

RAP Sheet

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

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TAKING A STAND — MAKING A DIFFERENCE



Looking Back with Pride

The Disabilities Rights Movement and 35 Years of Advocacy

Clyde E. Terry, JD, CEO. Granite State Independent Living

Welcome to the Spring Issue of the Rap Sheet celebrating the power of advocacy. Without effective advocates people with disabilities would not be entitled to a free and appropriate education, the Laconia State School would still be open, and the Americans with Disabilities Act would not be law. We hope you will be inspired by the stories of New Hampshire citizens who have made a difference.

In the day-to-day work of advocating for persons with disabilities it is easy to lose sight of the tremendous progress that the disability movement has made over the past three decades. Today, millions of Americans with disabilities have greater opportunities and more fulfilling lives because of the work and sacrifices of earlier activists. If all our citizens are to realize their full potential, we must remain steadfast in our commitment to fighting for equal opportunities.

In the late 1960's America was engaged in the struggle to make the 1964 Civil Rights Act a reality. While the Civil Rights movement was a fight to end racial discrimination, persons with disabilities shared a history of discrimination and added their voices to the call for civil rights. They too wanted a quality education, meaningful employment that paid a liveable wage, and opportunities to participate fully in the life of their community.

Though modest, the first gains achieved by the disabilities movement were significant as they set the stage for what was to come. Congressional passage of the Rehabilitation Act of 1973 marked a shift in federal policy; it recognized that if given supports, persons with disabilities could go to work. The law also included a federal requirement for the elimination of physical barriers in any facility receiving federal funds. It was this legislation and the writing of the accompanying regulations (something that wasn't completed until 1979) that ultimately led to the formation of the independent living movement. Increasingly, persons with disabilities were organizing to fight for positive changes.

Effective advocacy by parents and individual with disabilities continued to result in major legislative milestones. In the mid 70's Congress passed the Developmental Disabilities "Bill of Rights Act" which stated the principles of choice and self-determination for persons with intellectual disabilities. 1973 saw passage of the first version of the Individuals with Disabilities Education Act (IDEA) guaranteeing students with disabilities the right to a free and appropriate education. By the end of the decade Congress had passed the first Fair Housing Act. With the Carrier

SUSAN COVERT, EDITOR

(Cover story continued)

Assistance Act of 1980 airlines no longer could refuse to serve passengers with disabilities. The Voting for the Elderly and Handicapped Act of 1984 guaranteed citizens with disabilities access to polling places.

Through a process called reauthorization, Congress reviews previously passed legislation to assure its effectiveness in carrying out Congressional intent. During the 1980's, with oversight from disability advocates, Congress reauthorized the Rehabilitation Act, IDEA, and the Fair Housing Act improving them by adding due process and other protections to ensure that these programs were responsive to the needs of persons with disabilities and their families.

The most significant advancements for the disability movement came in 1990 with the passage of the Americans with Disabilities Act (ADA). ADA prohibits discrimination on the basis of disability, in employment, public accommodations, and by state and local governments. Disability advocates led the efforts to pass ADA; their leadership on this issue solidified them as a force in the nation's capitol. The fight for equality and opportunity continues as the needs for persons with disabilities change and as our culture changes. In recent years advocates have fought for and secured passage of the Assistive Technology Act of 1994, improvements to Air Carriers Act of 1998, and reauthorizations of the Rehabilitation Act, IDEA, and the Fair Housing Act.

At the turn of the 21st century advocates encouraged Congress to break the link between poverty and disability. The Ticket to Work and Work Incentive Improvement Act of 1999 (TWWIIA) allowed people with disabilities to work without jeopardizing their eligibility for needed health care supports. The Help America Vote Act of 2002 assured that voters with disabilities would receive the accommodations they needed to be able to vote. Finally, tucked away in the 2006 federal budget, are provisions of the Family Opportunity Act, which if adopted by the state will mean parents of children with disabilities will no longer have to choose between staying home to care for their children or working.

Through persistence and enormous effort the disability movement has realized significant accomplishments. Persons with disabilities and their families can be justly proud of an impressive record of legislative victories. Reversal of discriminating practices and increased opportunities for full community inclusion demonstrate the power of effective advocacy. While much still remains to be done, it is important to appreciate just how far we have come.

Being Your Own Best Advocate

Julia Freeman-Woolpert, Disabilities Rights Center

"You can't always get what you want. But if you try sometimes you just might find you get what you need."

– The Rolling Stones

This is not an easy time to be a person in need. Human service budgets are shrinking, programs are stretched thin or being cut altogether, and many people asking for help are hearing the word "No." The Disabilities Rights Center is receiving increasing numbers of calls from people needing help in obtaining or keeping benefits and services. While there are some circumstances that require a lawyer or trained advocate, with a few skills, some strategies, and persistence people can often solve their own problems. Here are some tips for becoming a successful advocate.

Find Support You don't have to go it alone. Joining a support group is a great way to find allies. These groups offer both emotional support and a way to connect with others who are facing similar problems. A

support group can be a source for ideas, contacts, advice, and practical solutions. Networking is one strategy successful people employ to get things done. A support group can be an effective way to network and as an extra bonus it's an opportunity to expand your circle of friends.

Identify the Issue It's hard to get somewhere if you don't know where you're going. Think carefully about what the problem is and what is needed to resolve it. Bemoaning your child's horrible school experience is not as effective as being able to pinpoint what is wrong. Be specific: "My fifth grader is reading at a third grade level. Her reading evaluation recommended individual instruction three times a week, but at the special education team meeting I was told that the school didn't have anyone to work with my daughter."

Ask for Help Look to your family, friends, doctors, case managers, state representatives, and advocacy organizations for help. Think about how others can help you. It might be writing a letter, having someone attend a meeting with you, getting information, helping fill out a form, or figuring out where to go for an answer. Most people are glad to help if they are asked to do something specific, and if it doesn't involve a huge amount of time.

Know Your Rights Most services are funded directly or indirectly by the state or federal government. There are rules concerning eligibility and provision of services. There is a formal process you can use if you are denied services or dissatisfied with an agency action, whether it be Medicaid, Social Security, the local education agency, HUD-funded housing, or other state or federal programs. Don't give up! If you are unhappy with services file a complaint; if you are found ineligible for services file an appeal. Social Security, for example, denies over half of initial applications. On appeal, over half of these denials are reversed!

Be Assertive Learn how to be assertive - but not aggressive - in negotiating for what you need. The squeaky wheel gets the grease, but if it's too noisy it may get thrown out. Try for polite persistence. If they don't call you back, you call them. Follow up with a letter, fax, or email. If that doesn't work, call their supervisor.

If you are initially told "No", think of it as the beginning of the conversation rather than the end of it.

Find out more. Why were you found ineligible? Did the decision-maker have all the necessary information? What criteria did the decision-maker use? Were these the correct criteria? What would have to change in order for the criteria to be met? How do you request reconsideration? Can the agency refer you to another agency that can help you?

If you are worried about your ability to communicate, ask a friend to rehearse a difficult phone call with you, or put your request in writing and ask someone to review it before you send it. If you don't understand something, ask for clarification and keep asking until you understand. Request an answer in writing, and make sure you get it and that it's accurate. If this isn't provided, send a written request and ask for a response. (Keep copies of your letters and any replies.)

Keep a Record Take good notes and keep them in one place! If you're like me, and have called lots of people searching for answers, in a few days it will all be a blur. An accurate written record of when you called, whom you spoke with, what you asked for, and what information you received will help you keep track of what you have done and what you've learned. This record also will be important if you need to file a formal complaint.

Keep a log of all the people you have spoken to, their telephone numbers, the name of their agency, and other important information. You may need to contact them again. Also, if you start getting the runaround, you can explain to the person putting you off exactly whom you've already spoken to and what the results were. Keep all documents and communication (print out email correspondence) related to the problem.

Share Your Experiences Finally, think about speaking to your elected representatives, government officials, and agency administrators about your experiences - both good and bad- with services. Policy makers need to know more about how government funded programs are helping people and what services and supports are still needed, but not being provided. Elected officials usually will try to help their constituents resolve their problems with government agencies. You may get some help and at the same time you will be providing them with a valuable education.

Breathing Easier

Julia Freeman-Woolpert, Disabilities Rights Center

You CAN take on the bureaucrats . . . and win! Just ask Cheryl Paquette of New Boston.

Cheryl has a lot of energy; with four children ages 2 to 17, that's a good thing. A strong and tireless advocate for her family, Cheryl is especially tenacious when it comes to her oldest child. Bryant, who has multiple disabilities, receives a variety of services and supports and relies heavily on technology. A social kid, Bryant communicates using a Dynavox. He loves movies and with environmental controls can operate his VCR independently. Bryant is a huge Star Wars fan and plays the Chewbacca the Wookiee scenes over and over again.

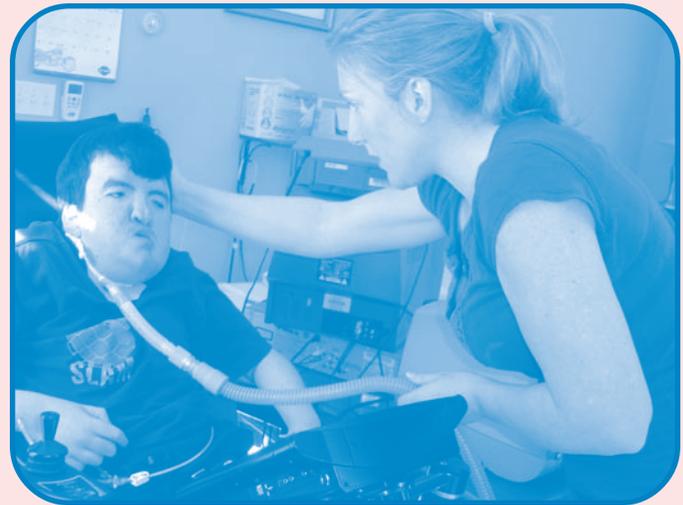
Technology provides Bryant with more than entertainment and social connections; it is also essential to keeping him healthy. Bryant is medically fragile and uses a c-pap machine, a suctioning device, and a pulse oximeter to manage his respiratory and other medical issues. Cheryl is a trained EMT, her skills have been invaluable on those occasions when Bryant has had a medical crisis.

In October 2004, Bryant contracted pneumonia and spent eight days in the Pediatric Intensive Care Unit (PICU) at Dartmouth Children's Hospital. Because he has limited lung function and is too weak to cough well on his own, pneumonia is life threatening for Bryant. In the hospital Bryant used a cough-assist machine to help get air into his lungs and bring up secretions. The machine played a vital role in Bryant's recovery and his Pediatric Pulmonologist, Dr. Dennis Stokes, recommended to the Paquettes that Bryant use a cough-assist machine at home to clear his lungs and to keep him from being readmitted to the hospital.

When Bryant's condition improved, he was discharged from the PICU straight home, rather than going to the hospital's pediatric unit. His needs are too complex for a regular care unit to manage. "He's pretty high-tech," explained Cheryl. The hospital ordered the cough-assist machine for Bryant to use at home, and Cheryl put in the request to Medicaid. She spoke with a representative from the Department of Health and Human Services and thought everything was all set. Then she got the denial letter.

Cheryl figured there must be some mistake. "I really didn't think it was real," she said. "I thought they must just not understand." Or perhaps, she reasoned, they did not receive the three doctors' letters strongly recommending the cough-assist machine. "I was sure it would be no big deal once they got the doctors' letters." Then the second letter arrived, the Department had received the doctors' request and still denied Medicaid coverage for the equipment.

Knowing how critical the machine was to Bryant's health, Cheryl refused to take no for an answer. She contacted the Disabilities Rights Center (DRC), appealed the denial, and asked for a hearing. Cindy Robertson, DRC Senior Staff Attorney, represented the Paquettes. Cindy discovered that the Department had applied the wrong standards in issuing their



Cheryl Paquette helps Bryant take a deep breath with his cough-assist machine.

denial. Rather than using the appropriate Medicaid Early Periodic Diagnostic and Treatment (EPSDT) rules, the Department based their denial on Medicare and private insurance rules for durable medical equipment. "It was really blatant," said Cindy. The DRC has learned that even after the Paquette case, the Department of Health and Human Services has continued to use the same wrong standards in making decisions on similar cases.

Cindy expressed other frustrations with the way the Paquette's request was handled by the Department. She stated, "There appeared to be a lack of serious consideration by the Department of the information provided by the Paquettes prior to the hearing. It seemed that not until the same evidence was presented through live testimony at the hearing did they seriously look at Bryant's situation."

At the hearing it was clear that the Department would lose the appeal. Before a decision could be issued, the Department decided that it would pay for the cough-assist machine after all. Was the fight worth it? Absolutely. Bryant now has his cough-assist machine and it's helping. He likes to use it and can feel the difference in his breathing. "The lesson," said Cindy, "is that even if you get a denial and have no new evidence to present, it's still worth appealing."

Having an Influence: Insights from Representative Elizabeth Hager on the State budget process and how families can educate the legislature

Carol Stamatakis, JD, Director of Planning, NH Developmental Disabilities Council

To better understand how individuals can influence the state's budget process, I recently met with Elizabeth Hager who, for nearly 24 years, has represented Concord in the New Hampshire Legislature. Currently Vice Chair of the House Finance Committee, Rep. Hager has served on House Committees for Health, Human Services, and Elderly Affairs; Education; Municipal and County Government; and Children, Youth, and Juvenile Justice. The depth of her experience in the legislature has given her a knowledge and perspective of State government that is truly exceptional. A former Concord City Councilor, she has witnessed first hand how decisions made at the State level impact New Hampshire's towns and cities. As Executive Director of the United Way of Merrimack County for the last ten years, Rep. Hager also is intimately aware of the challenges that human service agencies face as they struggle to meet community needs.

Rep. Hager explained that the State budget process originates in the House with a budget bill, traditionally identified as House Bill 100. Typically, the committee works from the Governor's proposed budget, but it may work from a "maintenance budget," which is based on the previous biennial budget adjusted for inflation, new federal mandates, or projected changes in caseloads. The Finance Committee's three "divisions" review line by line the budget for every State agency. As part of its review, the committee holds a public hearing that typically involves many hours of testimony, usually over two days. After the hearing and numerous work sessions, the committee sends the budget bill, with their proposed amendments, to the full House for action. Once passed by the House, the budget goes to the



Representative Elizabeth Hager, Vice
Chair of the House Finance Committee

Senate where the process is repeated. In addition to its work on the full budget, the Finance Committee also hears and makes recommendations on individual bills that require new or additional State spending, often referred to as "specials."

I asked what people with disabilities and their families can do to provide meaningful input on decisions concerning State spending. Rep. Hager noted that while testifying at a hearing is important, personally contacting representatives can be more effective if they are knowledgeable about a particular area of the budget. I wondered if legislators listen to someone who is not a constituent. Rep. Hager replied that depends on the situation. She is interested in hearing from someone who has unique knowledge about a subject; callers who are just expressing support or opposition to a bill are not likely to have much influence. Email is the least effective form of communication. She said that she generally deletes emails that are not from constituents.

State agencies play a very powerful role in the budget process. According to Rep. Hager, members of the Finance Committee rely heavily on State agencies for information about budgetary needs and the impact of proposed cuts. Those advocating for spending in excess of an agency's request "must have good reasons." She noted that everyone contacting legislators about the budget are advocating for spending. "We never get lobbied not to spend." For special spending bills, committee members tend to rely more on information provided by those advocating for additional or new spending. For these bills, it is extremely important to testify at the hearing and "speak from your heart as well as your head." In contrast, at the State bud-

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Public Policy - Powerful Parents

Linda Steir, Policy Coordinator, Community Support Services, Inc. (CSNI)

(This article first appeared in Family Voices Winter 2006)

New Hampshire is unique in so many ways. One example is our state's effective network of parents who advocate on the behalf of children and adults with developmental disabilities. It was parents who led the efforts to close Laconia State School and who created the vision of community-based care. In 1988 it was parents who fought for passage of New Hampshire's first Family Support legislation. Clearly moved by parent testimony, the legislature voted overwhelmingly to pass the Family Support bill. For many parents, working on this legislation was their first realization that they had the power to influence public policy. During every session of the legislature, parents have advocated for funding to eliminate the state's Developmental Services Waiting List.

For a variety of reasons some parents are reluctant to get involved in the policy process. Parents have their hands full caring for a child with special needs and even the idea of contacting legislators, attending hearings, and speaking out on issues can be intimidating. Yet parent advocacy is essential to maintaining the services we have and improving opportunities for the future. Nearly everything in our daily lives is influenced to some degree by laws passed by our state legislature or by Congress. Laws determine how fast we drive on the highway; the safety of over-the-counter medications; the degree to which our environment is protected; and how much revenue the state of New Hampshire appropriates to serve children and adults with developmental disabilities.

Elected representatives are bombarded from all sides with requests for funding. They are lobbied to fund highways, pay for the judicial system, and everything in between! Unless parents educate their legislators about what is needed to support children and adults with developmental disabilities, there is little hope that the needs of this vulnerable population will be adequately met. While representatives from state agencies attend hearings and present their budgets to the legislature, the most persuasive arguments are those made by parents and self-advocates who are willing to share their personal stories.

In New Hampshire advocacy efforts for developmental services are coordinated by a Public Policy group and supported by the Area Agencies through Community Support Network, Inc (CSNI). This is how it works:

- ◆ The Public Policy group monitors proposed legislation and determines what bills need to be followed. The Public Policy group has been working together for nearly twenty years; membership includes representatives from the Area Agencies; the Disabilities Rights Center; the New Hampshire Developmental Disabilities Council; Granite State Independent Living; the Institute on Health, Law, and Ethics at Franklin Pierce Law Center; and the New Hampshire Brain Injury Association.
- ◆ Each Area Agency has at least one person designated as a Legislative Liaison. Information generated at the Public Policy meetings is shared with the Legislative Liaisons who in turn get the word out to parents and self advocates in their Regions.
- ◆ As Policy Coordinator for Community Support Network, Inc. I attend all Public Policy meetings and work with this group to develop strategies concerning legislation that affects individuals with disabilities and their families. I regularly email "Action Alerts" to the Legislative Liaisons and they pass information on to families and individuals in their region who are willing to call their legislators, write letters to the editor, or attend hearings.

If you would like to share your talents and help influence policy decisions that affect services and supports for people with developmental disabilities, please contact the Legislative Liaison in your Region and volunteer to help.

LEGISLATIVE LIAISONS

Region 1 - North Country

Stacey Bilodeau 636-2311 x3558
sbilodeau@northernHS.org

Amy Mahoney 367-9432
aqmahoney@yahoo.com

Region 2 – Sullivan County & the Upper Valley

Dianne Milliken 826-4361
jdmilliken@adelphia.net

Region 3 Lakes Region

Chris Collier 536-1884
chriscollier@adelphia.net

Region 4 - Merrimack County

Sarah Aiken 1-800-499-4153 x241
saiken@communitybridgesnh.org

Region 5 – Monadnock Area

Larry Butcher 357-8383
lgbutcher@aol.com

Region 6 - Greater Nashua

Dave Hackett 459-2751
dhackett@region6.com

Region 7 – Greater Manchester

Jan Larsen 668-5423
jan.larsen@moorecenter.org

Ilene Wheeler 668-5423
ilene.wheeler@moorecenter.org

Region 8 – Seacoast

Sally Weiss 463-7104
Sallyaweiss@hotmail.com

Region 9 – Strafford County

Hugh Philbrick 749-4015
hphilbrick@bhdssc.org

Chuck Raymond 743-3909
chuck.raymond@comcast.net

Region 10 – Salem/Derry Area

Terri Cadorette 893-1299
tcadorette@region10nh.com

If contacting the Legislative Liaison in your Region is not successful, please contact me:

Linda Steir 362-9930
ljsteir@verizon.net

I look forward to hearing the roar of your voices!

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get hearing, it can be counter-productive “to hear the same points made over and over.” Rep. Hager noted that a handwritten letter or genuine phone call can be more effective than speaking at the hearing.

In its recent report the Governor’s Commission to Study Area Agencies and their Role in Providing Services to New Hampshire found that funding of developmental services has not kept pace with cost increases. The Commission expressed concerns that this will impact the quality of services and the system’s ability to provide essential supports in the future. I asked what families could do to help educate the legislature about this situation. Noting that the publication of the report was itself a critical step, Rep. Hager went on to say, “I really believe that people should continue training families to communicate with legislators to tell them what their needs are, how they live, what the pressures are having a person with developmental disabilities within the family. It is pretty much accepted that we are not going to institutionalize people.” Family members need to explain their willingness to shoulder certain responsibilities, while at the same time being clear about what their needs are. “It is extremely powerful to show a legislator that those in need of support are not faceless. It’s us. It’s your neighbors and friends. It’s me.”

Rep. Hager believes that one of the most effective things that a person with a disability or family member can do is to meet one-on-one with their legislators. When legislators become aware of the personal stories of people in their own communities, the impact is much more powerful. I asked if this was useful even if the legislator is not on the Finance Committee or a committee that deals with human services. Rep. Hager said that meeting personally with your representative was “absolutely critical,” regardless of the committee the legislator serves on. She said that most legislators will listen carefully to a constituent and recommended that people meet with their representatives during the “off-season” between legislative sessions, typically in the summer and fall. She stressed that having one-on-one conversations are much more effective than planning events that legislators may not attend.

NH Leadership Graduates make a difference — one person at a time

Beth Dixon, Leadership Series Coordinator, Institute on Disability, with Stacey Brooks, 2004 Leadership Graduate

On the first day of Leadership, I stood in front of a room of 35 participants and had to introduce myself. I got myself so worked up about what to say that by the time I made it to the front of the room, I was shaking and started to cry . . . I sobbed the whole way through my introduction. I was off to a great start!

Finally, I realized I was in a room where everyone else was just like me. I didn't have to explain Zenith or make excuses about why he was still drinking from a bottle, or why he wasn't potty trained, or why his language was so slow. Mind you, I've never made excuses for Zenith. Zenith is Zenith. And when I use the word "special" to describe my son, I'm not using it to describe his needs. I'm using the word SPECIAL because that's what he is. A special boy who brings a smile and happiness to each day and everyone he meets. He touches something inside me that makes me want to be a better mother and person. He touches each of you and because of your kindness to him and to our family makes you someone special too.

Stacey Brooks shared this account of the 2004 Leadership Series with community members who had gathered on the first night of November for a "Light the Barn" ceremony at her family's home in Madbury. In the flier advertising the event the family explained:

To raise awareness about Epilepsy, we have decided to Light the Barn on our property. This light will shine from 6:00 p.m. to 11:00 p.m. each night during the month of November. It is our hope that it will be a visible beacon and people will ask, "What's that purple light?" Please pass along the message and help raise the awareness and respect for those people who live with Epilepsy.

Lighting the Barn was both a way to raise public awareness about epilepsy and a way to raise funds to support the New Hampshire Leadership Series sponsored by the Institute on Disability at UNH.

Since its inception in 1988 the New Hampshire Leadership Series has provided leadership training to more than 500 individuals. Originally designed for parents of children with disabilities, the Institute has expanded

NH Supreme Court Affirms Rights of People with Mental Illnesses

James Fox, JD, Staff Attorney, Disabilities Rights Center

In a February decision, the New Hampshire Supreme Court affirmed the rights of individuals to be free from government intrusion and control. In reversing a probate court decision involuntarily committing B.T. to New Hampshire Hospital, the Court ruled in favor of personal liberty over paternalistic intervention. The Mental Health Center of Greater Manchester (MHCGM) attempted to commit B.T. in order to force her to take medications; the Supreme Court found that the MHCGM failed to prove that the woman was dangerous.

By law, a person involuntarily committed to New Hampshire Hospital can be required to comply with outpatient treatment through a conditional discharge. The discharge can be revoked if the person fails to comply with specific conditions set by the hospital and mental health center.

B.T. had been placed on a three-year conditional discharge that expired in June 2004. Three days later, believing that she might stop taking her medications, The Mental Health Center of Greater Manchester (MHCGM) sought to have B.T. committed to force her to take medications. The probate court ruled that MHCGM had demonstrated the requisite level of dangerousness for involuntary admission for the purpose of conditional discharge. The Supreme Court disagreed and reversed the lower court's decision.

the program to include a Leadership Series for adults with disabilities. Leadership participants attend seven sessions, each two days long, that are held from September through April. The series includes presentations on best practices and policies related to disabilities, information about how to use the legislative process, and help in developing strategies that participants can use to affect change at the personal, community, and statewide level. Between sessions participants have homework assignments and work with teams on projects that support the full inclusion of people with disabilities in their communities.



Stacey Brooks with her children, Zephyr, Zenith, Quest, and Phoenix

Stacey summarized her experience at Leadership, "I found a purpose and an outlet and a way to truly embrace the differences Zenith has from other children. With the things I have learned at Leadership, and the connections - and I hope lasting friendships - I have made, I know that I can and will make a difference in his life. I have dreams for Zenith, and more importantly, now I know that Zenith must have dreams for himself and I must help him to make those dreams possible."

Since graduating from Leadership, Stacey's own dreams continue to grow. In addition to raising her four children, she is a student at the Community Service

and Leadership Program at the Thompson School at UNH, a member of the Leadership Team for Strafford Learning Center, and a newly elected member of the Oyster River School Board.

For more information about the NH Leadership Series: www.nhleadership.org or email Beth Dixon at: badixon@unh.edu

The Supreme Court found that mental illness in and of itself is insufficient to involuntarily admit any person into the mental health services system. The Court declared that simple evidence of agitation, delusion, and paranoia that a person may experience when off medication is not enough to make her "dangerous" to herself as required by the law for commitment.

The Court ruled that a finding of dangerousness requires a threat of, a likelihood of, an attempt to inflict, or an actual infliction of serious bodily injury to oneself or another, or a lack of capacity to care for one's own welfare such that there is a likelihood of serious debilitation if admission is not ordered. The Court further stated that there be a finding by clear and convincing evidence that there are acts demonstrating "actual or likely serious bodily injury."

The fact that conditional discharge status means that the person would not actually be admitted to State Hospital does not relieve the petitioner (the MHCGM) from having to prove dangerousness. The Court again found that "a psychiatrist's finding of a dangerous mental condition does not automatically operate to trigger commitment; without evidence of dangerous conduct, even the most persuasive psychiatrist's report is insufficient to justify commitment."

The Court concluded that it was reversing the lower court because "though B.T. might benefit from treatment for her illness, she cannot be deprived of her personal liberty by an involuntary commitment without clear and convincing proof of her dangerousness."

It's All About Being a Team

Julia Freeman Woolpert, Disabilities Rights Center

Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.

– Margaret Mead

Dr. Mead, meet the Dog Guide Users Group of New Hampshire. This group of thoughtful, committed citizens knows what changes they want, they're busy making them happen, and they're having a good time in the process. Chairperson Carol Holmes explained, "We're a support group with a real purpose. We support each other, but our real purpose is advocacy, awareness, and education."

The guide dogs are the group's common denominator. The group began in 2001 with five people; today the membership is near 30 and includes guide and service dog users, puppy raisers, and spouses. Carol noted, "The dogs empower us to live more independent lives. We wanted a group to support each other, to come be social, to have lunch, and to talk about dog stuff."

Members have valued that support; Linda Vayens commented, "When I first got Nutmeg I felt like I was the only one who had a dog. It was a weird feeling. Once they invited me to join the group it's like, 'Wow! I don't stand out anymore.'" Larry Ashford first attended a meeting because he had friends who were members. With the group's encouragement Larry enrolled in the Seeing Eye School where he partnered up with Cameo. Since then, Larry and Cameo have been inseparable.

Over time the group's mission has expanded to include advocacy as well as support. During the 2005 legislative session, the group worked with Rep. Henry Parkhurst to pass legislation that made purposely harming a service dog a class A misdemeanor. This advocacy was in response to an incident where a dog viciously attacking Fen, a member's guide dog. The attack left Fen traumatized and unable to function as a service animal. Fen's law protects the dogs and, by extension, their owners. In memory of Fen, the group is working to educate the public about service animals. Governor Lynch will proclaim June 16th as "Service Animals Awareness Day." The Guide Dog Users will hold a celebration at the State House cafeteria and the Governor has been invited to read the Proclamation.

Following the wake of Hurricane Katrina the group was touched by the plight of guide dogs and their owners. Some people were forced to abandon their animals; others refused to leave without their dogs. The group currently is working with Rep. Elenore Crane on a bill requiring the New Hampshire Division of Emergency Management to address the evacuation of service animals as part of the state's emergency planning. Group members Carol, Linda, Larry, and Joan Nelson all testified at the hearing with their guide dogs Nugget, Nutmeg, Cameo, and Lexa sitting beside them giving their own silent testimony. At the hearing's conclusion, the vote looked like it would be in favor of the dogs.

The group looks for opportunities to educate the public about service dogs. People often don't understand that a service dog is working. "They come up and they grab them or pat them, they think they're pets," said Larry.

Carol talked more about this, "Every dog guide person is different. Some people don't want people to pat their dog regardless. So I usually say don't ever pat a dog guide unless you have gotten permission." For herself Carol confessed a weakness for children, "If my dog is lying down and a mother comes over, I'll say yes."

"Dogs are great icebreakers," Joan added. "People will approach you more readily if you're with your dog. I don't have a problem with that as long as they don't distract the dog."

As part of their public education campaign, the group organized an event at the Steeplegate Mall in Concord. The Guide Dog Users wanted businesses at the Mall to understand that service dogs have a right to accompany people as they shop. In preparation a member spoke with the Mall manager and informed him that they would be coming to the Mall. The manager let the stores know to expect the dogs, explained that service dogs are allowed in the Mall, and passed on the group's suggestions about the kinds of assistance the guide dog users might appreciate. The guide dogs were well behaved as always, but Joan reported, "A big runaway dog, a regular pet, was running all through the

Mall and in and out of the clothing stores. The salespeople were chasing him. It was comical."

The group discussed another problem that they want to tackle. According to Joan, "Our biggest problem is transportation. We don't drive. I live in Concord and wanted to work in Manchester. Forget it! Transportation is so lousy, I can't get back and forth." Even when transportation is available there can be problems for guide dog users. Main Street Taxi of Concord denied service to Larry when they

found out he would be accompanied by Cameo. Under the Americans with Disabilities Act, Larry is suing the taxi service to allow him to ride with his guide dog.

Problems with transportation have led the group to consider joining forces with others who also have trouble getting around. Carol explained, "Everyone with a disability and senior citizens - everyone in this state needs to come together and figure it out . . . It's all about being a team."

For more information or to join the Dog Guide Users, contact Carol Holmes at 434-6042, or go to their website, currently under construction but coming soon: <http://www.dogguideusersnh.org/>.



Joan Nelson with her guide dog, Lexa

Recovery Advocates Were Right All Along, Government Declares

Ken Braiterman, Coordinator In Our Own Voice

As "mental patients" we taught our caregivers that people with severe persistent mental illness could get well and stay well, have successful families and careers. For years professionals dismissed us as radical, but after a decade of growing acceptance, recovery is officially mainstream.

On February 15, 2006 the federal Substance Abuse and Mental Health Services Administration (SAMHSA) declared that "recovery must be the common, recognized outcome of the services we support," and outlined principles necessary for recovery-based treatment. This policy statement adds force and definition to the President's New Freedom Commission, which made recovery a national goal in 2003.

Recovery from mental illness is different from being symptom-free or stable on medication. It's about being satisfied with the person you are, and your quality of life. SAMHSA is telling the mental health system it must help us be all we can be, not just stabilized, out of the hospital, in dead end jobs.

I became a recovery advocate in 1977, the first time I was hospitalized. I'd lost my career as a writer and editor, my wife, Manhattan apartment, savings, and friends. I was driving a cab all night in New York City with a raging undiagnosed psychosis, sleeping on people's couches. The doctors told me that thinking I was a writer made me sick. I had to accept being a cab driver, get a furnished room, and go to day treatment. My response was, "If that's such a good thing to do, why don't you do it? I was a writer before I got sick and I'll be a writer when I get well." They called me arrogant.

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I got sick over a long period of time, so it took a while to get stable on medicine. In August 1978, I volunteered for the Democrats. I expected to stuff envelopes, but because of my writing experience, they made me press assistant for the state committee. After the November election (we beat Meldrim Thomson), I got two part-time reporting jobs, one with my hometown weekly, and one covering presidential primary events for Reuters News Service. Then I took off for graduate school in North Carolina.

I had a relapse, stopped school, and was back driving a cab. Again, a treatment team told me thinking I was a writer was the disease and driving a cab was the cure. They called me arrogant and uncooperative. They also called a mother who resisted foster care for her kids, defiant. They believed that they were doing us a favor by invalidating our hopes. Hoping made us harder to manage and would only frustrate us in the end.

I knew I could make my living as a writer again someday. With support from my family and help from medicine, I began to get well. Years later a breakthrough in psychotherapy, new recovery skills, and a social network enabled me to fully recover from my mental illness.

I returned to New Hampshire in the early 80's, got my Masters' degree from the UNH Writers' Program, and for fifteen years worked in the newspaper business.

Every day when I drove to work I thought about those doctors. But that job was who I was, not what I did. I went to work, did the work, and got ready to go back to work. On weekends, I slept, watched TV, and went to a movie if I had the energy. I was 100 pounds overweight, smoked cigarettes, couldn't walk ten minutes, and was incapable of personal relationships. I was isolated, crippled by anger and shame. When I got sick again and lost my job, I was nothing. That's "stable on medication with a job," not recovery.

By 1996, New Hampshire was experimenting with recovery-based services like consumer-run peer support centers, and wellness (WRAP) seminars based on the work of recovery advocate and mental illness survivor Mary Ellen Copeland. A mental health Consumer Council was established to work for system change. The state was closing group homes and day treatment programs that taught people to be helpless and dependent.

I now worked with a treatment team that practiced strength-based, collaborative therapy, which encourages recovery. They helped me let go of the anger and shame, and sent me to a peer support center. I found friends there who knew how I felt and didn't judge me. WRAP training taught me a recovery philosophy, a relapse prevention plan, and coping skills. Becoming an activist was easy; everybody wanted "consumers" on their committees. I became Consumer Council chair in 2000.

Special Education – The Right to a Hearing

Ronald Lospennato, JD, Disabilities Rights Center,

Federal and state governments are responsible for a wide range of services to people with disabilities. Many of these services are critical to an individual's life and welfare. To ensure adequacy and provision of services, an array of procedural safeguards are available for individuals to use whenever there is a proposal to deny, reduce, or even change benefits or services. One of the most basic safeguards is the right to a hearing to challenge governmental action.

Over the years the United States Supreme Court has upheld the right to a hearing. In the 1951 case, *Anti-Fascist Committee vs. McGrath*, the court found that the right to a hearing to contest a denial of a governmental benefit or other "grievous loss" is a "principle basic to our society." In its decision, the court wrote:

The heart of the matter is that democracy implies respect for the elementary rights of men, however suspect or unworthy; a democratic government must therefore practice fairness; and fairness can rarely be obtained by secret, one-sided determination of facts decisive to rights.

In their budget for 2003, the state's Bureau of Behavioral Health proposed a 55 percent cut in peer support that would close half our centers and cripple the rest. "When we have more money, we'll re-open those centers," the bureaucrats promised. Were they stupid enough to believe that, or did they think we were? As Council Chair, I convinced our members they could fight, and showed them how.

People who had spent their lives being marginalized and ignored by society fought City Hall and won. People filled the room for the state budget hearing; dozens submitted written testimony or phoned their legislators. Eighty-six people rallied outside the State House and we got heavy media coverage. The Union-Leader headline read, "Budget cut will cost the state money." Each consumer said in his own words that, because of peer support, they used fewer hospitals, emergency rooms, and one-on-one community supports, the most expensive Medicaid services. We submitted a Dartmouth study that verified these anecdotes. People also said they learned life skills, got jobs, and overcame their isolation and shame. Their



Recovery Advocates: Michael Cohen, Executive Director of NAMI-NH and In Our Own Voice Coordinator Ken Braiterman

dignity and determination were as persuasive as their words. The legislature voted to restore funding for peer support. Those who took up this fight would never feel powerless again.

Today, I write and lecture about recovery, teach WRAP seminars, and teach others to tell their recovery stories. I coordinate the In Our Own Voice speakers' bureau for the National Alliance on Mental illness (NAMI NH). Our speakers' presence and inspiring life stories prove that recovery is real. They disprove myths about people with mental illness. They give people hope for themselves, their loved ones, and their clients. Our audiences are students, family members, businesses and professionals, churches, and civic groups. The recovery movement gave me a new way to live and satisfying work to do. But I also have a successful family, satisfying supportive relationships, and a balanced life. Not bad for a homeless psychotic cab driver, who thought he could write.

(Ken Braiterman is coordinator of the In Our Own Voice speakers' bureau for NAMI NH. He can be reached at Kbraiterman@naminh.org. The SAMSHA statement is at www.samhsa.gov/consumersurvivor/.)

Due process rights include the right to be heard "at a meaningful time and in a meaningful manner." The court found that due process would have "little reality or worth unless one is informed that the matter is pending and can choose for himself whether to . . . contest." As Supreme Court Justice Jackson wrote in a 1959 case:

[M]any controversies have raged about the cryptic and abstract words of the Due Process Clause but there can be no doubt that at a minimum they require that deprivation of life, liberty or property by adjudication be preceded by notice and opportunity for hearing appropriate to the nature of the case.

The right to due process applies to the provision of special education services. Under the Individuals with Disabilities Education Act (IDEA), a parent is entitled to complain and request a hearing "with respect to any matter relating to the identification, evaluation, or educational placement of the child, or the provision of a free appropriate public education to such child." Due process is also guaranteed under Section 504 of the Rehabilitation Act of 1973.

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In New Hampshire, special education hearings are conducted by the state's Department of Education. As required by IDEA, hearings are conducted by an impartial hearings officer who may not be an employee of the public agency involved in the child's education and who may not have any conflicting interests. The Department of Education contracts with lawyers in private practice to provide this service.

All parties participating in special education hearings are entitled to the following:

- ◆ To have access to all education records (both in preparation for and during the hearing);
- ◆ To be accompanied and advised by counsel and by individuals with special knowledge or training in respect to children with disabilities;
- ◆ To present evidence and confront, cross-examine, and compel the attendance of witnesses;
- ◆ To prohibit the introduction of any evidence not disclosed at least five days before the hearing;
- ◆ To obtain a written or electronic verbatim record; and
- ◆ To obtain written or electronic findings and decisions.

Parents have the right to decide whether the record, findings, and decision will be provided to them in written or electronic form. A copy of the final decision must be mailed to the parties within 45 days after receipt of a request for a hearing unless a specific extension is granted.

IDEA provides that a party disagreeing with the hearing decision (when the hearing was conducted at the state level and there is thus no right of impartial review) or disagreeing with an impartial review decision may sue by bringing a civil action in any state court of competent jurisdiction or in a federal district court.



Planning for the Future – Self-Advocates Hold Statewide Retreat

On October 3, 2005 individuals with disabilities and representatives from advocacy organizations from across New Hampshire came together to develop a statewide plan to strengthen self-advocacy. The retreat was co-hosted by People First of New Hampshire and the New Hampshire Developmental Disabilities Council. Chester Finn, Board Chairman of Self-Advocates Becoming Empowered, helped to facilitate the daylong planning retreat. Those attending included self-advocates and representatives from the Bureau of Developmental Services, the Disabilities Rights Center, the Community Support Network, the Institute on Disability, and the Parent Information Center.

Mr. Finn began the meeting by sharing the following insights from self-advocates in other states. Self-advocates need social opportunities where they can make connections and develop personal relationships. A network of strong local groups is needed to build a statewide self-advocacy movement. Self-advocacy groups need to learn how to stay positive even when members disagree with one another. There are times when self-advocates must have the courage to disagree with their support organizations. A successful statewide effort will require long-term partnerships among self-advocates, support organizations, and community groups.

At the retreat participants reached agreement on the basic purposes and values of self-advocacy. Participants also discussed the importance of self-advocacy both for the individuals with disabilities, and for the greater community. Everyone agreed that learning self-advocacy skills are critical if persons with disabilities are to "speak up, stand up, and stick up" for themselves and their peers. Self-advocates can play an extremely valuable role in educating agency staff, elected officials, and community members about issues affecting individuals with disabilities.

A follow-up meeting to continue developing a statewide plan to strengthen self-advocacy is being planned for June. If you are interested in participating, please call the DD Council at 271-3236.

Fighting for an Adequate Education

Julia Freeman-Woolpert, Disabilities Rights Center

Money is like manure, it's not worth a thing unless it's spread around encouraging young things to grow.

– Thornton Wilder

It would have cost the Manchester School District \$630 to provide Craig Langton with the training he needed to learn how to use the computer software that was part of his educational program. Instead, the school district refused and took the Langtons to due process.

Craig Langton is a bright 17 year old who has dyslexia. His parents, Michael and Debra, have had to fight every inch of the way to get the Manchester School District to provide Craig with the special education and related services he needs to succeed at school.

The problems with the school district began when Craig was in elementary school. Michael explained, "What would take a normal kid maybe an hour to do his homework, he was taking three or four hours with help from Deb. We kept saying, 'this isn't right'." The Langtons had to argue hard to have the school find Craig eligible for special education. The family won that battle, but throughout their son's school career, they have had to fight to get the Manchester School District to provide Craig with an appropriate education.

When Craig was in high school, Deb learned about Kurzweil, a computer software that assists people with dyslexia develop reading and writing skills. A teacher herself, Deb recognized the benefits that this could have for her son.

The Langtons approached the school about getting this and other software for Craig. The school agreed to provide the software and a small amount of training. The training was not intensive enough for Craig to learn how to use the software. When the Langtons requested additional training, the school refused and initiated due process. After years of struggling to get the district to provide appropriate services, this was the final straw. In spite of

the enormous stress involved in going through due process, the Langtons decided not to back down.

Despite repeated offers from the parents, the school district refused to go to mediation and refused several offers of settlement. After a two day hearing, the hearing officer ruled that the Manchester School District had not provided Craig with adequate instruction, and ruled that the school should provide him with 8 hours of training in Kurzweil and the other software programs. Instead of providing the training, the school district appealed the case.

In its decision on the appeal, the U.S. District Court ruled, "This case concerns a dispute over \$630. It does not involve a matter of principle. It should not have been litigated in a due process hearing and it should not be the subject of a federal court complaint." The court ordered the parties to mediate the dispute; in mediation the school district finally agreed to provide Craig with the training he needed.

The Disabilities Rights Center represented the Langtons in their case. According to Ron Lospennato, Legal Director, "It's very difficult for parents to provide their own representation. School districts often corner parents in a way that leaves them very little choice – it's either give up their demands of the school district or go through a very expensive process. That can really be hard on parents. This is one instance where the school district's strategy to try to shove them into the ground backfired because we were able to get involved in the case."

For the Langtons, taking on the school district was worth it. In evaluating the Kurzweil program Craig reported that it "works great." He explained, "Before when I was reading stuff it took me probably an hour every ten-fifteen pages, now it takes me 20 minutes."

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Craig Langton with his parents, Debra and Michael

Advocating for Your Child with a Disability

Bonnie Dunham and Charlene Mayo, Training and Information Specialists, Parent Information Center

What is advocacy?

Advocacy is standing up for yourself, for another person, or for a principle. Advocacy can be intensely personal, making a difference for one individual, or it can affect a much larger community. Nearly every positive social change has come about through advocacy.

Who is an advocate?

Anyone can be an advocate – Rosa Parks, Freda Smith, Gandhi, Roberta Gallant, Don Shumway, Susan B. Anthony, Martin Luther King, and YOU!

Parents of children with disabilities, have many roles. They are caretakers, nurturing and supporting their children's development. They are teachers, helping their children to learn and grow. They are experts on disabilities and on their children's needs and interests. And, they are advocates, fighting for what is best for their children.

Why is advocacy important?

Without advocacy federal and state special education laws would never have been passed. Advocacy is the reason children with disabilities have a right to a free and appropriate education and have increased opportunities in the community. Advocacy brought about the closure of the Laconia State School and the development of community-based services.

Becoming a Successful Advocate

Effective advocacy requires knowledge of your rights, good communication skills, and the use of well thought out strategies to support your position. For parents of school-aged children, the Parent Information Center offers the following advice for effectively advocating for your child.

Preparation for meetings

- ◆ Understand the purpose of the meeting and ask who will be there.
- ◆ Gather information; talk with teachers, review your child's schoolwork and records, and talk with your child about his or her school experiences.
- ◆ Write down the points you want to make or questions you want to ask in the meeting.

Participation in meetings

- ◆ Be positive, prepared, and polite.
- ◆ Bring a support person with you.
- ◆ During introductions make a note of participants' names and roles.
- ◆ Don't jump to conclusions, until you know otherwise presume people have positive intentions.
- ◆ Recognize the importance of teamwork; respect the diverse experiences and perspectives of all team members. Together you can accomplish more than any one individual acting alone.

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I can make it read however many words a minute I want." His parents have noticed an increase in their son's independence, and have been amazed at how much his writing has improved.

The Langtons still wonder why the school was so adamant about not helping their son. "After all," Deb observed, "they're supposed to be there to help kids." The Manchester School District spent tens of thousands of dollars on attorney fees. With that money, it could have provided help to hundreds of students.

With improved reading and writing skills, Craig decided to challenge himself and is taking an advanced level physics course. "Without the Kurzweil program, I probably wouldn't have gone for that." Craig used the software in writing his college essays; he has been accepted at the University of New Hampshire where he will major in engineering. Deb Langton has been elected to the Manchester school board, where she plans to make a difference for other children who need special education.

For more information about Kurzweil software, visit their website at <http://www.kurzweiled.com/>.

- ◆ Listen to what each participant has to say.
- ◆ Contribute to the discussion; ask questions and be open to questions from others.
- ◆ Take brief notes and ask for copies of any documents generated by the meeting.
- ◆ Schedule any necessary follow up activities.
- ◆ Remember to thank people.

Follow up after meetings

- ◆ Review your notes and any meeting minutes or paperwork from the school.
- ◆ Ask to have any discrepancies in the paperwork corrected.
- ◆ Follow through with any activities for which you agreed to be responsible.
- ◆ Continue to monitor your child's progress and work with others to support your child's educational experience.

Ongoing work with the school

- ◆ Be an active and engaged member of your child's team.
- ◆ Make an appointment to review your child's file and obtain copies of any documents you do not already have.
- ◆ Don't wait for a crisis. Make an appointment to meet as soon as you have a concern - little problems are always easier to resolve than big ones.
- ◆ Create a homework diary and record the amount of time your child spends on homework, any difficulties, and the amount of parental support needed.

- ◆ When raising an issue follow the chain of command; don't make the superintendent of schools your first contact.
- ◆ Do everything in writing; if you have a telephone or in-person conversation, follow up with a letter to ensure there is no misunderstanding and to document the date of your request.
- ◆ Keep copies of everything.
- ◆ Keep track of services required in your child's Individual Education Plan (IEP) and write letters when you have concerns. Be specific; identify IEP services or modifications not provided, class work or homework not modified as required, and unmet timelines.
- ◆ If you do not receive a response to your request, ask for a meeting to review or revise the IEP.
- ◆ Have a Plan B or even a Plan C in case the first thing you try doesn't work.
- ◆ Trust your instincts.

By learning to be effective advocates, parents not only help ensure that their children receive the education and services they need, they also serve as powerful role models helping their sons and daughters learn to advocate for themselves. For more information on advocacy and free training opportunities contact the Parent Information Center at 800-947-7005.

Whose Meeting is This Anyway?

Richard Learned, Mental Health Self-Advocate and Todd Ringelstein, MSW, Administrator for Older Adult Mental Health Services, Bureau of Behavioral Health

Self-advocates are uniquely qualified to provide governmental agencies and service providers with valuable information and feedback. We offer the following recommendations to successfully support and include self-advocates as members of Advisory Councils or Boards of Directors.

- ✓ Create a Shared Vision – Include self-advocates in developing a shared sense of the Council or Board's purpose and mission.

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- ✓ **Build a Structure that Works** – Advisory bodies need an organizational structure that supports the recruitment and retention of their members. New members need adequate orientation and mentorship. Set a consistent time for meetings, send out agendas and minutes in advance, and contact members by telephone or mail to remind them of meeting dates. (Email is generally not the best way to communicate with older adults.)
- ✓ **Make Accommodations** – Schedule meetings at a time that is most convenient for the group in a location that is accessible. Provide a meal or refreshments, offer mileage reimbursements and if possible, a stipend for Council or Board members who are not supported by an agency.
- ✓ **Support Meaningful Participation** – Everyone's opinions are needed and important; provide adequate opportunities for self-advocates to share ideas and information. Acknowledge the contributions that each member brings to the group and let members know that their participation makes a difference.
- ✓ **Make Connections** – Set up opportunities for self-advocates to meet with elected representatives, Department and agency heads, and others who have decision making power.
- ✓ **Evaluate Your Efforts** – Periodically reflect on what works and what does not. Ask, "Why do some people participate and why do others drop out?" Develop a strategic plan to address issues and track its implementation. Hold an annual retreat to reflect on accomplishments and set new goals.

This information was originally presented to the Mental Health and Aging Consumer Advisory Council for the Bureau of Behavioral Health in a workshop on enhancing self-advocate participation.

Sticking Up For People's Rights

Diane Carignan, Co-chair, People First of NH

I've been a member of People First for five years. People First is a self-advocacy group. Tony Thibodeau and I are the co-chairs of the state group. I'm one of the oldest members of People First, besides Amber Parshley. Amber is the secretary, Tony is the co-chair, and I'm the co-chair and treasurer.

People First works to change laws. We have activities and go on trips. We're going to Atlanta, Georgia for the Self Advocates Becoming Empowered conference on civil rights. We'll learn about civil rights and then come back and share it with the group.

Last month we met with Jeanne Cusson from the Bureau of Developmental Service. She told us about changes to He-M 503 (rules for developmental services). We talked about the parts that we don't like in 503. We don't like the word "retardation." We asked if they could change that. She said that she'd work on it. The Concord group of People First is working with Dick Cohen from the Disabilities Rights Center on changing it.

We told her that we didn't like the ISPs (Individual Service Plans) that they have. Pretty much everybody thought we should get rid of the ISPs. They suck. You have to do it every year; it's just a nuisance to life. You have to sit through a meeting for an hour and a half for what? Nothing good comes of it. The others feel the same way. I told Jeanne we shouldn't have it at all. Jeanne said we need them for accountability. I think that's stupid.



Diane Carignan, Co-Chair and Treasurer of People First of NH

I think advocacy means to stick up for people's rights and help people advocate for themselves. I do a good job at that, believe me.

A long time ago I had a problem with The Moore Center. I was getting services in Region 4 (the Concord area), but then I moved to Manchester and the Moore Center said I wasn't eligible. I filed an appeal. I helped change the law. The change was to He-M 503.05. Now it says, "The determination of eligibility by one area agency shall be accepted by every other area agency of the state."

Here's something else I did for myself. I moved out of my last apartment. It didn't have any heat and they wouldn't give me heat. That's not why I moved. I moved because the rent was going way up. I told them I wasn't going to pay for it. Then I got this apartment, and now here I am a year and a half later. I like this one a lot better. They never did anything at my old apartment. They'd make me wait before they'd fix things.

Here's another way I stood up for myself. I go to a dentist in Lebanon, and they would ask my mom all the questions. I'm like, "Hey I'm here, why can't I answer the questions?" We want to talk for ourselves, not have anybody else speak for us.

Here is something else that People First is doing. Rich Crocker (the director of the area agency serving the Lakes Region) is leaving. I asked if People First could give Rich's going away party because we wanted to do something. They were going to do it around the same time, so People First will be a co-host.

What I like about People First is meeting new people and going to the meetings and learning new things. Sometimes there's personal stuff that has to be worked out in the group. I don't like the arguing. If we disagree, we talk about it. We work it out.

If you want to know about People First, you can go to our website: <http://www.peoplefirstofnh.org/>

Advocacy Has No Age Limits

Linda B. Bimbo, MS, Institute on Disability

"It really doesn't matter how old you are. If something needs to get done you get out there and do it!" advised Janet Stiles of Manchester. Janet, a long-time member of the State Mental Health and Aging Consumer Advisory Council, has been a leader in advocacy efforts for persons with mental illness – especially those who are considered "older adults."

Janet began her advocacy "career" in the 60's as a founding board member of the Mental Health Center of Greater Manchester (MHCGM). Janet, who has recovered from schizophrenia and depression, has worked with other advocates to fight for recovery-based services. In 1989 she led the effort to establish A Way To Better Living, a peer support organization in Manchester. In 2004, MHCGM presented Janet with the Wheelock-Nardi Advocacy Award, in recognition of her contributions.

In 1998 Janet along with three other New Hampshire representatives attended the first National Mental Health and Aging Advocacy Consumer Forum in Washington, DC. The conference provided the catalyst for establishing a state advisory council dedicated to the needs of older adults with mental illness. Upon returning to New Hampshire, the group met with the Bureau of Behavioral Health, Office of Consumer Affairs and convinced them to create the Mental Health and Aging Consumer Advisory Council. These four advocates became the founding members of the Council. Current Council membership includes consumers, family members of older adults who have mental illness, and mental health professionals. Today the Council has more than 70 members and continues to grow.

The purpose of the Council is to help the state's Bureau of Behavioral Health better understand and meet the mental health needs of New Hampshire's older citizens and their families. "They are well informed, outspoken and make their needs and opinions known," remarked Todd Ringelstein, Administrator for Older Adult Mental Health Services at the Bureau of Behavioral Health. The group meets monthly to exchange information, study the issues and develop recommendations for change. They are advocates in action – for themselves and others.

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At their annual retreat Council members come together to celebrate accomplishments and identify goals for the coming year. Council priorities have included transportation, housing, use of restraints, and faith-based education. The Council has become an effective partner in helping New Hampshire identify and meet the needs of older citizens with mental illness. The Council has submitted letters of support for federal grant proposals and participated in the Mental Health Block Grant review process.

Council members have presented at the state's annual Aging Conference and the Real Choice Best Practice Conference. Its members also work collaboratively with the New Hampshire chapter of the AARP, the Older Adult Consumer Mental Health Alliance, and National Alliance for the Mentally Ill-NH to address issues of common concern.

For more information on this active group please contact Todd Ringelstein, Administrator for Older Adult Mental Health Services, Bureau of Behavioral Health. (603) 271-5094.



Creating Critical Mass by Thinking Beyond Disability

Carol Stamatakis, JD, Director of Planning, NH Developmental Disabilities Council

Many people with disabilities and families become advocates to influence public policies that have a direct impact on their lives. However, people with disabilities do not live in isolation from the forces that shape the quality of life and economic opportunities within the larger community. In seeking employment, housing, education, and transportation people with disabilities encounter barriers that reflect societal issues of discrimination and poverty. Many disability activists are beginning to expand their vision and join with others who are fighting for economic and social justice.

Twenty-five years ago a small group of activists created an organization that became New Hampshire Citizens' Alliance (NHCA). To carry out its mission of "social, economic, and political justice for all," NHCA builds citizen power through voting, activism, and leadership training. The Alliance has fought for civil rights, health care, education, fair taxation, voting rights, campaign finance reform, and environmental quality. Their work has contributed significantly to advancements in public policy and resulted in thousands of disenfranchised citizens registering to vote. With a commitment to collaboration, NHCA has developed long-lasting relationships with allied groups and organizations, increasing their ability to respond to emerging issues.

Sam Mekrut, NHCA Executive Director, discussed the importance of finding common ground with other advocates. She explained that focusing exclusively on single issues "won't ever work in the long run. A worldview approach requires looking at power and what it takes to win the kind of public policy issues we want to win. Issues are discussed from a place of values, what connects all of us. It is a shift in perspective. People come in from a place of self-interest, but when we talk about all the work we do in terms of a common thread, people and groups with shared values can have a more common agenda focused on quality of life." This approach avoids framing issues in terms of "people versus trees," as has happened in budget debates in the past, often to the detriment of both.

"You must draw in other organizations and people to have the critical mass to move your issue forward," said Chris Collier, the father of a son with a disability. He talked about his own growth as an advocate.

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DENISE BREWITT NAMED EXECUTIVE DIRECTOR OF THE NH COUNCIL FOR CHILDREN AND ADOLESCENTS WITH CHRONIC HEALTH CONDITIONS

Denise Brewitt has been named Executive Director of the New Hampshire Council for Children and Adolescents with Chronic Health Conditions (CCACHC). An educator with more than ten years of experience, Brewitt will oversee the operation of the state-wide advocacy and education organization.

"I'm excited to have this opportunity to support young people with chronic illnesses and their families," said Brewitt. "By working closely with the State Legislature and educating the public, the Council can do much to improve the lives of the 42,000 children in New Hampshire with chronic illnesses."

Prior to joining CCACHC, Brewitt served as a community relations representative for the Children's Hospital Boston Trust and the Dana Farber Cancer Institute. She lives in Raymond with her husband and three children.

CCACHC was created by the New Hampshire Legislature to advise state healthcare agencies and the legislature on issues impacting children and adolescents with chronic health conditions. In addition to serving as an advisory and educational organization, the Council also manages a loan program designed to help families of children with chronic illnesses meet extraordinary expenses. The Council can be found on the Internet at www.ccachc.org.



INSTITUTE ON DISABILITY'S SUMMER INSTITUTES

The 3rd Annual Summer LiterAACy Institute will provide participants with assessment and teaching strategies to assist students with the most significant disabilities across the curriculum in their general education classrooms.

Stephanie A. Spadorcia, Ph.D. will lead this Institute. Dr. Spadorcia is an Associate Professor of Language and Literacy at Lesley University in Cambridge, Massachusetts and a researcher with the Center for Literacy and Disability Studies at the University of North Carolina at Chapel Hill. She teaches courses in reading and writing assessment, methodologies in literacy instruction kindergarten through high school, instructional strategies for struggling readers and writers, and literacy for children with developmental disabilities. Her research focuses on developing strategies to teach older students who are struggling with reading and writing. In literacy instruction, she promotes the use of technology, including assistive technology and coordination with augmentative and alternative communication.

The Summer LiterAACy Institute will take place on Tuesday and Thursday evenings from 5:00 to 8:00 in Pettee Hall at UNH in Durham. There will be a wrap-up session on Saturday June 27th from 8:30 - 4:00. The registration fee is \$650 and UNH credits are available. For more information, please contact the IOD at (603) 228-2084 or visit our website at www.iod.unh.edu.

The 8th Annual Autism Summer Institute focuses on creating solutions to include children with autism in general education classrooms. Participants will hear directly from individuals with ASD about the realities of living with autism. There also will be an opportunity to engage in interactive workshops and break out groups. Presenters at the 2006 Institute include four renowned authorities in the field of Autism Spectrum Disorders: author Steven Shore Ph.D., Vermont artist Larry Bissonnette; Ros Blackburn, an international speaker on ASD from England; and Chris Kliwer, Ph.D. from the University of Northern Iowa.

The Autism Summer Institute will be held on August 14, 15, and 16 in Holloway Commons at UNH in Durham. The registration fee is \$390 and UNH credits are available. For more information, please contact the IOD at (603) 228-2084 or visit our website at www.iod.unh.edu.

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"At first, it's about going to the school to make things better for my son. Then it broadens to education generally, to creating better schools for all kids. The next step is the town, then the tax structure. Pretty soon, I start making connections."

For Mr. Collier, now an organizer for Citizen's Alliance, this change in perspective has meant expanding his vision, not giving up disability advocacy. He has helped facilitate connections between disability advocates and environmentalists who both have interests in issues such as mercury exposure. "Part of the process is bringing your values to other areas. Come prepared to be as much a teacher as a student as you step out and make connections. By making a connection with activists outside the disabilities arena, you can bring an understanding of disabilities issues to their table."

Those in the disability movement learn to be advocates out of necessity, and it becomes a way of life. To affect real and lasting change, disability advocates must bring their passion and talents to the larger fight for social and economic justice. "It is easier to say what you don't want than what you do," observed Mr. Collier. "What kind of world do we want? Self-interest alone will not get us there."

Advocacy and Self Advocacy Resources

There are many organizations that provide advocacy or support for self-advocacy: any place that has information about your rights and how to advocate for yourself or others could be considered an advocacy resource. While there are too many to list them all here, the following organizations specialize in advocacy.

Autism Society of New Hampshire

PO Box 68, Concord, NH 03301
603-679-2424
Email: info@nhautism.com
Web: <http://www.autism-society-nh.org/>
Parent organization providing education, awareness, and advocacy

Brain Injury Association of NH

109 North State Street, Suite 2
Concord, NH 03301-4464
603-332-9891 Email: Ellenedge@metrocast.net
Web: <http://www.bianh.org/legis.htm>
To create a better future through brain injury prevention, education, advocacy and support.

NAMI New Hampshire

15 Green St., Concord, NH 03301
603-225-5359 or 1-800-242-6264
Email: info@www.naminh.org
Web: <http://www.naminh.org>
New Hampshire's voice on mental illness

National Federation of the Blind-NH

<http://www.nfb.org/>
NH contact: Bruce Gillis, State President
603-524-1945
bkgillis@localnet.com
Voice of the nation's blind

NH-ADAPT

New Hampshire contact: Tom Cagle
603-428-7652 or 603-428-7022
Email: nhadapt@conknet.com
Web: <http://www.geocities.com/CapitolHill/6482/>
Advocating so people with disabilities can live in the community with real supports instead of being locked away in nursing homes and other institutions

New Hampshire Chapter, National Spinal Cord Injury Association

P.O. Box 197, N. Salem, NH 03073
603-479-0560 Email: info@nhspinal.org
Web: http://www.nhspinal.org/about_us.html
Support, education, awareness, and advocacy for individuals with spinal cord injury

Advocacy and Self Advocacy Resources, Continued

New Hampshire Citizens Alliance

4 Park Street, Suite 403
Concord, NH 03301
603-225-2097
Email: nhca@nhcitizensalliance.org
Web: <http://www.nhcitizensalliance.org/>
Social, economic, and political justice for all

New Hampshire Family Voices

29 Hazen Drive
Concord, NH 03301
1-800-852-3345 x4525 or 603-271-4525
Email: NHFV@yahoo.com
Web: <http://www.nhfv.org/>
Families and friends speaking on behalf of children with special health care needs

New Hampshire Leadership Series

Beth Dixon
UNH Institute on Disability
The Concord Center, 10 Ferry Street
Concord, NH 03301
603-228-2084 voice Email: badixon@unh.edu
Leadership training for adults with disabilities and parents of children/adults with developmental disabilities. This is a seven-month series (two days a month) designed to help people create positive change through advocacy.

Parent Information Center

P.O. Box 2045, Concord, NH 03301
603-224-7005 800-947-7005
Email: picinfo@parentinformationcenter.org
Web: www.parentinformationcenter.org
Information, support, and educational programs for parents, family members, educators, and the community

Parent to Parent of New Hampshire

12 Flynn Street
Lebanon, NH 03766

1-800-698-LINK

Email: p2p@nhsupport.net
Web: <http://www.parenttoparentnh.org/>
Resources for parents of children with special needs

People First of New Hampshire

4 Park Street, Suite # 201
Concord, NH 03301
1-800-566-2128 or 603-568-2128
Email: peoplefirstnh@verizon.net
Web: <http://www.peoplefirstofnh.org/>
A statewide self-advocacy group

SHHH (Self Help for Hard of Hearing People) – New Hampshire

1-800-826-3700 (ask for Liz)
E-Mail: CliffCleary@att.net
Web: http://www.members.tripod.com/shhh_nh/
National Office:
7910 Woodmont Avenue, Suite 1200
Bethesda, Maryland 20814
Self-help for hard of hearing people

National Mental Health Consumers' Self-Help Clearinghouse

1211 Chestnut Street, Suite 1207
Philadelphia, PA 19107
Phone: 800-553-4539 or 215-751-1810
E-mail: info@mhsselfhelp.org
Web: <http://www.mhsselfhelp.org/training.php>
This national consumer technical assistance center has an online Freedom Self-Advocacy Curriculum

SABE - Self Advocates Becoming Empowered

Web: <http://www.sabeusa.org/>
People First is the New Hampshire Chapter for SABE

The RAP Sheet is published quarterly and free to subscribers. If you would like to be on the mailing list or to receive copies of back issues of the RAP Sheet please contact Judy Boynton at the Developmental Disabilities Council toll free, 1-800-834-1721 or by email jboynton@dhhs.state.nh.us

DISABILITIES RIGHTS CENTER, INC.

18 Low Avenue, Concord, NH 03301-4971

Voice and TTY: (603) 228-0432 ♦ 1-800-834-1721 ♦ FAX: (603) 225-2077

TTY access also through NH Relay Service: 1-800-735-2964 (Voice and TTY)

E-mail: advocacy@drcnh.org ♦ Website: 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

10 West Edge Drive, Suite 101, Durham, NH 03824-3522

Voice and TTY: (603) 862-4320 ♦ Fax: (603) 862-0555 ♦ Website: www.iod.unh.edu

Institute on Disability/UNH – Concord

Concord Center, 10 Ferry Street, Unit 14

Concord, NH 03301

Voice and TTY: (603) 228-2084

Institute on Disability/UNH – Manchester

250 Commercial Street, Suite 4107

Manchester, NH 03101

Phone: (603) 628-7681

The Institute on Disability advances policies and systems changes, promising practices, education and research that strengthen communities and ensure full access, equal opportunities, and participation for all persons.

NH DEVELOPMENTAL DISABILITIES COUNCIL

21 South Fruit Street, Suite 22, Room 290

Concord, NH 03301-2451

Phone: (603) 271-3236 ♦ TTY/TDD: 1-800-735-2964 ♦ Website: www.nhddc.com

Dignity, full rights of citizenship, equal opportunity, and full participation for all New Hampshire citizens with developmental disabilities.

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NH DEVELOPMENTAL DISABILITIES COUNCIL

21 South Fruit Street, Suite 22, Room 290

Concord, NH 03301-2451

RETURN SERVICE REQUESTED

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