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

Winter Issue 2005

MENTAL HEALTH CARE IN THE GRANITE STATE

Welcome

to the Winter Issue of the Rap Sheet. This issue explores the changing face of mental health treatment. Evidence-based interventions, peer support, mentorship, and advances in medications have made an enormous difference in the quality and effectiveness of treatment for mental illness. We hope you will find this issue both informative and thought provoking. We are especially grateful to those who have so generously shared their personal stories.

Susan Covert, Editor

Medicaid Modernization and Mental Health Services

Amy Messer, Esq. Disabilities Rights Center

The Department of Health and Human Services has begun the process of unveiling its long anticipated "Medicaid Modernization" initiative, dubbed "GraniteCare." While Health and Human Services Commissioner John Stephen advised that GraniteCare is still in the development phase, it is critical that legislators, mental health consumers, advocates, and the general public carefully consider whether the changes being proposed are in New Hampshire's best interest.

The State's mental health system, including all community mental health centers serving both children and adults, is funded primarily with federal Medicaid dollars. The Department's proposed changes to Medicaid have the potential to undermine this federal funding stream and jeopardize the State's safety net for those relying on mental health services.

Families, advocates, and policy experts all have raised serious concerns about the State's intention to place certain Medicaid services within an 1115(c) waiver. Such a waiver includes a cap on federal dollars, placing the State at risk of being fully financially responsible for higher than anticipated costs of the Medicaid program. This cap on federal funding may also result in both dramatic cuts in needed services and cost shifting to counties, towns, and healthcare providers.

Many within the mental health community have raised particular concerns about GraniteCare's proposed "Single Point of Entry." This proposal calls for a single office to determine eligibility, budgets, and service needs for all Medicaid-eligible individuals, including the elderly, as well as individuals with mental illness and developmental disabilities. It is difficult to conceive that a single office will be able to adequately understand and address the complex healthcare needs of these very diverse groups.

Those with mental health needs have reason to be concerned and skeptical about changes proposed by the Department. Within the past year, the Department has pulled funding for NAMI NH (National Association for the Mentally Ill), taken steps to place an arbitrary monetary cap on services for certain mental health consumers, reduced case management services, and closed peer support centers.

Individuals, legislators, and advocates are urged to stay informed and have their voices heard as the Department of Health and Human Services moves forward on any changes to the State's Medicaid Program.

For more information on "GraniteCare", please visit the Disabilities Rights Center's website at http://www.drcnh.org.

A collaborativeeffor t bythe Disabilities Rights Center, Instituteon Disability, and NH Developmental Disability Council

Evidence-based Practices in Mental Health Care

Paul G. Gorman Ed.D., Director of the West Institute at the NH-Dartmouth Psychiatric Research Center
Robert Drake M.D., Professor of Psychiatry at Dartmouth College, Director of the NH-Dartmouth Psychiatric Research Center

There is a significant gap between the time that a clinical practice demonstrates successful consumer outcomes and the time that such a practice is routinely offered in community settings. The National Evidenced-Based Practice Project seeks to close that time gap and make these clinical interventions available as quickly as possible.

The term "evidence-based medicine" refers to a process of combining scientific evidence, clinician expertise, and consumer preferences in clinical decision-making. Scientific evidence should be available to practitioners and consumers so that they understand the realistic outcomes and side effects associated with tests and interventions. Clinicians need to know how to share complicated medical and statistical information with their consumers and to adjust the information for each person and setting. Consumers are the best experts on their own preferences for risks, interventions, and health outcomes. All three of these components - scientific evidence, clinician experience, and consumer preference - are necessary for the best health care decisions.

Mental health administrators, clinicians, advocates, and researchers generally agree that society has an ethical obligation to make the most effective treatments available to users of the mental health system. The key question has been how to implement evidence-based practices. Research shows that routine mental health programs throughout the country are generally deficient in providing the most effective treatments and that it is indeed hard to change health care systems. Changing complex programs requires much more extensive interventions than is usually done by education or training. Among the strategies involved are: enhancing motivation, providing adequate resources, increasing skill development, and removing established organizational operations that may be constraints to change.

The National Evidence-Based Practices Project, which is directed by the New Hampshire-Dartmouth Psychiatric Research Center, attempts to meet the challenge of implementing effective mental health practices in routine settings in diverse states. This project includes three phases.

Phase 1 involved the development of structured resources, termed resource kits, for consultation, training, and implementation of the initial six evidence-based practices described below.

EVIDENCE-BASED PRACTICES

wILLNESS MANAGEMENT AND RECOVERY: a cluster of interventions including cognitive behavioral therapy, psychoeducation, and other interventions which can be used by the consumer to achieve his or her recovery goals.

wFAMILY PSYCHOEDUCATION: an intervention that is a partnership between consumers, families and supporters, and practitioners that emphasizes education about the illness and problem solving around the issues that mental illness presents to families.

w MEDICATION MANAGEMENT: the focus of this intervention is to develop with the consumer a shared decision making process in which the clinician works with the consumer to assure his or her understanding of the medication regime being recommended as well as a careful examination of all the alternatives.

w SUPPORTED EMPLOYMENT: this intervention supports the consumer in securing a job of his or her choice in the competitive work market. This includes a commitment on the part of the employment specialist to make available whatever supports are necessary to help individuals achieve their vocational goals. A distinctive element of supported employment is the rapid job search and placement bypassing much of the job preparation that characterized former models to get people with mental illness to work.

wASSERTIVE COMMUNITY TREATMENT (ACT):is an intervention with people who are transitioning from the hospital to the community or who are at high risk of hospitalization, homelessness, or incarceration. ACT involves intense clinical staff activity including assertive outreach with the consumer to achieve successful integration in the community

w INTEGRATED DUAL DISORDERS TREATMENT: A significant number of people with mental illness struggle with substance abuse. In this intervention the individual receives treatment that follows a step-by-step process in an integrated setting in which both the issue of mental illness and the substance abuse are treated simultaneously.

The resource kits include materials for evidence-based practices were specifically designed for, co-authored by, and reviewed by, five stakeholder groups: users of mental health services, their families, practitioners, mental health program leaders, and mental health policy makers. The kits currently are being revised based upon feedback from stakeholders around the country. The toolkits are intended for use in conjunction with a trainer/consultant who is knowledgeable about the practice and experienced in providing effective training and sustained consultation in a routine mental health setting.

Phase 2, which is also currently underway, entails an extensive field trial of the resource kits in eight states, including New Hampshire. This significant data gathering process will provide information that will be used both to revise the kits themselves as well as add to the mental health field's information about how to disseminate and implement practice change successfully.

Phase 3 involves a national effort to develop additional resource kits, that may include among others, peer supports and supported housing, and to implement the current evidence-based practices in each of the 50 states. Various components of Phase 3 are also underway.

As effective interventions are developed rapidly in mental health as well as the rest of medicine, it becomes increasingly important that we involve consumers and families in a process of shared decision making and have in place systems that are able to make use of these new science-based programs. New Hampshire is an active participant in this process.

RECOVERING

Recovery started with acceptance but didn't end there

Caroline Bacon

This morning I woke up at 6:30 a.m. and ate breakfast as I do every day. This morning I registered for a class at a local school. For a long time I wasn't able to do these simple everyday things.

For ten years I have been "sick." A year after I graduated from college I experienced my first bout of psychotic thinking and severe depression. I was living in Ohio when I became ill and my mother asked me to, "Please come home. You can no longer afford to stay there, and I cannot take care of you from such a long distance."

I returned to New Hampshire for the summer, but by the fall I'd left for Virginia, where my aunt lives. In Virginia I had horrible stomachaches, trouble getting out of bed, and I stopped eating. I ran around trying to find a job. I became more and more paranoid and depressed, and thought people were chasing me. I was anxious for my safety and afraid of the world I was being pushed into.

I was not taking the medication my doctor in Ohio had prescribed; it was too expensive and I wasn't convinced that I needed it. I went to a mental health center and within a week was transferred to the state hospital in Williamsburg. In the hospital all I wanted to do was sleep, but right after breakfast the staff locked the bedroom doors. I spent my days curled up in a chair in the common room trying to ignore my life. I was getting messages from the television and from the woman who constantly read the Bible out loud. When my mother came to bring me back to New Hampshire, I checked her for hidden microphones. I wanted an explanation.

It took four years and "visits" to five hospitals in three states to find a combination of medicines that worked for me. At one point my mother was so frightened by my behavior that the police were called. With my adrenaline sky high it took five male officers to physically subdue me and put me in an ambulance to New Hampshire Hospital. If my mother had not been there to tell the police that I have a mental illness and that I wasn't on illegal drugs and wasn't normally violent, I probably would have been taken to jail.

At New Hampshire Hospital I was introduced to Riverbend Community Mental Health Center and Medicaid and Medicare. A first step in my recovery was finding a safe place to live. In 1999 I moved to a HUD subsidized apartment in a building with other tenants who have mental illnesses. There was a certain comfort in that. I didn't have to explain why I slept 16 hours a day, why I was having a hard time with personal hygiene, or why I had constant nightmares. I didn't have to explain why I didn't trust anyone.

As I have learned more about my illness, I am more at ease and more accepting of my situation. I joined Riverbend's Speaker's Bureau and have met others with similar problems. I am no longer "in the closet" about my illness. Telling my story has helped me sift through my feelings and diminished my need to place blame for my illness.

Today I run a small cabinetmaking and stained glass business, which I started last year with a friend who also has a mental illness. I have a good relationship with my family; they are very supportive and understanding of my situation. Today, I don't care if I have to take medication for the rest of my life. My mental illness is no longer as all encompassing as it once was.

Caroline Bacon is one of twenty people recovering from severe mental illness who tell their recovery stories to groups of all kinds through NAMI NH's In Our Own Voice program. To arrange a presentation for your church, business, civic group, or school contact Ken Braiterman, In Our Own Voice coordinator, at 225-5359 or email Kbraiterman@naminh.org.

Meghan's Story: The Power of Wraparound Support

Gail M. Cormier, Executive Director of the Alliance for Community Supports and Scott Hunter

A longer version of this article first appeared in 2001 Illinois Family Wrap Professional Magazine EBD Family Network

Meghan's life had been in turmoil for most of her childhood. She grew up in a low-income household with a mother who has significant mental health issues. Meghan reflected on growing up, "My mom used to be real nice to me after a crisis in my home. She would ask me if I wanted to dress up in mommy's make up (to cover the bruises) and let me stay out of school a couple of days to make it up to me. One time, she chopped off my hair because I didn't clean the house."

As Meghan grew older, her own mental health issues surfaced. In addition to special education for her severe learning disabilities, by the time she was ten Meghan was receiving mental health services. In June of 1997 she began working with Project RENEW, a program established to provide comprehensive career and education services to youth transitioning from high school to work. The project utilizes several key strategies including personal future planning, flexible education services, mentoring, and wraparound support.

When Project RENEW staff first met Meghan, they found a quiet, withdrawn young woman. Meghan remembered, "I just wouldn't say anything because I was afraid I would get in trouble. Besides my mother always spoke for me anyway. It was like I was a person with thoughts, but no way to get them out." With support from Project Renew, Meghan began planning for her future. She set goals for herself; she wanted to finish high school, work in a laundry or daycare, and live independently of her mother.

On the eve of her 18th birthday, with support from her wraparound team, Meghan moved out of her mother's home. While Meghan considered the meetings around this move to be her first "wraparound", in actuality the members of her team had been communicating and working on Meghan's behalf for quite some time. Wraparound is an evolving, living process; each team is a unique entity whose work is guided by the creativity and energy of its members. Wraparound requires vigilance and constant nurturing by team members to be effective.

After three years of vigilant efforts to keep Meghan in school and help her to cope with multiple family and mental health issues, the wraparound team nearly lost her to the world of drugs and prostitution. Meghan had moved from her mother's home to live with friends and was attending an alternative high school. At school Meghan's behavior deteriorated to the point the school felt that they could no longer serve her. Her personal life was in crisis. She was exploited and controlled

Project RENEW is a statewide program of the Alliance For Community Supports. Its mission is to assist youth to achieve success in their personal lives. Career and Educational Specialists incorporate the values of self-determination, natural supports and mentoring into their daily work, while supporting progress toward goals identified in an individual's personal futures plan. The program embraces the wrap-around process and facilitates teams to create effective solutions for youth. Project RENEW has been recognized for its best practices by the National and Federal Alliance for the Education and Treatment of Children and the National Transition Alliance For Youth With Disabilities, with 90% of participants attaining employment, 80% completing high school, and 70% reducing their involvement with law enforcement. For more information on Project RENEW, please visit their website at www.allianceforcommunitysupports.com or call (603) 628-7681.

by her friends who took her money, introduced her to drugs and alcohol, and got her involved in prostitution. Meghan finally realized that she could not survive in her current living situation, but did not know where to turn.

Fortunately, Meghan's wraparound team was there to help. Her team included: RENEW staff, a mental health counselor, a school district case manager, school counselor, vocational rehabilitation counselor, and most importantly, a mentor (a former MSW student who had interned with RENEW). During this crisis RENEW acted as the central point of communication, receiving and delivering information to team members on a daily basis. The team's search for a safe living situation ended when Meghan's mentor invited Meghan to move in with her family while she completed high school. In the weeks that followed all team members contributed to helping Meghan make a successful transition. The mental health center offered additional clinical support to Meghan, as well as support to her host family, the school worked closely with Meghan, and RENEW used flex funds (flexible dollars used to support project participants) to help Meghan decorate her room and make it her own living space.

With her team's support and guidance and stability from her host family Meghan made it through her final school year. Members of her wraparound team were all in the school gymnasium the evening Meghan graduated. Meghan attributes her wraparound team with her ability to earn her high school diploma and to leave two unhealthy living situations. "I told them what I wanted and they used their individual authority to do what I could not do."

In April 2002 Meghan spoke about her education and the power of wraparound support at the national Emotional Behavioral Supports Education Conference in Chicago. Today Meghan lives in her own apartment in Manchester and is working 30 hours a week as a day care assistant. She is engaged and hopes to have a family.

Mentorship Inc , is a private non-profit agency that provides mentors to persons who want to learn to make better decisions and avoid the problems associated with poor judgment. This voluntary program is available to individuals with developmental disabilities, mental illness, learning disabilities, or other cognitive difficulties who specifically ask for a mentor's help. Once an individual has a mentor, the two stay in touch by telephone and come together once a month to discuss any problems. The mentor does not tell the individual what to do or how to think, but instead helps the person to appreciate all the options and possible consequences of each option. Mentors are reimbursed for expenses. Anyone interested in being a mentor or in having a mentor should call Robin Daning, Executive Director, Mentorship Inc. at (603)-226-4470.

With a Little Help From My Friends - The Role of Peer Support in Recovery

Shery Mead

Peer support is a critical link in the development of recovery-oriented services. As reported in the 2003 President's Freedom Commission Report:

Consumers who work as providers help expand the range and availability of services and supports that professionals offer. Studies show that consumer–run services and consumer-providers can broaden access to peer support, engage more individuals in traditional mental health services, and serve as a resource in the recovery of people with a psychiatric diagnosis.

Ways peer support services make a positive difference.

1. Many people with mental illnesses have become dependent upon professionals as their sole support system and have forgotten what it means to have meaningful reciprocal relationships. Peers can offer authentic empathy while also challenging each other to try new things. Mutual relationships help people re-learn what it means to be contributing members of their communities.

2. Peers can teach and model a range of self-help techniques that offer practical, non-medical responses to difficult situations.

3. Peers can be available to each other during times when professional offices are closed.

4. Peer support confronts the "learned helplessness" that causes many people with mental illnesses to feel unmotivated and hopeless. People who share similar experiences can help one another see where they might be getting stuck and together practice advocating for what they want and need.

5. Though the Olmstead Act prohibits hospitalization for people who are capable of living in less restrictive settings, many individuals still find themselves hospitalized for longer than necessary. Peer support services can be an effective component of programs that offer cost effective transitional housing and crisis intervention.

6. It is not unusual for people to over-identify with their illness. Many people may view their feelings as symptomatic of their illness, losing sight of the fact that everyone experiences emotional discomfort at one time or another. Peers can help each other explore new ways of making sense of their experiences while also offering successful coping strategies.

7. Typically, an individual who is newly diagnosed with a mental illness feels overwhelmed and alone. "Wow, I thought I was the only one!" is a frequent comment in peer support groups. For someone coping with mental illness it is comforting to be around others who "get it" and who are nonjudgmental. The sense of affiliation fostered in support groups helps people to feel valued and more self-confident.

8. Peer support programs play a valuable role in communities helping to break down the stigma and reduce the discrimination often associated with mental illness.

As a vital part of effective mental health treatment, peer supports encourage people to see themselves in terms of their strengths rather than their deficits. New Hampshire currently has 16 peer support centers providing a wide array of services including: telephone support; support groups; education in recovery; crisis prevention and intervention; assistance in finding housing, education, and jobs; education about substance abuse; and benefits counseling and other help with public assistance. For many individuals peer support services are critical to maintaining health and living safely in their communities. With adequate financial support these programs will continue to play a significant role in the promotion of mental health and the prevention of mental illness for all New Hampshire citizens.

For more information on peer support and peer-run crisis alternatives visit Shery Mead's website at http://www.mentalhealthpeers.com/index.html.

Peer Support In Action: Alternative Life Center is a Major Factor in Recovery

Julia Freeman-Woolpert, Disabilities Rights Center

For the past four years Janine Lapete has worked at the Alternative Life Center (ALC); she is also a member of the Center. It's the first job Janine has been able to hold since her breakdown, fourteen years ago. Though she tried many times to go back to work, it was her involvement with ALC, a peer support center in Conway, that finally gave Janine the confidence she needed.

Janine also credited peer support with keeping her out of the hospital, "Before that, I was a frequent flier." She knows many other people who have been hospitalized less frequently, or been able to stay out of the hospital altogether, due to peer supports. Two years ago Janine had a crisis that formerly would have landed her back at New Hampshire Hospital, but instead she received respite from Granite State Monarchs a peer support program in Keene. For four days Janine received round the clock support. Since she was struggling with trauma issues, all of her supporters were women. Janine talked about the "gifts" she received from these peers including help with her sobriety, and learning how to practice calming breathing techniques and visualizations. She emerged from her stay feeling understood rather than judged, and was able to go on with her life. The cost of Janine's respite care was a fraction of what a hospital stay would have been.

Pat Tal, ALC's Executive Director, pointed out that peer support centers could offer other substantial savings. Mental Illness Management Services (MIMS), currently billed at $104.00 per hour, include such supports as assistance with grocery shopping, bill paying, social interaction, and other help that enable people to stay in the community and avoid hospitalization. Many of these services could be provided by peer support at a significantly lower price.

Bonnie Campbell, a member and volunteer, said without peer support she would be isolated at home. Instead, she leads a busy life that includes volunteering with a variety of ALC projects. "Everybody understands your problems. There's a lot going on. You tend to get involved. There are tons of trips, wonderful trips." The Center also offers workshops on depression and recovery, and brings in guest speakers on a wide array of subjects.

Personal responsibility and respect are the underpinnings of peer support. While there are rules (no violence, no profanity), the atmosphere in peer support centers is nonjudgmental. People feel like they are treated as an individual rather than a "case." Janine noted that ALC provides certain therapies, "like a hug," that you can't get at a mental health center. ALC members reach out to people who are home alone, calling them and encouraging them to come in and get involved. The Center is open on all holidays, times when people tend to be most stressed and lonely.

There are peer support centers across New Hampshire to find the one nearest you call the Bureau of Behavioral Health at 271-5000 or the Disabilities Rights Center at 228-0432 or go to http://www.drcnh.org/psclist.doc.

Crisis Respite Care

New Hampshire has two peer support programs that provide crisis respite care Stepping Stone in Claremont and Granite State Monarchs in Keene. Crisis respite is a non-medical alternative to hospitalization for mentally ill individuals who need short-term intensive support, including 24-hour peer support. The philosophy of peer support is based on a mutually responsible relationship, a non-judgmental environment, and ongoing community building. The cost to the State for this program is $204 per day, compared to $756 per day for an inpatient stay at New Hampshire Hospital. For more information, call Stepping Stone toll free at 1-888-582-0920 and ask for Whitney Struse or Mark Nichols or call Granite State Monarchs at (603) 352-5093 and talk with Wayne Husted or Jodie Cota.

National Alliance for the Mentally Ill, New Hampshire (NAMI NH)

National Alliance for the Mentally Ill New Hampshire (NAMI NH) is a coalition of individuals, families, and friends coping with mental illness. We are a statewide education, support, and advocacy organization working for a quality, comprehensive mental health service system that promotes early intervention, treatment for mental and physical illnesses, and community services that promote recovery. NAMI NH has a statewide network of support groups that provide a safe environment for families and caregivers to share information and learn from the experiences of others. Group facilitators are experienced family members who understand the challenges and opportunities facing those whose loved ones have mental illnesses or severe emotional disorders. NAMI also offers educational classes for family members of adults with mental illness and for families who have children with severe emotional disorders; classes are taught by trained volunteers who have experienced mental illness in their families. To help communities build their capacity to support individuals with mental illnesses, NAMI provides specialized mental health training to schools, faith organizations, hospital emergency rooms and other first responders. NAMI promotes mental, physical, and community health and supports individuals with mental illnesses to sustain hope and achieve recovery.
Join us! For a membership form, call NAMI NH at 1-800-242-6264 or visit our website http://www.naminh.org.

More Than a Label, The Story of David Sawyer

Julia Freeman-Woolpert, Disabilities Rights Center

Meet David Sawyer: Master's level student at New England College, friend, son, brother, human services worker, gardener, and schizophrenic.

Now, which of those words caught your attention?

Unfortunately, the label schizophrenic carries such a degree of stigma that it overshadows the other attributes, accomplishments, and connections that make an individual unique.

Even for the individual a diagnosis can be all defining. David explained, "A lot of people with chronic illnesses get stuck feeling that the diagnosis is who they are, rather than being a human being first and a condition second."

David, now in his 50's, is an intelligent, articulate man with a professorial demeanor. His mental illness first manifested itself when he was a college student. David remembered that he was in the middle of a conversation when, "I suddenly found myself with a visual reality that wasn't actually happening." This experience was so unsettling and frightening that David went to his local mental health center (now Community Partners) where he was diagnosed with schizophrenia.

The following years were difficult. He dropped out of college and felt too ill to work. For a long time he blamed his family for his illness. David continued as a client of Community Partners where his treatment included individual counseling, case management, and medication. He is pleased with the therapy and services he has received from Community Partners. The counseling helped, and after trying half a dozen medications without success, both David and his psychologist were thrilled to finally find a medication that works. "It's proven to be very, very good for me with virtually no side effects."

Ten years ago David enrolled in a vocational program. "Before then I didn't think I could work. I didn't have the confidence that I could get there on time, stay there without absences, or maybe do the level of labor that was required." David finished his six-month trial work placement without one absence and has been working ever since. He currently has three part time jobs.

While he is not "cured", David Sawyer describes himself as "in recovery." He explained his day-to-day experience with schizophrenia, "I have a very active, vivid imagination. I don't say outright to someone that I have hallucinations… The word "hallucination" evokes a lot of concepts and it's kind of different for everyone. But I do imagine things very vividly and I'm used to that now. On a given day I could have 40 or 50 imaginations."

To assess how he's doing, David uses the check in system with family, friends, and his therapist. "It's something that I learned at New Hampshire State Hospital; you check in and share with the caregiver what you're feeling that day, what kind of experiences you have, and what you're looking forward to. It's a way of calibrating how you're feeling and how you want your day to go."

Living well with schizophrenia is an enormous challenge, but David's story makes it clear that it is an attainable goal. David has high ambitions for his future. Encouraged by his psychiatrist, David went back to school and earned his Bachelor's degree from the College for Lifelong Learning. He is now enrolled in his first year at New England College's Master's Program in Community Mental Health Counseling.

David Sawyer is a personal example and a strong proponent of recovery. "I think recovery is a very real thing. Recovery is an attitude that having a mental health condition does not limit the achievements or goals that one can have." For others with mental illnesses David advises, "Let's concentrate on our creative, positive side." By following his own advice David has refused to be defined by the diagnosis of schizophrenia. He is his own person.

THE STRUGGLE FOR JUSTICE

Seeking Legal Equity for Parents with Mental Illness

Susan Stearns, Director, Coalition for Family Law & Mental Health

People with mental illness, like others, work, get married, have children and get divorced. Nearly 50% of American adults report a psychiatric disorder during their lifetime; two-thirds of these women and over half of these men are parents. Studies show that as many as 80% of these parents lose custody of their children.

The Coalition for Family Law and Mental Health is a group of individuals and organizations dedicated to ensuring that people with mental illness are treated equitably in New Hampshire's family law system.

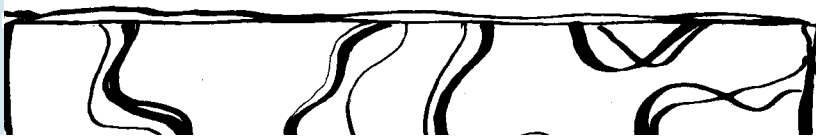
Recognizing that too often custody and visitation decisions were being based upon a parent's diagnosis rather than their parenting abilities, the Coalition developed a tool, Best Practice Standards for Adequate Assessment of Parenting Competency, as well as a reference sheet that provides Pointers for Legal Professionals Regarding Family Law Issues and Parents with Physical or Mental Illness.
(Available online at http://www.drcnh.org/ParentalAssessment.pdf and http://www.drcnh.org/ParentalPointers.pdf, respectively.)

Working with the Disabilities Rights Center, Probate Court, and others, the Coalition has helped to draft and facilitate the passage of legislation that provides parents with better protection under NH RSA 463, the Guardianship of Minors. Beginning in January 2005, courts shall make certain that parents understand the ramifications of a guardianship being ordered. For the first time, parents with mental illness will be fully apprised as to their rights and responsibilities under the statute. (For more information on the statute visit http://www.drcnh.org/minorguardianship.htm.)

Current activities of the Coalition include the development of a booklet to help parents prepare and implement a Power of Attorney and Parental Authorization that can provide for their children's care in the event that they are unable to do so because of illness. The Coalition is also participating on the Family Law Task Force to make New Hampshire's divorce and custody procedures less adversarial and working with the Probate Court to develop a protocol for court personnel to help ensure a smooth implementation of the revised RSA 463 revisions in January. (For more information on these or other projects, contact the Coalition at 228-0432, ext. 36 or at susans@drcnh.org.)

The potential for losing custody is never over.

Parent, Family Law Forum, November 1999



Double Whammy: Aging and Mental Illness

Linda Bimbo, Project Coordinator, Institute on Disability

Like it or not, we are all aging. This is not new information, but let's look at some facts:

- Numbering 35 million, today 12 % of Americans are over the age of 65.
- By 2020, one in six Americans, or 17 %, will be 65 or older.
- In New Hampshire, between 2000 and 2010, the older adult population will increase dramatically. The number of those aged 65-74 will increase by 25%, those 75-84 by 9%, and those 85 and above by an incredible 45%.

According to the Surgeon General's Report, more than one in five Americans aged 65 and older – including 26,072 of New Hampshire elders – experience mental illness. As many as 80% of elderly persons in nursing homes are affected by some kind of "mental impairment."

Mental illness among the elderly is one of the nation's most overlooked healthcare issues. Older adults typically have limited knowledge about mental health services and are frequently misdiagnosed and/or under-treated. In addition, the impact of physical illness and the mixing of multiple medications on the mental health of elders are not well understood. Compounding the problem, many older adults falsely believe that mental illness, particularly depression, is part of getting older.

Mental illness is not part of the normal aging process and left untreated can result in poorer overall health, family problems, and premature placement in a nursing home. While older adults experience the range of mental illnesses, the most prevalent is depression. Recent advances have made depression a highly treatable disorder, however, only a small percentage of depressed older individuals are receiving adequate treatment. Unfortunately, the majority of depressed elders accepts their feelings of profound sadness and often do not know that there is treatment for what they are experiencing. In addition, the stigma of seeking and receiving mental health treatment is difficult for some older adults and insurance (private, Medicare, or Medicaid) does not always fully reimburse for these services.

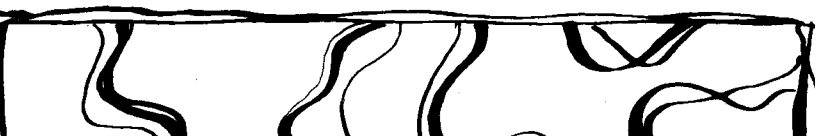
Untreated mental illness, especially depression, can lead to suicide. The statistics of suicide and elders are alarming; persons over the age of 65 are more likely to commit suicide than any other age group. For those over 85, the suicide rate is twice the national average. Of greatest concern is the fact that in 40% of these cases, older adults who commit suicide had seen their health care provider within a week of their death.

Myths about Mental Health and Older Adults

(Adapted from the Older Adult Consumer Mental Health Alliance)

1. Seniors are like everyone else. They don't need specialized services.

The nation's mental health system is geared toward people who recognize they have a problem, seek out help, and hope to recover and return to their work and family life. Many older adults don't fit into this picture. They are likely to have multiple health problems and do not recognize deep sadness or "not feeling themselves" as something that can be treated. Unfortunately, people over 60 often know very little about the availability of mental health services and how to access them. They trust their primary care physician, many of whom are not confident about dealing with mental illness, to provide all their health care. Seniors need professionals who understand older adults' specific psychological needs, complex physical problems, and service supports.



2. Older adults aren't overlooked; their doctors take care of them.

In older adults, the signs and symptoms of depression, anxiety, and other mental illnesses are often entangled with physical problems. As one senior noted, "Mental illness in older adults has many masks. It can look like stomach problems, lack of energy, irritability, the flu, grief, loss of weight, or lack of sleep." A survey by the National Mental Health Association shows that 68% of adults over 65 know little or nothing about depression; when they see their doctor they only discuss physical problems. Doctors miss diagnosing depression 50% of the time.

3. Depression is part of the aging process; there is no reason to think seniors will get better .

This is "ageism." People expect older adults to be depressed or disoriented because of their age and their loss of family, friends, and sense of purpose. The truth is that older adults can be helped through counseling and medication. Those over the age of 60 who receive treatment for depression have the same rate of recovery as younger people.

So now what?

Fortunately, innovative approaches are being developed to improve mental health care for older adults. As stated in Mental Health Weekly, 11/22/04, there are several models being considered that will ensure that the older person with mental illness receives needed health care including integrating mental health services into the primary care setting. Rather than relying on referrals to specialists, older adults are more likely to receive appropriate mental health care if there is a mental health professional on their primary care teams. Multiple appointments in different settings do not work for the majority of older adults who are also coping with other chronic illnesses, mobility problems, and limited transportation options. Another promising model is the use of facilitated case management with a nurse-case manager coordinating all aspects of an individual's physical and mental health care.

In New Hampshire, the Department of Health and Human Services, Bureau of Behavioral Health contracts with 10 regional community mental health centers. Each center has a team that provides care and treatment specifically for older adults. These teams, working in conjunction with community members, provide outreach, education, and a variety of culturally appropriate services and supports for older adults. To find the center nearest you contact ServiceLink at 1-866-634-9412.

Prevention and wellness are keys to remaining mentally and physically active in senior years. Adopting healthy lifestyles will help to reduce stress and promote physical and mental health. Activities such as going for a walk each day, taking a course at a local collage or senior center, or volunteering, cost little and can enhance a senior's quality of life.

If you, or a family member, have questions about depression or symptoms that are causing concerns, please contact your doctor, community mental health center, or NAMI New Hampshire at 1-800-242-6264 or http://www.naminh.org.

(NAMI NH has a guidebook: Mental Health, Mental Illness, Healthy Aging: A NH Guide for Older Adults and Caregivers that offers practical information on psychiatric problems in late life and includes information on available treatments and resources.)

Rebecca's Story

Julia Freeman-Woolpert, Disabilities Rights Center

Rebecca Barkhouse is an engaging, outgoing young woman with a wide variety of interests, including crocheting and writing poetry. She is an avid Rex Sox fan (Go Sox!) and is especially fond of Johnny Damon. Her favorite TV shows are Cops and America's Most Wanted. Rebecca also is a person who has a developmental disability and mental illness. Rebecca was willing to speak candidly about her situation and stated that her conditions include: schizoaffective disorder, borderline personality disorder, major depressive disorder, post-traumatic stress disorder, alcoholism, spina bifida, and diabetes. She has had many health crises, both emotional and physical, and has been in and out of New Hampshire Hospital.

Rebecca almost didn't make it into this world. Her father wanted her mother to have an abortion when he learned their baby would be born with spina bifida. Her mother refused; her father walked out on the family three days after she was born. The doctors didn't expect Rebecca to live more than a few days. While she survived, her family life was traumatic. Rebecca first attempted suicide when she was 7, she had her first drink at 9, and at age 11, due to abuse in her home, she went into foster care. She lived in a series of foster homes and for a time was placed at Crotched Mountain Rehabilitation Center.

Since she has a developmental disability, Community Bridges, the area agency, is her main service provider, and provides her residential and day supports. Riverbend, the mental health center in Concord, provides the psychiatric services which she needs and which Community Bridges is not qualified to provide. Both agencies coordinate their services through case management and their interagency team. Rebecca's weekly meetings with her team help her to stay on track and out of the hospital.

Rebecca's illnesses and chaotic life have taken a toll; in spite of her diminutive stature and perky nature, she can be one tough customer. "I used to be very abusive to people," she explained. "When I would have flash-backs of past abuse, I would get very physical. I would bite and spit, hit, kick, put my feet on the ground so the staff couldn't push the wheelchair." With help from her therapist at Riverbend, Rebecca has learned to curb her temper and proudly states that she has graduated from anger management training. While she is in much better control, Rebecca continues to need ongoing support to manage her behavior.

Rebecca can be hard on those who work with her, and many have not lasted long. "I have fear of getting close to people because I feel if I get too close to some-body that they're gonna just up and walk away from me; so I try to keep distant." She is getting better about trusting people and has been able to develop positive relationships. After a series of home providers who didn't work out, Rebecca has been with the same family for two years and loves them.

Rebecca said her biggest problem now is finding a job. "People say that there's not discrimination against people in wheelchairs and mental illness, but there is." She used to work as a receptionist for her provider agency, but due to budget cuts her position was eliminated. More than anything, Rebecca longs to go back to work, " I'd love to get a full time job that I could actually like and do away with the Social Security. I'm a very, very outgoing person, I don't like not being able to work full time."

With the exception of not having a job, Rebecca's life is much better now. Her interagency team and the coordinated support she gets from the area agency and the mental health center have played a critical role in Rebecca's increased stability and her continued progress.

Services to People with Dual Diagnoses Threatened

Julia Freeman-Woolpert, Disabilities Rights Center

New Hampshire has an established system of mental health centers for people with mental illness and another system of area agencies for people with developmental disabilities. People who have a "dual diagnosis" of a developmental disability and a mental illness have needs that span both service systems. (Dual diagnosis can also refer to the co-existence of a mental illness and a substance abuse disorder.) Providing effective treatment to this population can be complex and even controversial. The psychiatric problems of individuals with developmental disabilities are often overlooked or misdiagnosed. People with mental illness who have developmental disabilities often have serious problems with daily functioning. There is disagreement about which service system should provide services and either system acting alone may lack the expertise to provide the specialized care that these individuals need.

In New Hampshire, area agencies are the primary providers for dually diagnosed people. By regulation (He-M 403), mental health centers must make services, including regular interagency team meetings, available to persons who have both a mental illness and a developmental disability. These interagency teams work well in some parts of the state, not so well in others.

The state is currently seeking to limit mental health services to dually diagnosed people. The Department of Health and Human Services (DHHS) is proposing rule changes (He-M 426) that would allow only the primary serving agency to bill for case management. Typically, this will mean mental health centers will no longer provide case management to those with a dual diagnosis. Case management is a complex service that includes eligibility assessment, treatment plan development, care coordination, service linkage, monitoring, advocacy, and crisis intervention. Without financial support for case management mental health center participation on the interagency teams is likely to be severely limited.

Additionally, DHHS has informally instituted, and now is formally proposing through changes to He-M 426, a $4,000 cap for mental health services for "low utilizers." This group includes: 1) individuals with dual diagnoses; 2) people who are no longer severely mentally ill, but still need services to prevent relapse; and 3) those who have refused formal treatment and only receive outreach services.

These changes are expected to adversely impact people who are served by both systems. If you are affected please call the Disabilities Rights Center at 1-800-834-1721.

Involuntary Commitment

In New Hampshire, persons with mental illness who are determined to be dangerous may be involuntarily committed to New Hampshire Hospital or other psychiatric facilities and may be subject to certain conditions of treatment and supervision after their release. Because such confinement severely restricts a person's right to liberty, strict protections are in place to protect individuals from unnecessary admissions and commitments; these include court review and oversight, and procedural safeguards. An involuntary admission or commitment by itself does not authorize a facility to medicate a person against his or her will, although in some circumstances, forced treatment can be given. Commitment does not affect such civil liberties as the right to vote, to enter into contracts, to marry or divorce, or to hold motor vehicle or professional licenses. For more information and answers to Frequently Asked Questions about Involuntary Commitment go to the Disabilities Rights Center's website, at http://www.drcnh.org/commitment.htm or call the DRC at 1- 800-834-1721 and ask to speak with an advocate.

Mental Health Treatment at State Prison is Inadequate

Karen Aframe, Esq., Disabilities Rights Center

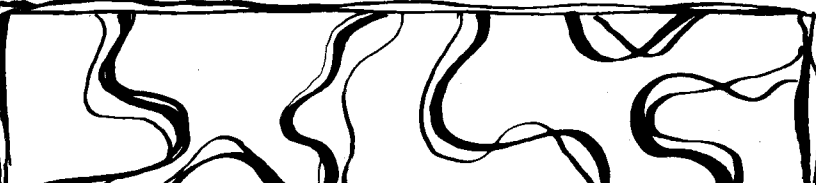
Over the last decade, New Hampshire State Prison has begun to house mentally ill persons in record numbers, but has failed to deliver adequate mental health services to this growing population. Adequate treatment is critical to prevent further deterioration of inmates' mental health and is essential if inmates are to successfully reenter society upon their release from prison.

In addition to the cost in human suffering, inadequate mental health services can lead to increased spending within the prison. Untreated mentally ill inmates are more likely to have difficulty complying with prison rules, jeopardizing the safety and security of other inmates and staff. Creating a safe and secure prison environment requires the expenditure of additional resources, costs that are ultimately borne by taxpayers.

In a series of consent decrees dating back to 1978 and two subsequent settlement agreements, the prison and New Hampshire's Department of Corrections agreed to meet certain standards in mental health care and to provide mentally ill inmates with specific mental health programs and services.

The state has failed to fulfill its obligations under the agreements. The Department of Corrections' violations include its failure to establish a residential treatment unit for seriously mentally ill inmates, to provide certain mentally ill inmates with group and individual therapy, to adequately staff the prison's mental health unit, and to comply with monitoring guidelines of mentally ill inmates in the prison's Special Housing Unit.

In June 2004, New Hampshire Legal Assistance (NHLA) filed an action in New Hampshire court to enforce the agreements. The Disabilities Rights Center (DRC) has joined NHLA in its nearly thirty-year effort to achieve adequate mental health treatment within the prison's general population and in the Secure Psychiatric Unit. The parties are currently engaging in the discovery phase of litigation. It is the DRC and NHLA's hope that as a result of this litigation, mentally ill inmates will receive the mental health treatment and services that they need to enable them to cope with their illness and eventually maintain productive lives outside of prison.



News You Can Use

The Bureau of Behavioral Health has made changes to the way mental health centers handle service planning for their clients. Individuals can now choose whether or not to have a formal conference each year. For more information, go to http://www.drcnh.org/401.htm.

About a year ago, the Bureau of Behavioral Health imposed a $4,000 per person cap on community mental health services for persons classified as "low utilizers." In general, these are individuals who receive mental health services to prevent a relapse or persons with a developmental disability who are primarily served through an area agency. The $4,000 cap is an attempt to reduce state costs; the Bureau hopes to decrease general fund expenditures by $1,000,000 per year by eliminating these mental health services. As this issue of the RAP sheet goes to press, the Bureau is in the process of changing the administrative rules to reflect this cap on services. More information can be found on the DRC website, http://www.drcnh.org.

Need Assistive Technology (AT) at work, school, home, or play? The AT Act of 2004 may make it easier to obtain the devices you need. For more information visit the Assistive Technology Act Programs webpage: http://www.ataporg.org/; New Hampshire's ATECH Services webpage: http://www.nhassistivetechnology.org/; or call the Disabilities Rights Center at 228-0432 or 1-800-834-1721.

NAMI NH has been awarded a statewide family network grant from the US Department of Health and Human Services. NAMI NH will get $69,735 per year over the next three years to involve families in mental health policies and programs affecting their children. The phone number for NAMI NH is 224-5359.

Justiceworks, in cooperation with the Institute on Disability, has issued a report, by Michael Skibbie, "Children with Disabilities in the New Hampshire Juvenile Justice System." The research, findings, and recommendations have been provided to the New Hampshire Department of Health and Human Services Division of Juvenile Justice Services. The full report can be found at www.drcnh.org/ChildrenwDisabilities.pdf (requires adobe acrobat reader) or can be viewed in web browser at www.justiceworks.unh.edu/Mike%Skibbie%20Report.htm.

DID YOU KNOW?

- An estimated 22.1% of Americans ages 18 and older – about one in five adults- suffer from a diagnosable mental illness in a given year. (NIMH, 2004)
- More than 54 million Americans have a mental disorder in any given year, although fewer than 8 million seek treatment. (SGRMH, 1999)
- Four of the ten leading causes of disability in the US and other developing countries are mental illnesses such as major depression, bipolar disorder, schizophrenia, and obsessive-compulsive disorder. (NIMH, 2004)
- More than 90% of people who commit suicide have a diagnosable mental illness, commonly a depressive disorder or substance abuse disorder. (NIMH, 2004)
- Older Americans are more likely to commit suicide than any other age group. Although they constitute only 13% of the U.S. population, individuals age 65 and older account for 20% of all suicides. (NIMH, 2000)
- The highest suicide rates in the US are found in white men over the age of 85.
- Four times as many men as women die by suicide, however, women attempt suicide two to three times as often as men. (NIMH, 2004)
- Suicide is the third leading cause of death for 15- to 24-year-olds and the sixth leading cause of death for 5- to 14-year-olds. The number of attempted suicides is even higher. (AACAP, 1997)
- Depression greatly increases the risk of developing heart disease. People with depression are four times more likely to have a heart attack than those with no history of depression. (NIMH, 1998)
- Up to one-half of all visits to primary care physicians are due to conditions that are caused or exacerbated by mental or emotional problems. (CFHC, 1998)
- One in five children have a diagnosable mental, emotional, or behavioral disorder and up to one in 10 may suffer from a serious emotional disturbance; 70% of children, however, do not receive mental health services. (SGRMH, 1999)
- As many as one in every 33 children and one in eight adolescents may have depression. (CMHS, 1998)
- Once a child experiences an episode of depression, he or she is at risk of having another episode within the next five years. (CMHS, 1998)
- Teenage girls are more likely to develop depression than teenage boys. (NIMH, 2000)
- Children and teens who have a chronic illness, endure abuse or neglect, or experience other trauma have an increased risk of depression. (NIMH, 2000)
- Approximately one in four individuals diagnosed with mental retardation are diagnosed with mental illness or behavioral disorders. (Jacobson,1990)

Coming Up

INSTITUTE ON DISABILITY/UCED

In 2005 the Institute on Disability will be offering training opportunities that focus on mental health issues. Get out your new calendars and save these dates. For information or to register, please call (603)228-2084 or visit the IOD website at http://www.iod.unh.edu

WORKSHOP SERIES - TRANSITION FROM SCHOOL TO ADULTHOOD *

With the right support, a graduating student can embark on a lifelong journey towards a meaningful employment, postsecondary education, and community participation. This series features researchers who have done exemplary work on making transition successful for young adults with disabilities. Workshops will be held 9:00-3:00 in Manchester, the cost is $80 per workshop, $350 for the series.

- March 24, 2005 Building Person-Centered Planning Teams and Personal Profiles
  Dr. Ernest Pancsofar, Department Chair, Central Connecticut State University
- March 25, 2005 Transition Services for Youth with Emotional and Behavioral Disabilities
  Gail Cormier, Executive Director Alliance for Community Supports
  JoAnne Malloy, M.S., Institute on Disability, UNH and David Hagner, Ph.D., Institute on Disability, UNH
- April 15, 2005 Off-Campus (Non-School) Transition Services for Youth Ages 18 – 21
  Pat Rogan, Ph.D., Associate Professor, Indiana University
- May 11, 2005 Effective Strategies and Supports for College Students with Disabilities
  Elizabeth Getzel, Program Director, Virginia Commonwealth University
- June 2, 2005 Transition Service Integration Project: Systems change for seamless transition to customized competitive employment and full community inclusion
  Denise Mautz, Ph.D., San Francisco State University

*This Series is cosponsored by the NH Developmental Disabilities Council's U.S. Department of Labor Transition Services Realignment Grant which supports resource mapping and local intermediary organizations to integrate transition resources for persons aged 14-24.

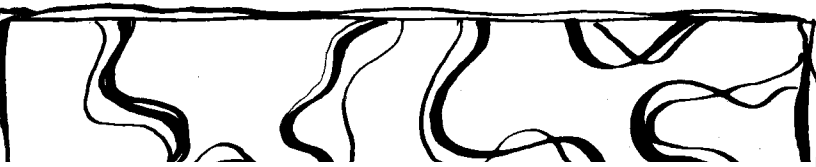
NH'S 7TH ANNUAL AUTISM SUMMER INSTITUTE AUGUST 15-19, 2005

EDUCATING STUDENTSWITH AUTISM SPECTRUM DISORDERSIN GENERAL EDUCATION CLASSROOMS

This summer institute at UNH Durham campus will provide state-of-the-art information on supporting students with autism spectrum disorder in general education classes. Each morning, a national leader in the field of autism will deliver a keynote address; in the afternoon, participants will work in small groups to synthesize this information and develop strategies for supporting students and families. Conference registration is $600 if received before April 30, $650 after April 30.

NEW HAMPSHIRE DEVELOPMENTAL DISABILTIES COUNCIL

The Council is pleased to announce that the Strafford Learning Center, SAU-35 in Littleton, Monadnock Developmental Services, and North Country Education Services will be participating in the New Hampshire Youth Transition Alignment Project funded by the US Dept. of Labor's Office of Disability Employment Policy. The purpose of these four year pilot projects is to integrate all transition services for youth with disabilities and fill in service gaps to maximize the success of youth aged 14-24 in transitioning from high school to a full adult life in their communities. For more information please contact the Council at 1-800-834-1721.



Mental Health Resources

NH Bureau of Behavioral Health, 105 Pleasant Street, Concord, NH 03301, (603) 271-5000, http://www.dhhs.nh.gov/DHHS/BBH/default.htm

The Disabilities Rights Center's website has a section on mental health at http://www.drcnh.org/Issue%20Areas/Mental%20Health.htm, including:
wNH Peer Support Center contact info: http://www.drcnh.org/peer-support.pdf
wNH Community Mental Health Center contact info: http://www.drcnh.org/cmhcs.htm

The Federation of Families for Children's Mental Health, http://www.ffcmh.org/

National Alliance for the Mentally Ill – NH Chapter: 15 Green Street, Concord, NH 03301 (603) 225-5359 or (800) 242.6264 http://naminh.org/

National Alliance for the Mentally Ill: http://www.nami.org/

National Mental Health Consumer's Self-Help Clearinghouse, a consumer-run national technical assistance center serving the mental health consumer movement. http://www.mhselfhelp.org/techassist.html

National Empowerment Center: http://www.power2u.org/

Dartmouth Psychiatric Research Center's website has information about Evidence-Based Practices: http://www.dartmouth.edu/%7Epsychrc/

National Association of State Mental Health Program Directors: http://www.nasmhpd.org/

National Mental Health Association: http://www.nmha.org/

US DHHS Substance Abuse and Mental Health Services Administration: http://www.samhsa.gov/index.aspx

National Institute of Mental Health: http://www.nimh.nih.gov/

The Bazelon Center for Mental Health Law: http://www.bazelon.org/

Center for Public Representation, a Massachusetts non-profit public interest law firm providing mental health law and disability law services. http://www.centerforpublicrep.org/.

The Center for Psychiatric Rehabilitation, Boston University Sargent College of Health and Rehabilitation Sciences: http://www.bu.edu/cpr/

Mary Ellen Copeland's website: http://www.mentalhealthrecovery.com/index.html
Copeland is a well-respected expert on peer support and self help strategies.

DISABILITIES RIGHTS CENTER, INC.
18 Low Avenue, Concord, NH 03301-4971
Voice and TDD: (603) 228-0432 w 1-800-834-1721 w FAX: (603) 225-2077
TDD access also through NH Relay Service: 1-800-735-2964 (Voice and TDD)
E-mail: advocacy@drcnh.org w 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
Phone (Tel/TTY): (603) 862-4320 w Fax: (603) 862-0555 w Website: www.iod.unh.edu

Institute on Disability/UNH – Concord
Concord Center, 10 Ferry Street, Unit 14
Concord, NH 03301
Phone (Tel/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 w TTY/TDD: 1-800-735-2964 w 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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The Latest in Disability Research, Advocacy, Policy, and Practice

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