, the worker's spouse is eligible if he or she is 62 or older, or at any age if he or she is caring for a child under 16, or a child of any age who is disabled.

Children receive SSDI dependents’ benefits up to the age of 18. However, a child with a disability may continue to receive SSDI-Childhood Disability Benefits (CDB) as long as that child remains disabled (according to the Social Security definition of disability).

All recipients of SSDI receive monthly cash payments (see chart). People receiving SSDI will not lose their benefits automatically when they begin to work.

Supplemental Security Income (SSI)

SSI, however, is not paid through the Social Security Trust fund, but through general revenues. So, benefits are not based on paying into the system first.

SSI is designed for people with disabilities and people 65 and older who don't have much money. The amount of a person’s monthly check is based on his or her income, which includes such things as SSDI, wages, and Veteran’s Administration (VA) benefits.

For children, the family's income level is used to determine eligibility, based on the number of people in the family. For adults (18 and over) the individual's income level is used.

Supplemental Security Income (SSI), is another federal benefit program that provides monthly cash payments.

Aid to the Needy Blind (ANB)

This state program, provides cash payments twice a month for eligible applicants., Eligibility for ANB is not based on ability to work.

The eligibility criteria for this program is the diagnosis of blindness, according to the state's definition. There is no age criteria.

The income criteria are the same as APTD. Like APTD, this benefit is for people who have limited income and assets. One eligibility for this benefit is established, the applicant is automatically eligible for Medicaid and potentially eligible for Food Stamps, as with APTD.

And, similar to SS, recipients can “work themselves off” this benefit

Aid to the Permanently and Totally Disabled (APTD)

This is a state program that awards twice-a-month cash payments to those individuals who are eligible. To be eligible, a person must be disabled according to the state’s definition of disability.

A person may work, but must meet the “substantial gainful employment” criteria. In addition, where formerly a person's disability had to have been permanent and total, now the definition requires that a person's disability condition be expected to last for at least four years.

Eligibility is also based on income level and resources. Monthly payments can be small and may discourage people from applying. However, there is a major incentive to applying for this benefit. Eligibility for APTD automatically makes one eligible for Medicaid, and potentially eligible for Food Stamps.

## Cash Benefits—What Families Need to Consider in New Hampshire**

**A simplified, non-official guide for families—consult your local government offices for complete details**

<table>
<thead>
<tr>
<th>TITLE</th>
<th>SOCIAL SECURITY DISABILITY INSURANCE (SSDI)</th>
<th>SUPPLEMENTAL SECURITY INCOME (SSI)</th>
<th>AID TO PERMANENTLY AND TOTALLY DISABLED (APTD)</th>
<th>AID TO NEEDY BLIND (ANB)</th>
</tr>
</thead>
<tbody>
<tr>
<td>APPLY AT</td>
<td>Social Security Office or call 1-800-772-1213</td>
<td>Social Security Office or call 1-800-772-1213</td>
<td>Division of Human Services Office</td>
<td>Division of Human Services Office</td>
</tr>
<tr>
<td>BASED ON</td>
<td>The Insured paying FICA and being disabled or blind</td>
<td>Being disabled or blind and income resources not exceeding set limits</td>
<td>Disability of applicant (definition same as SSI) and income and resource level not exceeding set limits and resources</td>
<td>Being blind and income not exceeding set limits</td>
</tr>
<tr>
<td>RESOURCE CRITERIA</td>
<td>$500.00 gross monthly earnings test. If earnings are in excess of $500 monthly, SSA may not consider individual disabled. Different rules for blind people—call SSA office.</td>
<td>Needs based resource test. Individual cash assets not to exceed $2000. Couple cash assets not to exceed $3000. Can own the home they live in. May own a car worth $4500. Excluded if used for doctor's visits. Burial account and plot must be irrevocable. Whole life insurance with face value of $1500, or more/cash surrender value is counted. Household belongings valued at more than $2000. are counted.</td>
<td>$1500.00 cash assets</td>
<td>$1500.00 cash assets</td>
</tr>
<tr>
<td>MONTHLY INCOME LIMITS FOR ELIGIBILITY</td>
<td>Call SSA Office</td>
<td>Income needs to be less than maximum benefit after deductions. Max benefits limits depend on the person's living arrangements (limits change every January)-based on living in own household, limits decreased by 1/3 when living in household of another.</td>
<td>Benefit amount based on living arrangements.</td>
<td>Same as APTD</td>
</tr>
<tr>
<td>WAITING PERIOD</td>
<td>Five full calendar months from date of disability. Payments begin on seventh month.</td>
<td>None. Benefits begin the month after the date called in to get appointment.</td>
<td>None. Benefits based on when eligibility is determined.</td>
<td>Same as APTD</td>
</tr>
<tr>
<td>AGE CRITERIA</td>
<td>None</td>
<td>Can apply at any age. Under age 18, income criteria based on family income. Over age 18, income criteria based on disabled individual's (and spouse's, if any) income only.</td>
<td>18 years to 64 years.</td>
<td>None</td>
</tr>
<tr>
<td>ADDITIONAL CONCERNS</td>
<td>After nine months of earning more than $500.00 gross per month, may lose benefit.</td>
<td>Can “work yourself off” gradual decrease of benefits as earnings increase.</td>
<td>Can “work yourself off” earned income deductibles are more restrictive than SSI</td>
<td>Can “work yourself off” earned income deductibles are the SAME as SSI</td>
</tr>
<tr>
<td>OTHER BENEFITS?</td>
<td>After two years of cash benefits, can become eligible for Medicare (see Medicare)</td>
<td>Nothing</td>
<td>Automatic eligibility for Medicaid &amp; potential eligibility for food stamps</td>
<td>Same at APTD</td>
</tr>
<tr>
<td>DATE RECEIVED</td>
<td>Usually, 3rd of the month. Effective 5/97, may be any week during month. Benefit paid is for previous month.</td>
<td>1st of the month, for that month.</td>
<td>2 times a month</td>
<td>Same as APTD</td>
</tr>
</tbody>
</table>

Medical Benefits

Medicare

Medicare is a federal health insurance program administered by the Social Security Administration. A person becomes eligible for Medicare at age 65, or by receiving Social Security Disability Insurance (SSDI) or Childhood Disability Benefits (CDB). However, a disabled recipient must wait for two years after SSDI or CDB cash payments begin before the Medicare coverage begins.

Part A of Medicare coverage is at no cost and covers hospitalization and related costs. Part B includes a monthly premium and covers physician’s charges, therapies, outpatient visits and some equipment. Medicare does not cover such things as routine physical exams, prescription drugs, eyeglasses, and hearing aids.

For more information, contact your local office or call the HCFA QMB office at 1-800-638-6833.

If a recipient loses SSDI payments because his or her earnings have increased above the set limits, it is still possible to “buy into” the Medicare program so as not to lose medical benefits.

Medicaid

Most Medicaid programs are based on a family’s or an individual’s income and resources. Disability is not always a requirement.

Medicaid will cover more than just medically related services and can be used to pay for such services as respite, case management, rehabilitation, and personal care.

Those adults between the ages of 18-21 who are still in school (as well as children under 18) may have certain services in their school district paid for by Medicaid.

It is crucial to investigate the impact of increased income on Medicaid eligibility before securing a job. Medicaid pays for services not often covered under private insurance. Additionally, many people with disabilities work part-time and are not eligible for health insurance coverage from their job.

The loss of Medicaid coverage can have serious implications.

A person found eligible for Medicaid coverage is issued a permanent plastic card. Since Medicaid eligibility is based on a person’s monthly income, a person could lose eligibility in one month, and regain it the next. The status of a person’s income level is reviewed periodically.

Home Care for Children with Severe Disabilities (HC-CSD)

Medicaid was originally designed to benefit children with and without disabilities in very low income families. A family’s income is still the primary criterium for eligibility in most of the Medicaid Programs in New Hampshire.

However, a change in the federal rules for Medicaid has allowed families caring for a child with severe disability to enroll that child in the program regardless of the family’s income.

The Home Care for Children with Severe Disabilities (HC-CSD) Program (also known as the Katie Beckett Option) came about because of one family’s experience.

The eligibility criteria for the HC-CSD has become more flexible recently to enable more children to be enrolled. Basically, in order for a child to be eligible for HC-CSD, that child must have a disability which requires 24-hour supervision or care (the level of care that an ICF/MR or nursing facility provides), and must be living at home with his or her parents.

When applying for the Katie Beckett waiver, collect as much current information about your child as possible: physicians’ reports, school testing, current IEP, any evaluations done outside the school.

By submitting that information with the application, you help speed up the process of determining eligibility.

**Medical Benefits—**  
What Families Need to Consider in New Hampshire**  
**A simplified, non-official guide for families—consult your local government offices for complete details**

<table>
<thead>
<tr>
<th>TITLE</th>
<th>MEDICAID</th>
<th>MEDICARE</th>
<th>CHILDREN WITH SEVERE DISABILITIES (CSD-MEDICAID)</th>
<th>HOME CARE CHILDREN WITH SEVERE DISABILITIES (HC-CDS MEDICAID)</th>
</tr>
</thead>
<tbody>
<tr>
<td>APPLY AT</td>
<td>Dept. of Health and Human Services Office</td>
<td>Social Security Office or call 1-800-772-1213</td>
<td>Dept. of Health and Human Services Office</td>
<td>Dept. of Health and Human Services Office</td>
</tr>
<tr>
<td>BASED ON</td>
<td>Disability/blindness and income. Automatic if receiving APTD or ANB. If not receiving APTD/ANB, based on Protected Income Level (P.I.L.)</td>
<td>Receipt of any SS disability benefits for 2 years.</td>
<td>Disability (less restrictive than HC-CSD), Income level (income, resources &amp; expenses of parents &amp; applicant are counted).</td>
<td>Disability-child MUST live w/parents &amp; meet institutional level of care. Parents income &amp; resources do not count.</td>
</tr>
<tr>
<td>RESOURCE CRITERIA</td>
<td>Asset limit for individual in community is $2500. If individual is in group home, contact DHHS office for details. (Note: for ANB, parental income and assets not counted).</td>
<td>None</td>
<td>$2500 in assets, a portion of parents resources will be counted.</td>
<td>$2500</td>
</tr>
<tr>
<td>MONTHLY INCOME LIMITS FOR ELIGIBILITY</td>
<td>Monthly eligibility of Protective Income Level (P.I.L.) as of 1/97 is $484.00 for an individual in the community. If individual is in a group home, contact DHHS Office for detail.</td>
<td>If SSDI cash benefit no longer received, Medicare remains in effect for 39 months with &quot;buy in&quot; option.</td>
<td>Net combined income for a two-person household is $642.00 a month; for 3 person household, $652.00; for 4 person household, $662.00. SSI benefits not counted as income.</td>
<td>Gross income $1159.00 per month for applicant (child) ONLY. SSI benefits not counted as income.</td>
</tr>
<tr>
<td>WAITING PERIOD</td>
<td>None. Benefit based on the date of application.</td>
<td>SSDI Recipients—2 year waiting period if under 65.</td>
<td>Same as APTD/Medicaid</td>
<td>Same as APTD/Medicaid</td>
</tr>
</tbody>
</table>
| AGE CRITERIA | APTD: 18 to 64 years  
ANB: no age limit | Age 65, or receiving SSDI for 2 years. | Age 0-18 | Age 0-18 |
| ADDITIONAL CONCERNS | P.I.L. limit—can have Medicaid In/Out about this level | Can “buy into” Medicare if ineligible for SSDI as benefits end. | N/A | N/A |
| OTHER BENEFITS? | "Deductible" program for over-income. Ages 18-21 Child Health Assurance Program (CHAP). Beyond 21, potential Medicare buy in. | Nothing | Child Health Assurance Program (CHAP) | Child Health Assurance Program (CHAP) |
| DATE RECEIVED | Permanent plastic card issued when first eligible | Red, White & Blue permanent cards issued when first eligible | Same as Medicaid | Same as Medicaid |

Planning for the Future

Life Plans & Letters of Intent

Developing a "Life Plan" for your child is an important tool for your child's future. This will require you to think about what you want for your child and what your child wants for themselves. The next step is to insure that this information will be communicated to the people who will be primarily responsible for your child's care after your death.

"A comprehensive life plan leaves nothing to chance". All family members (including the person with the disability), or anyone else who may be expected to take responsibility, should take an active part in developing the plan. The plan should include "everything that is important in your child's life". You, as the parent, know what is and isn't important, what works and doesn't.

One of the most important things to consider when developing a life plan is where your child will live. What type of residential care will they need? What will that environment look like? Will your child live near community activities, or in a more country setting? Employment and continuing education plans are also critical to these decisions, as location may determine the availability of supports and choices.

REMEMBER: Parents are typically the most consistent support person in their child's life. The assets you own and may later want to leave to your child to support them are one of the best protections they will have. Now is the time to consider the question: How do I protect my assets to ensure financial stability for my child long term, including their own final arrangements?

1 & 2. Planning for the Future: Providing a meaningful life for your child with a disability after your death, by Mark Russell et. al. To obtain a copy of this book or the Life Plan workbook, you may call 1(800)247-6553. It is published by the American Publishing Co., PO Box 988, Evanston, IL, 60204-0988.
Considering Your Son's or Daughter's Future

For each applicable area below, consider your son’s or daughter’s future. **List 3-4 options** to guide future caregivers in decision making and interaction with your child. Draw upon what you know about your son or daughter, through observation and through discussion with your child, and share what you’ve learned!

| Residence: | If something should happen to you tomorrow, where will your son or daughter live? |
| Education: | You have a lifelong vision of your son or daughter’s capabilities. Share it! |
| Employment: | What has your son or daughter enjoyed? Consider his or her goals, aspirations, limitations, strengths, interests, experiences. |
| Medical Care: | What has and has not worked with your son or daughter? What should future caregivers know? |
| Behavior Management: | What consistent approach has worked best during difficult transition periods in your son or daughter’s life? |
| Social/Spiritual: | What activities (church, club, hobbies, sports) make life meaningful for your son or daughter? |
| Financial: | Will your child manage his/her own income (benefits, trusts, wages), or is there someone to whom you would entrust this responsibility? |
| Advocate/Guardian: | Who will look after, advocate for, and be a friend to your son or daughter? |
| Final Arrangements: | What final arrangements do you want to provide for your child? |

*News Digest,* published by National Information Center for Children and Youth with Disabilities (NICHCY)
Legal Issues

Planning for the future eventually leads to involvement with legal issues. Once you and your child have made decisions about your child’s future, legal and possibly financial planning professionals will be needed to turn your plans into reality.

What kind of legal issues will be involved?

- guardianship
- wills
- trusts
- powers of attorney (financial, health, etc.)
- living wills
- conservatorship
- representative payee

For more information on legal issues the following agencies or individuals may be of help to you.

New Hampshire Division of Developmental Services
   Client and Legal Services ................................................................. 271-5024
Disability Rights Council ............................................................ 1-800-834-1721
Lawline (2nd Weds of the month, 7-9 p.m.) .............................. 1-800-868-1212
N.H. Legal Assistance ................................................................. 603-644-5393
NH Bar Association ................................................................. 603-224-6942
Lawyer Referral Service ........................................................... 603-229-0002
Legal Advice and Referral Center ........................................... 1-800-639-5290

In the following pages you will find a definition of estate planning terms. If you would like more information pertaining to any of the above topics, please talk with your area agency, your lawyer or personal estate planner.

Your area agency may be able to assist you in finding lawyers in your area who are familiar with issues pertaining to individuals with disabilities.

When you do consult with a lawyer, ask questions to find out what experience your lawyer has had with the particular issue, and if possible ask if there are individuals to whom you might talk who have received services from that lawyer.
Estate Planning Issues Wills and Trusts

When parents have a son or daughter with a disability, they must plan their estates carefully to best benefit that child. How parents leave their assets after death may greatly affect the quality of life for their son or daughter with special needs. Even if parents think that they have no estate, they need to plan for how their assets will be distributed.

Writing a Will

All parents, but especially parents of individuals with disabilities, need to have a will. The object of a will is to ensure that all of the assets of the deceased parent are distributed according to his or her wishes. A person could write a will on his or her own, but because of the technical nature of wills, it is advisable to have a lawyer prepare one. Parents of individuals with disabilities particularly need legal advice because they often have special planning concerns.

The Special Needs Trust

How do I make sure that the inheritance for my son or daughter actually has a chance of reaching him/her when he/she needs it without jeopardizing his/her benefits?

The Special Needs Trust is a legal device that is developed to manage resources while maintaining the individual’s eligibility for public assistance benefits. How is this done?

The family leaves whatever resources, that they decide are appropriate, to the trust. The trust is managed by a trustee on behalf of the person with the disability. Government benefits provide minimal assistance to help with basic living needs. Funds placed in a special needs trust will enable the person with a disability to maintain a lifestyle that is meaningful to that individual.

Government agencies recognize special needs trusts, but they have imposed very strict rules and regulations upon them. It is vital to consult an experienced attorney who is knowledgeable about Special Needs Trusts and current government benefit programs.

When seeking out a lawyer, be sure to find out if the lawyer has ever prepared estates for other parents who have sons or daughters with disabling conditions. A person may wish to ask if the lawyer is a certified estate planner.

**Glossary of Estate Planning Terms**

**Administrator**—If an individual does not write a Will, the courts will appoint an Administrator to handle the deceased person’s estate according to the laws of the state.

**Advocate**—An advocate is a person or institution that will serve as a friend and advocate and look out for the best interests of the disabled person. The advocate is not court appointed. In some cases where the disabled person can manage most of their own affairs, an advocate from a charitable organization may be more appropriate than a legal conservator/guardian.

**Beneficiary**—The persons or institutions who receive the benefit of the Will, Trust, Life Insurance policy, etc.

**Codicil**—An amendment to a Will. The codicil is a separate document that is signed with witnesses just like the Will, but amends some portions of the Will.

**Conservator/Guardian**—The person appointed by the courts to assist the disabled person.

**Conservatorship/Guardianship**—A court-ordered mandate by which an individual or institution is appointed (a) to manage the estate of the person judged incapable (not necessarily incompetent) of caring for his/her own affairs; (b) to be responsible for the care and decisions made on behalf of a person when that individual, again, is determined to be unable to care for herself/himself. A Conservator/Guardian can be appointed to serve in either one or both ways. In some states a Guardian assists the person and the Conservator assists the estate of the person.

**Estate**—All of a person’s possessions including all properties and debts remaining at the time of death.

**Estate Tax**—In most states, there is no tax on estates. However, the federal government does have an estate tax for estates valued at more than $600,000.

**Executor/Personal Representative**—The individuals or corporations that are appointed in the Will who will have the legal responsibility for carrying out the provisions of the Will to the best of their ability according to the current laws of the land. The executor may seek the assistance of an attorney to complete the probate process.

**General Conservatorship/Guardianship**—This type of Conservatorship/Guardianship gives the conservator/guardian the legal rights to manage all aspects of the individual’s affairs.

**Heir**—The person who inherits property under state law.

**Income Beneficiary**—Generally, the person in the trust agreement who will receive the income from the trust during his or her lifetime.

**Intervivos Trust**—It is a Living Trust. It functions during the lifetime of the Grantor.

**Irrevocable Trust**—An irrevocable trust means that the items placed in the trust cannot be taken out of the trust except by ending the trust and disbursing the items to the appropriate remainderman. This trust will have its own tax number and be taxed as a separate 11 person. It will also file an annual report. The trustee does have the right to manage the trust funds by normal prudent man rules of investment, etc.

**Letter of Intent**—This is one of the most important documents of an estate plan. In this very personal letter, parents will express their hopes and desires for their disabled child’s future care. Please see the guidelines for writing a Letter of Intent.
Limited or Partial Conservatorship/Guardianship—This type of Conservatorship/Guardianship generally applies to the developmentally disabled and restricts the areas in which the Conservator/Guardian may act on behalf of the individual.

Minor—Any person under the age of 18 in most states. Parents have responsibility for their children until age 18 when they legally become adults. The disabled may not have the capacity to act as an “adult” and the parents may want to continue in their previous role by obtaining Conservatorship/Guardianship.

Probate—The court proceedings in which there is supervision over the property passing from a deceased person to beneficiaries under the provisions of the Will or, if there is no Will, under the provisions of the less generous state law.

Remainderman—The persons or institutions who will receive the remainder (what is leftover) of the trust after the income beneficiary has died and the trust ends.

Revocable Trust—A revocable trust means that the items placed in the trust can be taken out of the trust. This type of trust is taxed as part of the estate of the grantors.

Special Needs Trust—Also known as a Spendthrift, Luxury, Discretionary or Supplementary Trust. It may be created as a Living Trust during the life of the person (grantor) or as a Testamentary Trust after the death of the person (grantor). It is designed to provide for the supplementary needs of the disabled person over and above that being given by the government. The trust funds are not to supplant or replace government programs. Once the basics of food, shelter, medical care, education, etc. are met by the government, the trust can provide additional funds to enhance the quality of life. The trustees should never give more funds than would cause a loss or reduction of government benefits unless there is an emergency. The trust is not in the name of the child. The disbursement of funds is left to the “discretion” of the trustee/successor trustee. This type of trust is not considered an asset for determining government benefits. Only those funds which are actually disbursed directly to the child will count as earned or unearned income.

Successor Trustee—This person(s) takes over the responsibility of managing the trust after the death or legal incompetence of the initial trustee(s).

Testamentary Trust—This trust document will not go into effect until after the death of the person who requests it. The request is contained in the Will. Any special provisions for the trust are mentioned in the Will, but it will not go into effect until after the Will has been probated. The normal probate period is usually 6 months to 6 years, so the trust will not be funded until that time.

Trust—A legal entity established either by written agreement signed during the life of the person or by a Will. The trust is governed by the terms in the written document.

Trust Corpus—The property (and funds) held in the trust. It is also called the trust estate.

Trustee—This person(s) manages the trust. There is a fiduciary responsibility for seeing that the funds are properly invested and disbursed according to the wishes of the Trustor and the laws of the state. The grantor and initial trustee may be the same person.

Trustor—Also known as a “Grantor” or “Settlor.” This is the person(s) who sets up the trust.

Will—The purpose of a Last Will and Testament is to direct the distribution of the assets of the estate to all the beneficiaries. Parents of the disabled should “disinherit” their disabled child, so that he or she will not receive any portion of the estate which would create major assets and, therefore, reduce or eliminate government benefits. The disabled child’s share should be left to a Special Needs Trust.

*These terms have been acquired and modified form a variety of sources.*
Guardianship

WHAT IT IS & WHAT IT IS NOT

At 18 years old a person becomes his/her own guardian, unless a guardian is appointed by the court. Parental rights and guardian rights are different issues. Guardianship should be considered necessary only when it is the least restrictive option and all other alternatives have been explored.

ALL GUARDIANS ARE RESPONSIBLE TO:

- Act on behalf of individuals to secure services and supports.
- File court reports on behalf of the individual.
- Act as part of a team in determining individual support needs and services.
- Apply for services, entitlements, and supports on behalf of the individual.
- Treat the individual with dignity and respect, regardless of the individual’s level of ability.
- Advocate for the best interests of their ward.
- May be responsible for specialized options deemed necessary by the court.

GUARDIAN OVER PERSON ONLY:

In conjunction with the individual -

- Make medical decisions regarding care and treatment
- Make decisions about where the person resides

GUARDIAN OVER PERSON AND ESTATE:

- Is responsible for all of the above

GUARDIAN OVER ESTATE ONLY:

- Enter into legal agreements or sign contracts on behalf of the individual
- Assist with financial coordination

UNLESS SPECIFIED IN THE GUARDIANSHIP DECREE, NO GUARDIAN HAS THE RIGHT TO:

- Choose friends
- Choose personal clothing styles, hair styles, etc.
- Decide how a personal spends personal free time and money
- Limit or censor mail
- Prevent the individual from having visitors or having confidential correspondence

- Choose social activities
- Speak on behalf of the individual if they are able to speak for themselves
- Decide if a person marries, votes, dates, choose their occupation, testify, make a will or own property
- Prevent the individual from being involved in intimate relationships

The Guardianship Decree will specify the particular powers a Guardian may possess.
Guardianship should only be sought when impaired judgement poses a major threat to a person's welfare.
Guardianship is not intended to protect a person from normal daily risks.
A Guardian should not be appointed simply because a person shows poor judgement or has trouble sticking to a decision.

OTHER, LESS RESTRICTIVE OPTIONS:
- Own Guardian (a right of all persons)
- Co-guardianship
- Temporary Emergency Guardianship (60 days)
- Power of Attorney - Financial/Medical
- Conservator - Estate
- Representative Payee

For More Information You May Contact:
- Your local Area Agency
- Division of Behavioral Health/Developmental Services, Client and Legal Services [603] 271-5000
- Disability Rights Center, Inc. - [603] 228-0432 or 1-800-834-1721
- New Hampshire Legal Assistance - [603]644-5393
- Your local Probate Court
- Your own attorney

NOTE: A Handbook for Guardians is available from the Division of Behavioral Health/Developmental Services, Client and Legal Services, 105 Pleasant St., Concord, NH 03301
Advance Directives

Why would a person need an advance directive? At any time any one of us could be in a situation where we are not able to make decisions about medical care. It is important for others to know a person’s desires regarding medical care and who would make decisions if the person were incapacitated. Individuals with disabilities need to make those decisions too when possible. A guardian may be asked to make medical decisions for the ward, but even so, needs to know what that person might decide if he/she were able to make the decision.

What is an advance directive?

An advance directive is a legal document, written before a person becomes ill, that allows a person to state one's preferences about medical care. The State of N.H. recognizes two forms of advance directives - a living will and a durable power of attorney for health care.

What is a living will?

A living will tells your doctor not to administer life sustaining procedures if you are in a terminal condition or permanently unconscious.

What is a durable power of attorney for health care?

A durable power of attorney for health care is a document in which you name another person to act as your agent to make your medical decisions if you become incapacitated. You can include instructions about which treatments you do or do not want.

Do I need both a living will and a durable power of attorney for health care?

It is a good idea to have both documents because they serve two different purposes. A living will takes effect only when there is no hope for recovery. A durable power of attorney takes effect whenever you become unable to make decisions - for instance during surgery or even when you become temporarily unconscious. Under New Hampshire law, if the terms of your living will and durable power of attorney conflict, the durable power of attorney controls.

What if I have more questions?

You should discuss any questions about advance directives with your family and physician. The hospital’s social worker, patient representative or chaplain may be able to assist you, but they can’t provide you with legal advice. If you have legal questions, you should consult an attorney.

Information taken from the N.H. Hospital Association pamphlet on Advance Directives.
Community Resources

There may be some times when you need to find information or answers and want to talk with someone directly who can help you. Below is a listing of agencies and organizations that can assist you. The phone numbers can be found in your local phone book or by calling the area agency that serves your family. The area agency phone numbers are in this manual.

SCHOOL SYSTEM

Local Schools:
• Aides, teachers, counselors, OT’s, PT’s principals, PTO-Parent Teachers Organization
• Call the school your child attends

SAU Office:
• Superintendent of schools
• Special Ed Directors and Coordinators of Elementary and High School Special Ed programs
• Local School Board members

FAMILY SUPPORT

• Coordinators, Advocates, Director
• Service Coordinators (Case Managers)
• Local Family Support Council

ASSOCIATED AGENCIES AND ORGANIZATIONS

State Department of Education: ..................................................... (603) 271-3741
State Family Support Council: ..................................................... 1(800) 852-3345 x5057
P.I.C.: Parent Information Center: .............................................. 1-800-232-0986
D.R.C.: Disability Rights Center: ................................................... 1-800-834-1721
Granite State Independent Living: ................................................ 1-800-826-3700
Institute on Disability: ................................................................. (603) 862-4320
Home of Your Own: .................................................................. 1-800-220-8770
NH Housing Finance Authority: .................................................. 1-800-439-7247
Client and Legal Services-State of NH: ................................. 1-800-852-3345

The following agencies can be found in your local phone book or by contacting the Area Agency that serves your family:

D.C.Y.F.: Division of Children, Youth and Families
Community Mental Health
Family Health Clinics
Home Health Services
Social Security Administration
Wrap Around
DHHS: Medicaid/Medicare
Guardianship Issues: Local Probate Court-Registrar of Probate
### Area Agencies

<table>
<thead>
<tr>
<th>Region</th>
<th>Agency</th>
<th>Address</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Northern NH Mental Health and Developmental Services</td>
<td>87 Washington Street, Conway, NH 03818</td>
<td>447-3347</td>
</tr>
<tr>
<td>II</td>
<td>Developmental Services of Sullivan County</td>
<td>RFD #3, Box 305, Claremont, NH 03743</td>
<td>542-8706</td>
</tr>
<tr>
<td>III</td>
<td>Lakes Region Community Services Council</td>
<td>PO Box 509, Laconia, NH 03247</td>
<td>524-8811, 800-870-7555</td>
</tr>
<tr>
<td>IV</td>
<td>Community Bridges</td>
<td>525 Clinton Street, Bow, NH 03304-4609</td>
<td>225-4153, 800-499-4153</td>
</tr>
<tr>
<td>V</td>
<td>Monadnock Developmental Services</td>
<td>640 Marlborough Street, Rte. 101, Keene, NH 03431</td>
<td>352-1304, 800-469-6082</td>
</tr>
<tr>
<td>VI</td>
<td>Region VI Area Agency</td>
<td>144 Canal Street, First Floor, Nashua, NH 03060</td>
<td>882-6333</td>
</tr>
<tr>
<td>VII</td>
<td>Moore Center Services</td>
<td>132 Titus Avenue, Manchester, NH 03103</td>
<td>668-5423</td>
</tr>
<tr>
<td>VIII</td>
<td>Community Developmental Services Agency</td>
<td>Parade Office Mall, Suite 40, 195 Hanover Street, Portsmouth, NH 03801</td>
<td>436-6111, 800-660-4103</td>
</tr>
<tr>
<td>IX</td>
<td>Developmental Services of Strafford County</td>
<td>113 Crosby Road, Suite 1, Dover, NH 03820-4375</td>
<td>749-4015</td>
</tr>
<tr>
<td>X</td>
<td>Region X Community Support Services, Inc.</td>
<td>8 Commerce Drive, Atkinson, NH 03811</td>
<td>893-1299</td>
</tr>
<tr>
<td>XI</td>
<td>Center of Hope</td>
<td>PO Box 2048, Conway, NH 03818</td>
<td>356-6921, 800-290-0905</td>
</tr>
<tr>
<td>XII</td>
<td>United Developmental Services</td>
<td>85 Mechanic Street, Lebanon, NH 03766</td>
<td>448-2077</td>
</tr>
</tbody>
</table>
**Transition-Related Internet Websites**

Transition for Students with Learning Disabilities
www.LDonline.org/ld/endpoint/transition/transition.html

Transition Research
www.ed.uiuc.edu/SPED/tri/institute/html

Listing of Related Transition Sites
www.ed.uiuc.edu/SPED/tri/internetsites.html

National Information Center for Children & Youth with Disabilities
www.nichcy.org

Parent Advocacy Coalition for Educational Rights
www.pacer.org

Financial Aid (Post Secondary)
www.finaid.org

Post Secondary Schools
www.petersons.com/special/

IDEA 97
www.ed.gov/offices/OSERS/IDEA

Inclusive Education
www.uni.edu/coe/inclusion

Kids Together (Inclusion)
www.kidstogether.org

New Hampshire Challenge
www.nhchallenge.org

Information on Colleges/Financial Aid/Career Choices & More
www.petersons.com
Advocacy: Your Role, Your Challenge

This manual may provide you with information on how to become more knowledgeable, strong advocate for your child. There are times when most of us wish for someone else to assume this leadership role, if even for a short time, as it can become overwhelming. Hopefully, you will be fortunate in developing strong working relationships with a few trusted advisors (and these will most likely change over the years) who will assist you in creating a vision, working to fulfill it, and in troubleshooting when you hit barriers.

You, as a parent, will always be your child’s greatest support, resource, and advocate, even when you don’t feel like it! No one will ever oversee the affairs of your child with as much love and completeness as you. Even if you do not eventually take over guardianship for your adult child (they may not need it, or you may decide someone else can take that on more efficiently), your presence and input in their life will always be invaluable.

This is a very difficult job. You will have successes and failures. You will find, in the end though, that it is a very rewarding job. Ultimately, you have two basic choices: Jump in and do it, making sure something good happens, or sit on the sidelines and hope something good happens.

May your journey bring you strength and contentment!
We Welcome Your Feedback!

In order to provide helpful information, we will be updating this manual as resources permit. We value your suggestions and will incorporate them as we are able, so please fill out this form and return it to your Transition Coordinator. Thank you for your input!

1. What did you find helpful? ______________________________________________________
   _____________________________________________________________________________
   _____________________________________________________________________________
   _____________________________________________________________________________
   _____________________________________________________________________________

2. What would you do differently? _________________________________________________
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   _____________________________________________________________________________
   _____________________________________________________________________________
   _____________________________________________________________________________

3. What is missing? _______________________________________________________________
   _____________________________________________________________________________
   _____________________________________________________________________________
   _____________________________________________________________________________
   _____________________________________________________________________________

4. Any additional comments you would like to share? ________________________________
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   _____________________________________________________________________________
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Name (Optional): __________________________________________________________________
Acknowledgements

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