

RAP Sheet

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

Spring/Summer Issue 2014

STAYING HEALTHY



IT TAKES A TEAM

By Deborah Scheetz, Project Manager, CareConnect Health Home

Welcome to the Spring/Summer Issue of the RAP Sheet. Martin Luther King said, "Of all the forms of inequality, injustice in healthcare is the most shocking and inhumane." Disparity in health care has long been a reality for people with disabilities. In this issue we share findings from the IOD's Health Disparities Project and look at what is being done in the Granite State to improve access to healthcare for our most vulnerable residents.



Bobby works with his CareConnect Team to stay healthy and smiling.

Bobby and his longtime girlfriend Linda share an apartment in Nashua. He works part time doing maintenance at Gateways Community Services and supplements his income with odd jobs. Bobby was born with a developmental disability and although he struggled in school, he has always had an incredible work ethic. Bobby gives a hundred percent to every job he takes on. He worked for years as a stitcher at a local shoe factory. Doing physically demanding work and walking everywhere have kept Bobby in tip-top shape. A huge sports fan, Bobby attends all the home games

at Nashua's two local high schools and every spring the start of Red Sox season brings a huge smile to his face.

In the last two years, Bobby has struggled with back pain and muscle soreness. Now 64, he is starting to feel his age, but does not want slow down. He has been sick more often and has been missing work. "I like to work. I like the money. I don't know what I'd do if I couldn't work," explains Bobby.

In the fall Bobby began getting support from the CareConnect Health Home pilot project. He now has an Integrated Care Team who is helping him to stay healthy. His Health Service Coordinator at Dartmouth Hitchcock clinic has worked with him to create a personalized care plan with goals. She spoke with the medical team about Bobby's back problems. An x-ray was scheduled and Bobby was diagnosed with arthritis. He now has a management plan to ensure he stays active.

(Continued on next page)



CARECONNECT HEALTH HOME: A PILOT PROJECT OF DARTMOUTH HITCHCOCK & GATEWAYS COMMUNITY SERVICES

By Beth Raymond, VP of Individual and Family Services & Deborah Scheetz, Development Director, Gateways Community Services

Lately we have been hearing a lot about “care coordination” as a means to achieve better care, improve outcomes, and reduce health care costs. In reality, care coordination often falls short of meeting these goals. Staffing issues and billing limitations make it difficult for primary care physicians (PCP) to provide the patient outreach, care planning, and individualized support that are necessary for quality care coordination.

Patients rarely connect with their PCP outside of the office setting. Meanwhile, life happens between office visits. Patients go to the ER or drop into an Urgent Care Center. They are seen by other doctors, prescribed new medication or stop taking medications. They change their diet and exercise habits. They experience behavioral or mental health concerns. Patients rarely inform

their primary care physician about these changes and health providers traditionally share information about patients only in response to a specific request or if a patient is in crisis.

For patients, care management typically entails an evening phone call from a health plan nurse. After a long day at work and with dinner getting cold, patients are not eager to talk on the telephone. They do not want to discuss, their entire health history with a stranger or go through a lengthy scripted questionnaire. They are not excited to improve their lifestyle and make changes.

The current method of care coordination is especially ineffective for patients with developmental disabilities. Family members report that their health plans do not understand the needs of people with developmental disabilities. One mom observed, “If my child could answer the phone and answer the questions, he probably wouldn’t have a developmental disability. He cannot fill out a questionnaire. He is non-verbal. He needs community supports that we get from our Area Agency. He has a doctor that knows him and gets him – accommodates him. Yes, we need care coordination, but it has to be specific to his needs and it needs to be supported by someone who understands his disabilities. We’ve got to do better than this phone call, check-off approach. Care coordination should do more than approve health care costs.”

Moving Forward

We can improve on today’s payer-based nurse call and form letter approach to care management. We need to recognize that commercial care coordination does not translate well for the lion’s share of people with developmental disabilities. To improve care coordination for this population, the medical community and developmental service providers need to be working in partnership.

The Centers for Medicare and Medicaid Services (CMS), as part of the Affordable Care Act, is encouraging states to develop Health Homes that provide specialized services,

(Cover story continued)

In the past, when Bobby was sick he wouldn’t take time off from work to see his doctor. The Community Navigator has helped Bobby understand that he actually will miss less work if he goes to the doctor when he first gets sick. The Community Navigator also helped Bobby make changes in his diet to get his high blood pressure under control. When Bobby has a doctor’s appointment, the Community Navigator goes with him. If Bobby has a question about his medication or isn’t feeling well he checks in with his Community Navigator.

Bobby likes his physician at Dartmouth Hitchcock and has been seeing him for years. Now, when he leaves an appointment Bobby has a team of people he knows and trusts to help him follow through on his doctor’s instructions. “I like Carolyn and Dr. Patel. They help me all the time.” As Bobby sees it, having a few more Red Sox fans working hard to keep him in tip-top shape is a very good thing!

improve care, and include payment reform to reward outcomes. In New Hampshire, the Department for Health and Human Services has provided seed funding for a pilot Health Home for people with developmental disabilities in the Nashua region. Gateways Community Services, an Area Agency with thirty plus years of experience supporting people with developmental disabilities, is leading this effort.

CareConnect Health Home – Hands-On Care Coordination

In September 2013, Dartmouth Hitchcock Nashua and Gateways Community Services began the CareConnect Health Home pilot for 45 of Gateways' most challenging clients. In addition to developmental disabilities, these individuals have complex medical and mental health needs. CareConnect has embraced a team approach to caregiving. Doctors and nurses work collaboratively with the Gateways Health Service Coordinator, who is on-site at Dartmouth Hitchcock clinic, to develop a comprehensive joint care plan for each Health Home patient.

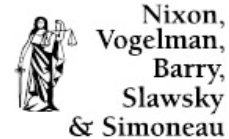
The Integrated Care Team knows about every illness, medication, and doctor visit. As importantly, they also understand the patient's living situation, support needs, communication accommodations, and guardianship status. Gateways' staff is consulting with medical professionals at Dartmouth Hitchcock on how to work most effectively with people who have intellectual disabilities, seizure disorders, behavioral concerns, and communication issues. Together, as a team, with input from the patient and/or patient's representative, care is being managed to support the individual's goals. Mental health specialists also provide care for some patients. Goals for the Health Home include good preventative care, as well as reducing emergency room visits and avoiding costly hospitalizations.

Joint care coordination does not stop when the patient leaves the clinic. Gateways' Community Navigator works with patients in their homes, helping them to follow

through on medical instructions and to stay on track with their health goals. The Community Navigator and Health Service Coordinator work together to ensure that patients in the Health Home are holistically supported not only to meet their health goals, but to lead meaningful lives in their community.

Effective care coordination is much more than a phone call from a health plan nurse or a doctor visit, it is ensuring that patients are fully supported, for the long term at home and in the community. This is the next generation of care coordination and it is making a positive impact for those enrolled. Already, CareConnect patients are keeping appointments, preventative care is happening, and, with on-going support from the Integrated Care Team, they are meeting goals in their personal health plans.

To learn more about the CareConnect Health Home, please visit the Governor's Commission on Medicaid Care Management information page at <http://www.governor.nh.gov/media/news/2013/pr-2013-04-10-medicaid-care-2.htm> or contact Gateways at 603-882-6333.



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DISABILITY SEVERITY IS ASSOCIATED WITH CANCER SCREENING

By Michelle L. Stransky, Postdoctoral Research Associate, Institute on Disability/UNH

Does having a severe disability mean that you are less likely to be screened for cancer compared to people with less severe disabilities? If you're a woman, it may.

In reviewing studies concerning health screening among women with disabilities, Elena Andresen, Ph.D. and her colleagues found that women with more severe disabilities may be less likely to receive mammograms and clinical breast exams than women who are less severely disabled. The relationship between pap tests and disability severity was unclear.

The review found that few studies have examined breast and cervical cancer screenings among women with disabilities. More research is needed to determine whether

the likelihood of being screened is lower for women only with the most severe disabilities or whether it declines as the severity of a disability increases.

Previous research has found that women with disabilities are less likely to receive sex-specific cancer screenings than are women without disabilities.

This research was conducted as part of the Institute on Disability Health Disparities Project, funded by the National Institute on Disability and Rehabilitation Research. For more information, including the full research article and a health brief about this research, please visit: http://iod.unh.edu/Projects/health_disparities/project_description.aspx.

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Advocacy

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Grappone Conference Center
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For more information, call 228-2084
To register, go to
http://iod.unh.edu/Services/eventdetail/14-04-10/2014_Advocate_NH_Conference_Advocacy_Learn_It_Live_It_Love_It.aspx

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DENTAL CARE AND PEOPLE WITH DISABILITIES

By Kimberly G. Phillips & Sara B. Rainer, NH Disability and Public Health Project, Institute on Disability/UNH

Only 50% of people with disabilities visit a dentist as often as recommended, according to new research from the University of New Hampshire Institute on Disability (IOD). Adults should see a dentist at least once each year for teeth cleaning and an oral health check-up.

IOD researchers looked at seven years of data from the national Medical Expenditures Panel Survey (2004-2010). Five disability types were studied, including physical limitations, cognitive limitations, visual impairments, hearing impairments, and multiple limitations (having two or more disabilities).

The study found that among people with disabilities, those with physical limitations were the most likely to get annual dental check-ups (52%) and people with multiple limitations were the least likely (39%). As a comparison, 64% of people without disabilities get the recommended oral health care.

FREQUENCY OF ANNUAL DENTAL CHECK-UPS BY DISABILITY TYPE

Type of Disability	Percent (%) who visit the dentist at least once per year
No Disability	64
Physical Limitation	52
Cognitive Limitation	45
Visual Impairment	48
Hearing Impairment	49
Multiple Limitations	39

The IOD research team wondered what factors, besides disability, contributed to a person's likelihood to go to the dentist. This is what they found after reviewing additional information about the people in the study.

Insurance. People with disabilities, no matter what the type of disability, were more likely to go to the dentist at least once a year if they had health insurance.

Education. People with disabilities who had graduated high school or gone to college were more likely to go to the dentist at least once a year than people who had less education. The amount of education did not matter for people with a cognitive impairment, but it was a factor for every other disability group in the study.



Age. The study looked at adults who were between 18 and 64 years old. For people with certain types of disability (physical, cognitive, or multiple limitations) the older they were, the more likely they were to see the dentist at least once a year. Age was not a factor for people with visual or hearing impairments.

The NH Disability and Public Health project encourages people with disabilities to get annual dental care. The project has created a series of materials that offer health care reminders and tips, including two handouts about oral health. Check out the project's health promotion materials, *A Healthy Me...* and *A Caregiver's Guide*, on the web at www.iod.unh.edu/dph/healthy-me.

The research study described in this article is part of the Disability and Rehabilitation Research Project: Health Disparities Project and is funded by the National Institute on Disability and Rehabilitation Research. The health promotion series, A Healthy Me... and A Caregiver's Guide, is produced by the NH Disability & Public Health project, which is funded through a cooperative agreement with the U.S. Centers for Disease Control and Prevention (CDC).



MEDICAID'S SPECIAL COVERAGE FOR CHILDREN AND YOUNG ADULTS

By Karen Rosenberg, Staff Attorney, Disabilities Rights Center

Regular screening, proper diagnosis, and timely treatment are essential components of quality healthcare. For all Medicaid-eligible individuals under age twenty-one, federal Medicaid law requires states to provide Early and Periodic Screening, Diagnosis, and Treatment (EPSDT). States like New Hampshire that contract with managed care organizations (MCO) to provide health insurance for Medicaid recipients must ensure that the MCO's coverage complies with federal EPSDT's requirements.

Under EPSDT, states must assess children's health needs to ensure health problems are diagnosed and treated before they become more serious or complex. States are required to adopt a schedule for medical screenings and developmental assessments. New Hampshire follows the American Academy of Pediatrics' schedule for pediatric care; this calls for screenings and checkups to begin right after birth and to continue on a frequent basis as children develop.

Medicaid eligible individuals under the age of twenty-one are entitled to a broad range of screenings including: 1) health and developmental history, 2) complete physical exams, 3) immunizations, 4) lab tests, and 5) vision, hearing, and dental exams. States must take affirmative steps to encourage and assist Medicaid eligible children to have medical screenings. This includes informing parents about the importance of early screenings for their children and providing assistance with scheduling and transportation. **If a physical or mental illness or condition is identified, the child must receive diagnostic tests and necessary medical treatment, even if the condition is identified outside of a regularly scheduled screening.**

EPSDT require states to cover medical services when necessary "to correct or ameliorate" physical and mental illnesses and conditions¹. Unlike the adult Medicaid program, EPSDT requires coverage of *all* medically

necessary services that could be covered under federal Medicaid law. For example, even though New Hampshire's Medicaid Plan for adults does not cover most dental services, under EPSDT, children and young adults under 21 must have access to a broad range of dental treatment including regular examinations, x-rays, topical fluoride, dental sealants, and treating cavities. A wide variety of medically necessary services must be covered. Among these are "rehabilitative services, including any medical or remedial services (provided in a facility, a home, or other setting) recommended by a physician . . . **for maximum reduction of physical or mental disability and restoration of an individual to the best functional level.**"²

In addition, under EPSDT states cannot limit the amount, duration, and scope of medically necessary services for children, even if the state's Medicaid plan for adults includes such limits. For example, New Hampshire's Medicaid plan for adults caps coverage of occupational therapy (OT), physical therapy (PT) and speech therapy (ST) services. Under EPSDT, Medicaid-eligible children and young adults are entitled to receive as many OT, PT, and ST services as are medically necessary.

There are some limits on medical services that must be covered under EPSDT. States may place tentative limits on the amount, scope, or duration of services for individuals under twenty-one years of age, provided that there is a process to allow for coverage beyond the limit, if medically necessary. In addition, states may require prior authorization for certain types of services, as long as the prior authorization process does not delay delivery of necessary medical care. States may choose to cover a service in the most economic manner, as long as the alternative method proposed is equally effective as the service recommended by the treating physician. Finally, states do not have to cover treatment that is unsafe or experimental.

Despite the strong provisions of federal EPSDT law to protect children's health, states do not always comply with

the letter of the law. Medicaid agencies may attempt to cut back, limit access, or deny access to particular healthcare services for children and youth. Medicaid recipients have a right to challenge any denials, limits, or termination of treatment that they believe is medically necessary.

If the service coverage dispute is with a MCO, the first step is to follow the MCO appeal process. For more information on how to contest a medical service denial or termination from a MCO, see *"Know Your Rights: New Hampshire Medicaid Managed Care Health Plans - Your Right to Appeal or File a Grievance,"* available at www.drcnh.org/MMCapealsgrievances.html. If you are not satisfied with the result of the MCO appeal or your child's Medicaid coverage is not provided through a MCO, you may request a fair hearing before an impartial hearing officer at the State's Administrative Appeals Unit (AAU). For more information on appeals to the AAU see *"Fair Hearing Rights Under Medicaid,"* <http://www.drcnh.org/medicaidhearings.htm>.

If you have specific questions or concerns regarding Medicaid/EPSTD-covered services, feel free to contact the Disabilities Rights Center to schedule an appointment with one of our intake attorneys.

¹ 42 U.S.C. §1396d(r)(5)

² 42 U.S.C. §1396d(a)(13) Emphasis added.

COVERING NH – THE AFFORDABLE CARE ACT COMES TO THE GRANITE STATE



By Alex McIntire

The Affordable Care Act (ACA) has brought many changes to the country's health care system since it was signed into law in 2010. Young people can stay on their parents' insurance policy until the age of 26. Insurance companies cannot refuse coverage to people because they have a preexisting medical condition, and Americans have expanded access to affordable health insurance plans through the Health Insurance Marketplace.

These benefits have been widely covered in the media, but less attention has been given to how the ACA is improving and expanding care for people with disabilities. Examples of how the ACA is making a difference for people with disabilities include:

Preventive Care for Better Health – support for innovations in health care that prevent illness and disease before they require more costly treatment.



Accessible Examination Equipment – improved access to medical diagnostic equipment so people with disabilities can receive routine preventive care and cancer screenings by establishing exam equipment accessibility standards.

Health Disparities – improved data collection on health disparities for persons with disabilities, as well as training and cultural competency of health providers.

(Continued on page 15)

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HELPING NH'S BHUTANESE COMMUNITY ACCESS HEALTH CARE

By Julia Freeman-Woolpert, Disabilities Rights Center

It has been only a few years since the Bhutanese Community of New Hampshire (BCNH) incorporated as a non-profit organization. Tika Acharya, Executive Director of BCNH, and the staff and board have worked hard to support the Bhutanese in our state; they provide social services to elders, teach citizenship classes, and most recently helped people sign up for health insurance plans through the Health Insurance Marketplace.

Rohit Subedi, a Health Insurance Marketplace assister with BCNH, came to the United States several years ago from a refugee camp in Nepal. "I didn't even know about the basics of health insurance," he said. "All the concepts – co-payments, premiums, deductibles, networks...it was pretty tough."

Subedi and Marketplace assister Suraj Budathoki helped Southeast Asian immigrants and refugees apply for health insurance in accordance with the Affordable Care Act (ACA). They contacted each Bhutanese household in New Hampshire and conducted several group trainings to explain the ACA and the Health Insurance Marketplace. They met with people individually to review options and helped people sign up for health insurance plans on the ACA website HealthCare.gov. Assisters also identified and referred people who would be eligible for New Hampshire Medicaid Services.

The limited Marketplace network of health care providers is a source of worry for Concord's Bhutanese-American community as Concord Hospital and its affiliates are not in the network. Virtually all refugees who arrive in Concord receive their primary medical care through Concord Hospital Family Health Centers. The Centers have experience working with interpreters and managing health issues that are uncommon in the US. Losing access to these health care providers is a significant



Photographer - Julia Freeman-Woolpert

Rohit Subedi, BCNH Marketplace Assister, discusses health insurance with Rup Timsina.

issue. Fortunately, with Medicaid Expansion now the law in New Hampshire, individuals covered through Medicaid Expansion will be able to continue to receive their health care through Concord Hospital and its affiliates. It is anticipated that next year additional insurance providers will offer health plans through the Health Insurance Marketplace, increasing the number of health care providers in the network.

Even though the March 31 enrollment deadline has passed, BCNH will continue to provide assistance for those with qualifying life events that allow them to enroll after the deadline.

BCNH can be reached at 856-7507 (Concord), 935-9620 (Manchester), or bcnh@bhutanesecommunitynh.org.





REFUGEES FACE UNIQUE BARRIERS TO HEALTH CARE

By Julia Freeman-Woolpert, Disabilities Rights Center

Unequal access to quality health care for minority populations is a significant problem in New Hampshire and across the nation. Bhutanese refugees did not come to America directly from Bhutan; they lived for 20 years in refugee camps in Nepal. For those born after their parents were forced to flee to Nepal, the refugee camp was the only home they had ever known. Many Bhutanese refugees arrived in the United States with significant health care needs, including post-traumatic stress disorder. Lack of transportation, language barriers, and cultural differences all make access to health care complicated.

For Bhutanese and other people whose first language is not English, accessing appropriate health care is a challenge. Clear communication with health care providers is essential to quality care, patients need to be able to schedule appointments, describe symptoms, and understand instructions from their physician. Professional interpreters are essential. While a provider may expect a family member who speaks English, even a child, to serve as an interpreter this is not recommended. Having a family member present during an appointment may

inhibit the patient from sharing personal information. In addition, family members' unfamiliarity with medical terms may cause confusion or result in incorrect information being shared. Some providers use telephone language banks, but in-person interpreters are preferable. However, in a small ethnic community the interpreter is likely to know the patient, which can be uncomfortable for both parties.

Cultural differences can also create problems. Bhutanese prefer to see a doctor of the same gender and may not fully disclose medical issues to a doctor of the opposite gender. Many Bhutanese believe there is a spiritual basis for both physical and mental illness. Some patients pursue a spiritual cure in addition to a medical one and may rely on other traditional healing practices that they are reluctant to talk about with their medical providers.

Nationally and in New Hampshire there is an unusually high rate of suicide among Bhutanese immigrants. The reasons for this aren't clear. The Centers for Disease Control and Prevention has investigated and found that people reporting PTSD symptoms, those with increased family conflict, or those unable to find work were more likely to consider suicide. In response to a suicide in the Concord Bhutanese community, BCNH, with support from other service organizations, conducted a two-day seminar for leaders in the Bhutanese community. These leaders are now educating members of their community about how to recognize the warning signs for suicidal behavior and to intervene when someone is at risk.

BCNH has been reaching out to community partners to help address the barriers confronting Bhutanese Americans. "Collaboration is very important," said Bhagirath Khatiwada, BCNH Board member. "If we work together, we can reduce the problems."



Photographer – Julia Freeman-Woolpert

Bhutanese refugees in the doorway of their home in a refugee camp in Nepal. The house is made out of bamboo and newspaper.



SUPPORTED HOUSING – PART OF THE COMMUNITY MENTAL HEALTH SETTLEMENT AGREEMENT

By Julia Freeman-Woolpert

Now that the judge has approved the Settlement Agreement in the mental health lawsuit *Amanda D. v. Hassan*, the next step is implementation of services and other provisions in the Agreement. One of the central components of the Agreement is the development of permanent supported housing in New Hampshire.

As defined by the U.S. Substance Abuse and Mental Health Services Administration, permanent supportive housing is the provision of "voluntary, flexible supports to help people with psychiatric disabilities choose, get, and keep housing that is decent, safe, affordable, and integrated into the community. Central to the approach is a belief that people with psychiatric disabilities should have the right to live in a home of their own, without any special rules or service requirements."

Many men and women with serious mental illness have become homeless or landed in psychiatric institutions or jails because they lacked affordable housing or did not have the supports needed to remain in their homes. For years, Mandy, a lead plaintiff in the lawsuit, cycled in and out of emergency rooms, hospitals, and temporary living arrangements. Now on a waiting list for Section 8 housing, Mandy feels that with supported housing she would have the help she needs to deal with her hoarding problem and be able to manage successfully in her own apartment. She said, "I think it [supported housing] will be very helpful to a lot of people."

Supported housing under the Agreement must be permanent housing with tenancy rights. Participation in treatment cannot be a condition for living in supported housing. It must be "scattered site" (no large congregate settings) homes or apartments integrated in the community. To prevent the creation of segregated housing that isolates and further marginalizes people with mental illness, no more than 10 percent of a multi-unit building and no more than two units in a building with nine or fewer units can be supported housing.

The Agreement calls for phasing in permanent supported housing over the next several years. By June 2016 New

Hampshire must have a minimum of 450 units for people with serious mental illness. By July 2017 New Hampshire must have applied for federal funding for an additional 150 units. After January 2017 the State will maintain a waitlist for those in need of supported housing. When the list exceeds 25 people who have waited for two months, the State must create additional units. The wait for supported housing should be no longer than 6 months.

The Settlement Agreement includes a provision for people with complex health care needs who now live at Glencliff Home and cannot be cost-effectively served by supported

housing. By 2017, the state will have the capacity to serve at least 12 people with complex health care needs living in community residences, enhanced family care, or with a supported roommate.

Supported housing includes mental health and tenancy support services provided by community mental health

programs or other providers. Supports are individualized, and may include services provided by Assertive Community Treatment teams, Case Managers, or housing specialists. Support services are designed to enable individuals to attain and maintain integrated and affordable housing. Those providing supported housing services are trained to do "whatever it takes" to help the person live successfully in their home and community.

Choice is an critical component of supported housing. People need to be able to decide where they want to live, whether or not to have roommates, and what type of housing makes the most sense for them. Having choices, not surprisingly, increases the likelihood that even individuals with severe mental illness can live successfully in the community. Mandy, who wants to live in her own apartment with her dog, summed it up, "It's important for everybody to feel comfortable in their own home."

Photographer – Julia Freeman-Woolpert



Mandy on the Court House steps following the approval of the Community Mental Health Settlement Agreement.



YOUR RIGHT TO APPEAL OR FILE A GRIEVANCE NEW HAMPSHIRE MEDICAID MANAGED CARE HEALTH PLANS

By Rebecca Whitley, Staff Attorney, Disabilities Rights Center:

If you are a Medicaid recipient and have a problem with your Medicaid managed care health plan, or your managed care organization (MCO), you have many important rights. **This article is only a general overview of your rights.** Each MCO has its own internal grievance and appeal process. For more in-depth information on MCO appeals and grievances, review your MCO handbook and see Disabilities Rights Center website's Question and Answer page on the subject, <http://www.drcnh.org/MMCappealsgrievances.html>.

Whenever an MCO takes an action you disagree with, you can appeal over the telephone or in writing. You also may designate someone, including your provider, to file the appeal for you. If you are a member of a Medicaid managed care plan, there are two levels of appeal. The first is a request for the MCO to review any action it has taken. You must go through the MCO's appeal process before requesting a fair hearing with the State. If taking the time to do this would seriously jeopardize your life or health or your ability to attain, maintain, or regain maximum function, you may request an **expedited resolution** of your appeal from the MCO.

Appealable MCO actions include: 1) denial or limited authorization of a requested health care service, 2) reductions or limits on services, 3) suspension or end of services, or 4) failure to provide services in a timely manner. You are entitled to receive a written notice at least 10 days before the MCO takes an action. You must file your appeal with the MCO within 30 days of the date of the MCO's written notice. *If you wish for your services to remain in place pending the appeal, you must file your appeal within 10 days of receiving the notice and specifically request that your services remain in place.*

MCOs are required to issue a written decision within 30 calendar days after receipt of your appeal request. The MCO is permitted to request an extension of up to 14 calendar days if: 1) you request the extension, or 2) if the MCO shows that there is a need for additional information and the MCO can show that the extension is in your best interest.

If you disagree with the MCO's resolution of your appeal, you may appeal the decision to the State and request a fair hearing. This is the second level of appeal. You must request a fair hearing within 30 days of the date of the MCO's written decision on your appeal **OR** within 10

days of receiving the decision if you wish for your services to remain in place pending the appeal. You must once again specifically request that your services remain in place pending the appeal, even if you requested continued services during your appeal to the MCO. If you lose your fair hearing, you may be responsible for the cost of continued services provided pending the appeal.

In New Hampshire, Medicaid fair hearings are usually held at the Administrative Appeals Unit in Concord or at your local District Office. A hearing officer from the Administrative Appeals Unit will conduct the hearing. Medicaid beneficiaries have a number of important procedural rights associated with fair hearings. You can learn more about those rights on our website, <http://www.drcnh.org/medicaidhearings.htm>. Pursuant to federal law, the State is required to issue a written decision within 90 days of the date you requested your first appeal to the MCO. This does not include the number of days it took for you to request a fair hearing with the State.

If you have a complaint for any reason other than an action taken by the MCO, including the quality of care or services provided; the way you are treated by your plan's employees, providers or contractors; or if you believe the MCO is not respecting your rights, you can file a grievance with your MCO over the phone or in writing. You may also designate someone to make the grievance for you. MCOs are required to resolve a grievance and provide notice to members within 45 calendar days from the date the MCO received the grievance. MCOs are required to respond in writing to grievances involving clinical issues. If your grievance does not involve a clinical issue, the MCO may respond to your grievance over the phone. An example of a non-clinical grievance is a complaint that an MCO employee was rude to you over the phone. You do not have the right to appeal the MCO's response to your grievance. However, you do have the right to voice any concerns to NH Medicaid at any time by contacting NH Medicaid Client Services at 1-800-852-3345, ext. 4344 or 603-271-4344.

Call the Disabilities Rights Center at 1-800-834-1721 for more information about the MCO grievance and appeal process or for advice and/or representation in a fair hearing. *This article first appeared in Brain Injury Association of NH Spring 2014 Headways Newsletter*

☆ FINDING THE GEMSS IN SCHOOLS: ☆

☆ How Genetics Education Materials for School Success (GEMSS) ☆ Can Help Your Child and School Team

By Ann Donoghue Dillon, parent, M.Ed., OTR/L

"If you are like me, I always had my eyes and ears open to learn about any information to help my daughter receive a good education. Having a genetic condition that was both rare and new for her school, she made all of us on the team try our best and then hope. I wish GEMSS was available when she was starting out in school! It would have been a great source of information that we could have used as a foundation, and then branched out as needed."

– Ann Donoghue Dillon

Are you the parent of a child who has a genetic condition such as Down syndrome, Fragile X, or Marfan syndrome? Do you spend energy wondering HOW your child should be included in typical school programs? You may want to check out the website GEMSS – Genetics Education Materials for School Success www.gemssforschools.org. New England Genetics Collaborative provides the site as a public service to help teachers and parents better understand the needs of children with genetic conditions.



GEMSS reinforces the belief that, ALL children, including those who happen to have a genetic condition, can be educated in typical classrooms alongside their peers if they have the right supports. Launched in 2012, GEMSS now features over 20 conditions, with more conditions being added to the site each year. The site also includes personal stories and interviews with parents and children who share their experiences and offer advice. GEMSS relies on feedback from parents, teachers, and viewers to help make the site as useful as possible.

For each condition, GEMSS addresses six important areas of school life:

- ◆ Dietary/Medical Needs
- ◆ Education Supports
- ◆ Behavioral and Sensory Support
- ◆ Physical Activity, Trips, and Events
- ◆ Emergency Planning
- ◆ Resources

GEMSS are tools for schools! They explain genetic conditions and offer helpful strategies for the classroom. GEMSS' *Print this page* feature makes it easy to share information. For example, you can find and print out a simple chart that gives parents and teachers a framework for reviewing educational plans.

Schools can use GEMSS to:

- ◆ Develop lesson plans/ IEPs
- ◆ Support children who are not diagnosed
- ◆ Prepare for educational and medical transitions
- ◆ Support for field trips
- ◆ Plan for meals and snacks
- ◆ Post link to Newsletter/Web
- ◆ Staff and parent education
- ◆ Develop emergency plan
- ◆ Modify physical activity/education

If your child's condition is undiagnosed or is not listed, GEMSS can still be a valuable resource. Clicking on the FAQs Section is a great place to start. You can also look under similar conditions to find ideas on how to help your child.



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JACK, "THE MAYOR"

Excerpt from GEMSS:
Fragile X - "Meet a Child"



"Jack is one of the happiest children I have ever met," says his mother. He has a smile that can light up a room and an endless supply of hugs. He is never too busy to say hello to a friend or to tell a stranger to "have a great day." Being such a friendly little guy has earned him the nickname "The Mayor" at his elementary school.

Jack loves tractors, trains, cows, and music of all types. "He is the only seven year old I know that enjoys listening to jazz while eating his after school snack or singing Tom Petty classics while getting dressed in the morning," quips his mother. He prefers British cartoons to American and has a whole repertoire of funny little voices and accents that he uses on a regular basis. It is difficult to be around Jack and not smile! In fact, when the family goes out into the community, it is not unusual for him to leave a trail of smiling strangers behind him.

Ever since Jack was a baby he has loved books. Snuggling and reading a favorite book has always made him feel better when sad or anxious. When he started talking at age four, his family realized that "he could read really well." They also realized his anxiety was more severe than they imagined. "Over the years he would spontaneously cry when we were outside. It was only after he started talking that he was able to tell us that he was afraid of car horns," his mother remarks.

Jack has made huge gains since his diagnosis of Fragile X Syndrome at sixteen months. "He has most of the symptoms typically found with Fragile X including: dyspraxia, sensory processing disorder, hypotonia, difficulty with communication and anxiety," according to his mother. But with dedicated and experienced school staff, private therapists, and peer supports, he has overcome the challenges that the symptoms cause.

The staff at his school communicates with his family and his private therapists on a daily basis to provide consistency. His classmates include him in school activities and social engagements outside of school. "They are a great group of kids who, despite being very young, are patient and supportive," his mother says. Jack has a nine year old brother named Michael who reminds Jack on a daily basis that he is "the best brother in the world."

His mother feels that "Jack will face many more obstacles as he grows but I am confident that he will continue to conquer them as long as he has the support he needs."

GEMSS – A Great Resource for Schools

Gretchen is a 6 year old girl who has Down syndrome. Her teacher, excited to welcome Gretchen into her first grade class, explored GEMSS website with the school nurse. They made a list of questions to ask Gretchen's parents at an upcoming get-acquainted meeting. Some of their questions included:

- *Does Gretchen have cardiac issues?*
- *Does she have any dietary restrictions?*
- *Does she have muscle tone issues that affect her eating or swallowing, or her ability to sit in the typical classroom chairs?*

Gretchen's parents, who had learned about GEMSS from a national list serve, also reviewed the site and developed their own list of questions for the meeting.

- *What communication strategies and technology can help Gretchen to fully participate in the regular curriculum?*
- *What therapies will help her fully participate in a typical day at school?*
- *What supports will help Gretchen develop socially and enjoy relationships with her peers?*
- *What can we do to be prepared for any emergency that may arise?*

When the team met, they not only worked through these questions, but also realized that they had more questions. They found additional information on GEMSS and sought input from others involved in Gretchen's care, including her pediatrician.

IOD TRAINING & EVENTS

Inclusive Education Webinar Series: Moving from Vision to Action

This live webinar series is designed to support parents and educators who want a road map to guide the membership, participation, and learning of students with more significant disabilities in general education classrooms and other inclusive settings.

May 13, 2014: Maximizing Social Relationships at School and at Home

May 27, 2014: Think College! Planning for Post-Secondary Education

Presenter: Dr. Cheryl Jorgensen

Time: 3:30pm - 4:30pm

Location: Online

Cost: \$59 each

Methods, Models, & Tools for Facilitated Person-Centered Planning

This course incorporates lecture, role-playing, action learning, and peer support to provide an interactive forum for participants to develop and practice effective group facilitation skills. The curriculum addresses theories of group development, offering experiential methods for process design, questioning and recording skills, and strategic planning.

Dates: May 22, 23, 29, 30, and June 2, 2014

Presenter: Patty Cotton, M.Ed., Pam McPhee, MSW

Time: 9:00am - 4:00pm

Location: NH Hall, 124 Main Street, Room G44, and The Browne Center, 340 Dame Road, Durham, NH

Cost: \$650*

**\$50/person group discount available (3 or more)*

**Required text available for purchase at first session for \$30.*



INSTITUTE ON DISABILITY / UCED
A University Center for Excellence on Disability

Advocate NH Annual Conference - Advocacy: Learn It! Live It! Love It!

This statewide conference will focus on self-advocacy skills and making connections that build community. The conference is open to all, but the content will cater to self-advocates in the developmental disability community. Participants will have opportunities to engage in hands-on learning and to network with other advocates.

Date: Saturday, June 28, 2014

Presenters: Keith Jones, Keynote Speaker, Founder SoulTouchin' Experiences

Time: 9:00am - 3:30pm

Location: Grappone Conference Center, Concord, NH

Cost: \$25

2014 Conference on School Culture, Climate, and Positive Behavior Support - What Works: Effective Strategies within Multi-Tiered Systems of Support

Establishing a safe school environment using a multi-tiered system of support improves outcomes for all students. This year's conference will include presentations by national leaders, instruction in cutting-edge strategies for school improvement, and opportunities for educators, youth, and community partners to work together.

Date: Wednesday, August 20 - Thursday, August 21, 2014

Presenter: George Sugai, Ph.D. and Hank Bohanon, Ph.D., Keynote Speakers

Time: 8:00am - 4:00pm

Location: SERESC Event & Conference Center, Bedford, NH

Cost: Professionals: \$379;
Teams of 3+, Family Members, or Full-Time Students: \$329 each;
Youth (ages 12+): Free

4 EASY WAYS TO REGISTER!



1 online
WWW.IOD.UNH.EDU



2 call to register or to request a registration form
603.228.2084



3 mail a completed registration form
INSTITUTE ON DISABILITY
56 OLD SUNCOOK ROAD, SUITE 2
CONCORD, NH 03301



4 fax a completed registration form
603.228.3270

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Improved Care for Chronic Disease - investments in innovations such as care coordination demonstrations in Medicare and Medicaid to prevent disabilities from occurring and progressing and to help the one in 10 Americans who experiences a major limitation in activity due to chronic conditions.

Making health insurance more affordable and accessible is a major component of the Affordable Care Act. New Hampshire is the latest state to take advantage of federal funding that expands the number of people eligible for Medicaid. In March, Governor Maggie Hassan signed into law legislation that will expand New Hampshire's Medicaid program to cover an additional 50,000 lower-income adults. Federal Medicaid dollars will be used to fund private health insurance for people making less than 138 percent of the federal poverty limit, or about \$16,000 a year for a single adult.

New Hampshire residents who are uninsured and cannot get coverage through work, now have access to the Health Insurance Marketplace. The Marketplace gives people the ability to review available health care plans and determine which plan makes the most financial sense, based on their medical needs. When people buy through the Marketplace, they are also eligible for tax subsidies that lower the cost of the monthly premium, making these plans even more affordable.

Covering New Hampshire is the state's official free resource for information on the Affordable Care Act. During the recent Open Enrollment period, Covering New Hampshire spoke with more than 100,000 people about their health insurance options under the Affordable Care Act. Covering New Hampshire and its website <http://coveringnewhampshire.org/> also offered people help comparing health care plans and enrolling online in the plan of their choice.

For 2014 coverage, the Open Enrollment period ended on March 31. Enrollment for 2015 plans won't open again until November 15, 2014. However, you may still be eligible to enroll for coverage through the Marketplace after Open Enrollment has closed if you have a complex situation related to applying in the Marketplace or have a qualifying life event. Examples of qualifying life events include:

- ◆ Marriage
- ◆ Having a baby
- ◆ Adopting a child or placing a child for adoption or foster care
- ◆ Moving outside your insurer's coverage area
- ◆ Gaining citizenship
- ◆ Losing other health coverage - due to losing job-based coverage, COBRA expiration, divorce, turning 26 on your parents' plan, or losing eligibility for Medicaid or CHIP. Important – Voluntarily ending coverage does not qualify you for special enrollment

For more information about special enrollment see <https://www.healthcare.gov/how-can-i-get-coverage-outside-of-open-enrollment/#part=2>

When the Health Insurance Marketplace reopens in November, New Hampshire residents will have more plans and options from which to choose. The Affordable Care Act not only has made health insurance more affordable, it has also ushered in new initiatives aimed at improving care for millions of Americans with disabilities. For more information about the ACA visit http://www.hhs.gov/od/affordable_care_act.html

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RAP Sheet

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

Spring/Summer Issue 2014

NH COUNCIL ON DEVELOPMENTAL DISABILITIES

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DISABILITIES RIGHTS CENTER, INC.

18 Low Avenue, Concord, NH 03301-4971

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

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

E-mail: advocacy@drcnh.org ◆ Website: www.drcnh.org

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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.

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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.

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

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