

RAP Sheet

The Latest in Disability Research, Advocacy, Policy, and Practice

Summer Issue 2004

TRANSITION TO ADULTHOOD



Rites of Passage and Students with Disabilities

Mary Schuh, PhD - UNH Institute on Disability/UCED

There are rites of passage to adulthood that should be available to all young people, including those with disabilities. Going to the prom, instant messaging, taking driver's ed, and attending college fairs are examples of typical activities for high school students. For older students, visiting colleges, enjoying flexible senior schedules, registering to vote, opening a checking account, or applying for a credit card are experiences that are taken for granted. Growing up is a time of both opportunity and risk. Teenagers learn how to negotiate the world of adulthood through a wide variety of experiences, most of which do not happen in a special education classroom.

In NH, students with disabilities are entitled to educational services until they turn 21; students without disabilities typically graduate at 18. Students with disabilities should graduate with their peers and utilize their time between graduation and "aging out" of special education to explore - with support from the school system - opportunities outside of the school building. These opportunities might include higher education, travel, career exploration, national community service, and independent living. Buy-out financial arrangements between schools and adult service agencies and pooling transition resources can expand the options available to young adults with disabilities.

Students with disabilities and their families must actively begin planning for the future well before the end of high school. For all students, setting goals and having positive dreams evolve out of a wide variety of school experiences including classes, extra curricular activities, internships, community service, relationships, and after school jobs. Inclusion and participation in typical high school activities helps students better understand what they want for their future.

Lifelong habits of learning and working are inherently promoted and developed though participation in typical educational experiences and traditional rites of passage. These experiences lead to connections, career and educational opportunities, increased social relationships, and a greater likelihood for entering adulthood as valued, contributing members of their communities.

Welcome to the first issue of the Rap Sheet. This quarterly newsletter is a collaborative effort of the NH Developmental Disabilities Council, the UNH Institute on Disability/UCED, and the Disabilities Rights Center. We hope the Rap Sheet will be a valuable source of information and practical help for individuals with disabilities, their families, and those who work with them.



Dear Readers,

We would like to dedicate this inaugural issue to Janet Smith, a pioneer in New Hampshire's move to establish community-based services. Janet passed away on March 20, 2004.

I first met Janet in 1977 as counsel on the *Garrity v. Gallen* lawsuit, better known as the Laconia State School lawsuit. In the 1960's community services for individuals with developmental disabilities were almost nonexistent. Janet was cared for at home until her mother's health failed, with no resources in their community, her family had no choice but to place Janet at Laconia State School. Her years in the institution were filled with pain and anguish; it was a heartbreaking time for her entire family. The inhumane conditions at the State School led Janet's mother, along with other families of Laconia residents, to sue the state. As a result of the lawsuit, NH developed a system of community-based services and became the first state in the country without a state run institution for people with developmental disabilities. For her efforts on behalf of persons with disabilities Freda Smith, Janet's mother, was selected by the *Concord Monitor* as one of the 100 most influential people in New Hampshire history.

Janet returned to Salem and for the last 23 years of her life lived within blocks of her family. Cared for by Easter Seal, her years in the community were ones of growth and happiness. Janet Smith taught us what human quality is really about. She will be missed.

Richard Cohen

Executive Director
Disability Rights Center

Mike Sgambati



Kathy Sgambati says of her son, "He's got a very kind heart. He's very caring and very sensitive." Last November Mike took care of his mother when she was recovering from a serious accident. Kathy recalled, "I was totally dependent on him." Mike not only provided physical care; he also kept his mother's spirits up. When her face was bruised and swollen, he would start her day with, "Hi beautiful! How you doing this morning?"

Graduating from high school was a major accomplishment for Mike. He took a full academic load with a special education aide helping him in his classes. The social aspect of high school was especially tough. Kathy reflected, "Lots of kids weren't open to what Mike could give to a friendship."

Now that he's graduated, Mike would like to be working. He has dreams of working in law enforcement, becoming an EMT, or maybe going into business for himself. Instead, Mike is unemployed; it's been a discouraging time. His mother noted, "It's been hard over this past year to watch him withdraw more and be less confident in his interactions with people."

Mike faces a number of barriers to employment. Prospective employers will need to make accommodations for his difficulties with reading, writing, and math. He doesn't drive and will need a job within walking distance from his house. Mike has the capacity to be a valuable employee, but will need training. Kathy explains, "To walk into a paid job where the performance demands are high and they expect people to learn and do quickly, would be a really significant challenge for him. But, if he had an opportunity to work alongside someone and to repeat the task, he could handle most any position."

Julia Freeman-Woolpert

Transition Services: Ensuring Success for Students with Disabilities

Wendy Paget, Esq. - Disabilities Rights Center, Inc.

Too often students involved in special education leave school without the necessary skills or experience to make a successful transition into adulthood. The Individuals with Disabilities Education Act (IDEA), the federal law that provides educational rights for students with disabilities, makes it clear that students' educational programs must be designed towards future goals. The essence of transition planning is aligning a student's educational experience, from age 14 forward, with his or her goals for life after high school. The student's input is the centerpiece of transition planning and should be included at each stage. The following is an explanation of the transition planning process, including the legal rights guaranteed under the IDEA and identification of pitfalls that can make transitions less than successful.

Prior to Congress passing the IDEA in 1975, children with disabilities frequently were excluded from education altogether. The original purpose of the IDEA was to enable children with disabilities to access education. When amended in 1997, the focus of the IDEA shifted from access to outcomes. Congress found that while children with disabilities now were allowed in the classroom, a disproportionate number of students receiving special education either did not graduate or were not prepared for adult life upon graduation. The amendments strengthened the transition planning provisions with an eye toward ensuring that students with disabilities were not just attending class, but also gaining needed skills and making the connections necessary for lifetime success.

With that goal in mind, Congress has integrated the notion of transition planning throughout the IDEA. Congress has identified the purpose of the

IDEA as follows, "To ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs **and prepare them for employment and independent living;**"

34 C.F.R. §300.1 (emphasis added).

Several key components are required by law to ensure that transition plans are successful.

TRANSITION PLANNING: THE ESSENTIALS

Conceptually, transition planning should include components that assist students and their parents to think about and plan for life after high school. The student's education during the high school years should be directed by these goals. (Depending upon the level of their needs, some special education students may require more than the traditional four years of high school. In New Hampshire students with disabilities are eligible to receive special education services until they either receive a regular high school diploma or reach the age of 21.) Finally, whatever agencies or service providers the student may need post graduation should be involved.

AT AGE 14 (or younger when appropriate):

The student's IEP (Individual Education Plan) must include a statement of transition service needs

- ▶ The student must be actively involved in IEP development
- ▶ A determination of post-school goals should be made

34 CFR §300.347(b)(1)

Transition Service Needs, which should be incorporated into an IEP when a child is 14 or younger when appropriate, is the term that addresses how the student's educational programming can be linked to the student's post-secondary goals. For example, if the student's post-secondary goal is to be a computer programmer, a transition service need would be a curriculum that includes computer classes; if the student's goal is to pursue a post-secondary education the transition services may include college preparatory coursework.

Fourteen has been singled out as a critical age when children with disabilities need to become more actively involved in directing their education. Beginning transition planning early is an important step in addressing the high dropout rate of high school students with disabilities. Just as in the IEP process, parents should be fully involved in transition planning. Parents bring a unique perspective to the planning process and can ensure that their child's needs are heard and addressed by the educational team.

AT AGE 16:

- ▶ The IEP must continue to address all areas of transition service needs addressed at 14
- ▶ The Student's post-graduation goals should be refined and coursework should be checked to ensure it is aligned with those goals
- ▶ A statement of needed transition services should be added to the IEP, including (as appropriate to the child):
 - ▶ Instruction
 - ▶ Related services
 - ▶ Development of employment and other post-secondary adult-living objectives
 - ▶ Acquisition of daily living skills
 - ▶ A functional vocational evaluation

34 CFR §300.347(b)(2)

By age sixteen, transition services should be a coordinated set of activities, involving the student, school, and any agency that might assist the student after graduation. Services should focus on assisting the student in obtaining the skills and experience necessary to prepare for life after graduation. For example, a student with post-graduation goals of independent living and employment in customer service might need a wide array of services, including instruction in bill paying, assistance from Vocational Rehabilitation to find an internship in a local business, a link with the housing agency for assistance in applying for state subsidized housing, and training on how to use public transportation. All of these services should be coordinated through the transition planning process.

COMMON PITFALLS IN TRANSITION PLANNING

The most significant and common problem with transition planning is that it does not happen. Students involved in special education routinely graduate high school with no more of a plan than, "This student will need to be followed by the Area Agency after graduation." Not only does this fail to address the needs of the student, it is legally insufficient. To ensure a successful transition, the principles of transition planning need to be incorporated throughout the IEP. While there does need to be a statement of needed transition services in the IEP, there is no legal requirement that a transition plan must be separate from or an addendum to an IEP. Perhaps the best and most practical way to approach transition planning is to begin when the student turns 14 looking at each IEP objective and making sure that it will further the student's ability to reach his or her ultimate goals following graduation.

There are a number of reasons that a large portion of students with disabilities never participate in the full transition planning process:

- ▶ students involved in special education are routinely pushed out of school: school officials may tell a parent or the student directly that a child can sign themselves out of special education and out of school at 16. This commonly occurs with students who have had behavioral difficulties in school. If a child with a disability is signed out of school prior to high school graduation, that child can be re-enrolled and can take advantage of both educational and transitional services. Many teenagers who have been signed out or are contemplating signing out are disillusioned with the educational process. Because these students' IEPs often are inadequate, their lack of success in school is understandable. With a good IEP and appropriate transitional services, a student can be refocused on attaining the skills and services necessary to succeed as an adult.

- ▶ If a student has graduated with a regular diploma, the entitlement to special education and transition services ends. Therefore, it is essential to ensure that a student has met all of the requirements for graduation. If the student has simply been pushed through from year to year, it may be possible to regain services.

- ▶ Agencies are not involved. Many agencies will attempt to delay their involvement with children - even those who are eligible for their services - until after graduation. Students have a right to services from agencies when they are eligible. Agencies need to play an integral role in transition planning.

Simple steps parents can take to ensure successful transition planning:

1. Ask for a meeting – parents have the right to request a TEAM meeting at any time – let the school know the purpose of the meeting is transition planning. The meeting should focus on problem solving that supports the student to achieve his or her goals for the future.
2. Ask for the right agencies to be involved. Parents have a better understanding of what their children need than anyone else. For example, a parent knows when his or her child needs tutoring, communication assistance, or mental health services. Ask for the school's help to determine what services your child is eligible for and to help in applying for services through agencies such as the Mental Health Center, Vocational Rehabilitation, and the Area Agency.
3. Make the student's GOALS the focus of transition and work to overcome any barriers that stand in the way of the student's success. Your child has the right to dream of and to pursue an interesting adult life. A spirit of collaboration should drive transition planning with the school supporting the student on the journey towards a positive future.
4. Involve your child. Ask your child to participate in the development of his or her transition plan, this will help ensure that your child will be invested in the plan.
5. Go to the meeting prepared. Make a list of the areas that need to be addressed and the services you think your child needs, and discuss them with the TEAM.
6. Call the Disabilities Rights Center. If you have concerns regarding the transition planning for your child, and you have had an unsuccessful meeting with the school, call the DRC and schedule an intake. We may be able to help you through the process or give you further information about your rights.

Improving Transition Services

Joanne Malloy, M.S.W., UNH Institute on Disability/UCED

The following changes in special education policy and practice are recommended to help improve transition services for NH's special education students.

1. Schools must have incentives to collaborate with other agencies and programs. Typically, special education transition services, planning, and funding occur solely within the context of the school setting. The legal and educational burden for transition planning lies with the school, with limited State funding the school is often the only entity that can support the costs of implementing transition plans. Schools do not have incentives to develop resources and linkages in their communities. It takes a substantial commitment of time on the part of schools to bring in community providers such as Area Agencies, mental health centers, or technical college staff. When community providers do come to the table, they are often unable to offer tangible resources for the student.

2. The State standards for high school diplomas must be revised to include multiple options for completion of secondary education requirements. The current standards require students to complete "clock hours" in core subjects (Carnegie Units) and do not allow for more than a few hours in educational modes such as internships, work-related experiences, and other individually designed programs. The development of more individually tailored programs could better meet the transition needs of special education students and help schools avoid costly out of district placements. Additionally, individualized programs help reduce the exceptionally high drop out rates for students with disabilities.

3. School personnel should learn how to facilitate student-centered plans and develop the necessary resources and supports students need to successfully complete the secondary transition process. Portfolios, greater student input into career planning, and person-centered planning are accessible, proven tools to assist individuals in making successful life transitions. Schools need support and training to ensure the availability of student-centered planning. *(continued on page 8)*



J e s s e A n n e t t

Jesse Annett attended a special education boarding school, followed by a year of vocational training. Jesse and her friend Roger, who she met at school, share an apartment and get support from Jesse's parents.

Jesse, who is a client of Vocational Rehabilitation, hoped to get a job in an office or working with animals. Instead, she was hired as a bagger in a supermarket. Barbara Annett, Jesse's mother shared her frustration with the process, "(There) wasn't any career advancement or exploration beyond they'd located this one job and she should do it." Jesse was let go after just three weeks. As Barbara explained, "There was a need (for Jesse) to talk to customers and nobody had prepped Jesse and helped rehearse the lines of what you would say in various situations." Jesse is very friendly, but naturally shy and quiet, without support Jesse was uncertain about how to interact with the public.

Even though Jesse was clear that she did not like cleaning, the next job VR found for her was in housekeeping services at a nursing home. The job coach who was supposed to help Jesse was never hired. This job lasted a week. Asked what she's doing now, Jesse replied, "Nothing much. Watch TV. Go to the Mall, Target, the library, the movies." Jesse is still hoping to find a job.

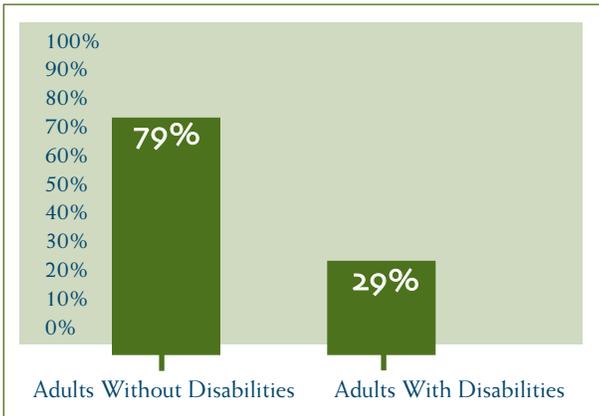
Julia Freeman-Woolpert

4. Special education funding within each school should be highly individualized and flexible enough to meet student needs, especially for 18-21 year olds. Older students, along with their families, should be primary decision makers in developing individualized transition services and be able to use educational funding for options that are available to their same-age peers including technical colleges, four year colleges, training programs, and employment. School districts should work to ensure that these students, where appropriate, have access to Medicaid, are receiving support from adult service providers, and have the supports they need to work and live as independently as possible.

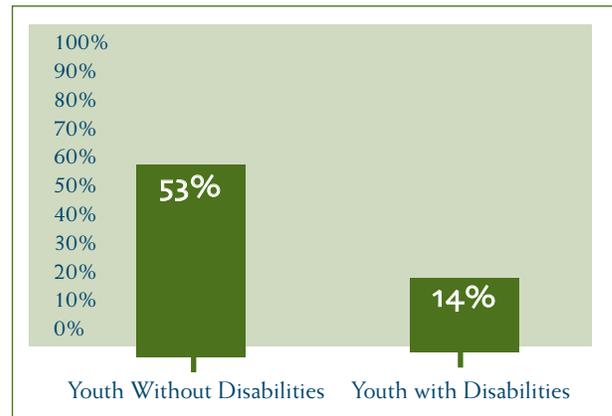
5. Transition services should be evaluated based on successful outcomes for students with disabilities. There are standard criteria on positive post high school outcomes for students with disabilities. The NH Department of Education should develop and require research on post high school outcomes for former special education students. Research findings can be used to help schools develop more effective transition services.

NOD/Harris survey, 1998 surveyed 1000 adults with Disabilities and found that only 29% of working-age persons with disabilities were employed (full or part time), as compared to 79% of non-disabled persons. From "A Paradigm for Evaluation of the Federal-State Vocational Rehabilitation Program", Dean, Dolan, Schmidt, et al.

"Youth with disabilities also continued to lag behind non-disabled youth in postsecondary enrollment with 14 percent of youth with disabilities and 53% of non-disabled youth participating in postsecondary education." From 2002 Literature Review Summary, National Collaborative on Workforce and Disability, quoting Blackorby & Wagner, 1996.

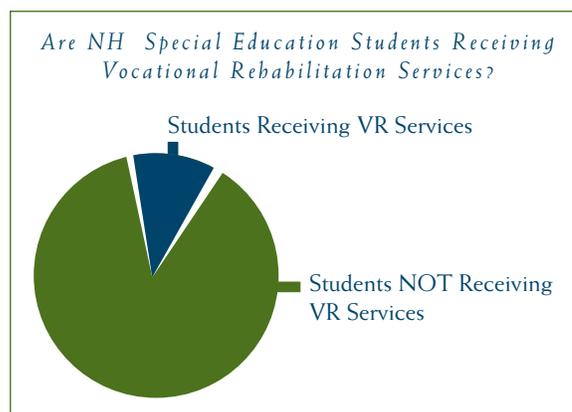


Percent of Adults with and without who are employed.



Percent of Youth with and without disabilities going on to Postsecondary Education

Secondary Transition: Prologue to the Future, NH Dept of Education Plan to Address the Role of Vocational Rehabilitation in Secondary Transition, Nov 2003.



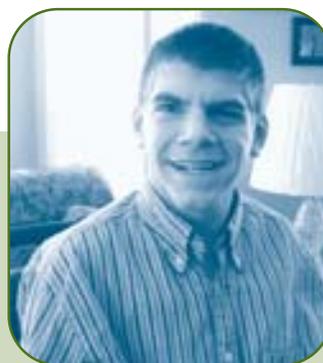
NEWS YOU CAN USE: Recent legal developments that might affect you

► Does your child need DENTAL services? There is a recent Consent Decree in a class action case brought in federal court by NH Legal Assistance. The State is required to take a number of steps to ensure that dental services are available to Medicaid-eligible children who need them, including help locating a dentist and transportation to and from the appointment.

► Eligibility for Area Agency services: The NH Supreme Court ruled in October 2003 that an individual with a specific learning disability is eligible for Area Agency services when his ability to function is substantially impaired. The court stated that such a person was eligible even when other non-developmental disabilities such as mental health or alcohol problems may also be contributing to his functional impairments. The case was *Petition of Moore Center Services, Inc. (Area Agency VII)*.

► Parents have the right to go to federal court without a lawyer (pro se), on behalf of their child in special education matters: In another October 2003 decision, the US First Circuit Court of Appeals affirmed that parents have the right to proceed in federal court without a lawyer. The case is *Maroni v. Pemi-Baker School District*. This case is especially important because few lawyers take special education cases, so many parents have no choice but to proceed pro se.

Find out more about these issues on the DRC website, www.drcnh.org.



Todd Rossetti

For Todd the hardest thing about leaving school was losing social contact. Todd, who cannot speak, uses facilitated communication (FC) to express himself. According to Todd, "It was hard to leave because you were around your friends every day." His mother, Paula Payne, noted that now that he is no longer in school there are few opportunities for Todd to be with people his own age.

While he hopes one day to have his own apartment, Todd currently lives with his family. Todd has significant disabilities, to meet his needs the family is supposed to receive several hours of help each day. However, Paula noted, "It's very hard to retain people, whether it be a case manager, job coach, job developer, or a person to assist Todd, with either personal care or facilitated communication." When aides call in sick or leave, one of Todd's parents stays home from work.

His mother believes employment is possible for Todd, but she says it is difficult to find an organization with the level of expertise and commitment needed to help people with significant disabilities find work. Paula talked about her experience with Vocational Rehabilitation, "There just doesn't seem to be anyone that does job development for people (like Todd). I think the wheelchair is a huge thing, along with the physical and vocabulary-communication."

Transportation is a major problem. The family has a donated van, but it's not in great shape. Paula explains, "When we have the van and it's working and the driveway's not ice, he can get out. Then it's making sure to have enough money and the person with him has to have money to go do anything. (We're) still trying to find appropriate social opportunities; it is very, very difficult."

Todd spends most of his days staying home and watching TV.

Julia Freeman-Woolpert

Jenn Hoffman

In spite of incredible odds, there are individuals who manage to create a better life for themselves. Jenn Hoffman, a 21 year old college student, has been living on her own for the last few years. With a 3.96 GPA, and plans to pursue a degree in Social Work, Jenn's future is looking bright.

That Jenn is attending college at all is remarkable. Even though Jenn exhibited significant emotional problems, her school never identified her as needing special services. Jenn explained, "My grades were very low. I skipped school a lot. I got suspended. ... (I) had a lot of meetings with my guidance counselor, they knew about my emotional problems and self-mutilation and eating disorder, but they just thought I was being a delinquent. They didn't realize that anything was going on at home." Finally at 16, Jenn was removed from an abusive family situation and placed in foster care.

In her senior year, Jenn landed at Manchester Memorial High School. She was uncomfortable in the new environment, avoided classes, and wandered around the building. Fortunately, an alert school nurse spotted self-inflicted marks on Jenn's arm. The nurse's intervention led to testing, identification of her emotional handicap, and special services for most of her senior year. Jenn said, "They helped me out a lot. I went to the classes that I felt I could go to, but I was also allowed to not go to class. (I could) get my work, and bring my work to the resource room and do my work there. ... They helped me out significantly. And so did the school psychologist who I met with. They're pretty much the only reason I graduated."

While Jenn was grateful for the help she received in school, there were gaps in the services she needed. Jenn was supposed to have received help from Vocational Rehabilitation, but this never occurred. Unhappy in her foster placement, Jenn abruptly left. Her life was chaotic; there was a series of hospitalizations, a brief period of homelessness, and a seedy rooming house that Jenn described as worse than being homeless. Following one of her hospitalizations Jenn entered the adult mental health system, where she connected with a therapist. "(We) work together great. I've made some great progress with my self-mutilation and my eating disorder." Jenn's therapist provided more than just counseling, she helped her obtain Social Security benefits and a housing subsidy. Jenn began working with the mental health center's vocational program. Project RENEW helped Jenn with her college applications and provided support with independent living and schoolwork once she entered college.

Jenn's success in college is exceptional, even extraordinary. Jenn receives financial assistance and has been able to get the accommodations she needs to do well academically. Jenn recognizes that not every college provides this support, "My friend, also has emotional difficulties. She went to college, and they didn't want to help her with her learning disability. ... She failed all of her classes her first semester in college - she dropped out because nobody wanted to help her."

Jenn is a striking example of what can happen when someone receives the resources and support that she needs.



Use of student and family-directed futures planning processes such as PATH or MAPS (Making Action Plans) ensures that transition planning is aligned with the student's dreams. Planning should include acknowledgement of obstacles and identification of specific agencies, programs, and resources the student will need to succeed. Ideally, student-directed futures planning should be part of the student's individualized educational planning (IEP) process.

Available Resources for Transition

- ▶ Alliance for Community Supports (603) 628-7681
The Alliance offers a Youth Leadership Series, professional development, and student specific career planning.
- ▶ Association for Career and Technical Education (ACTE)
Information on educating youth and adults for careers. www.acteonline.org
- ▶ Healthy and Ready to Work
Information on family-centered, community-based care for youth with special health care needs, includes downloadable publications on transitional issues. www.mchbhrtw.org
- ▶ HEALTH Resource Center--National Clearinghouse on Postsecondary Education for Individuals with Disabilities
Information on educational support services, adaptations, and opportunities on campuses, vocational technical schools, and other training sites. www.health.gwu.edu
- ▶ Institute for Community Inclusion at the University of Minnesota
Publications about employment and social inclusion. www.qualitymall.org
- ▶ Institute on Disability at the University of New Hampshire
Extensive publications and projects including: "Transition: A Manual for Young People with Disabilities and Their Family Members," Revised April 2004 www.iod.unh.edu
- ▶ NAMI-NH Concord, New Hampshire (603) 225-5359
Information and advocacy for individuals with mental illness and their families. www.naminh.org
- ▶ National Center on Secondary Education and Transition
Coordinates resources, offers technical assistance, and disseminates information related to secondary education and transition for youth with disabilities. www.ncset.org
- ▶ New Hampshire Department of Education: www.edu.state.nh.gov
- ▶ New Hampshire Bureau of Adult and Rehabilitation Services: (603) 271- 3471
- ▶ The Student with a Brain Injury: Achieving Goals for Higher Education
A paper on the impact of a brain injury on an individual's postsecondary education includes a directory of organizations, publications, and Internet resources.
www.heath.gwu.edu/bookstore/pdf/brain_injury.pdf
- ▶ Training Resource Network, Inc.
Wide range of publications on full inclusion of people with disabilities www.trninc.com
- ▶ NH Developmental Disabilities Council.
The U.S. Department of Labor Transition Services Realignment Grant supports resource mapping and local intermediary organizations to integrate transition resources for persons aged 14-24. (603) 271-3236

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NH DEVELOPMENTAL DISABILITIES COUNCIL

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e-mail: advocacy@drcnh.org www.drcnh.org**Protection and Advocacy System for New Hampshire***The Disabilities Rights Center is dedicated to eliminating barriers to the full and equal enjoyment of civil and other legal rights for people with disabilities.***INSTITUTE ON DISABILITY/UCED – UNIVERSITY OF NH**

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*The Institute's mission is to promote the full inclusion of people with disabilities into their communities.***NH DEVELOPMENTAL DISABILITIES COUNCIL**

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Phone: (603) 271-3236 TTY/TDD: 1 (800) 735-2964 www.nhddc.com*Dignity, belonging, and equal opportunity for all NH citizens with developmental disabilities to contribute to society, exercise all rights and responsibilities, and fully participate in the universal human experience.*

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