

RAP Sheet

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

Winter Issue 2015

PUTTING ALL THE PIECES TOGETHER



WHEN THINGS FALL APART

By Julia Freeman-Woolpert, Disability Rights Center - NH

Welcome to the Winter 2015 RAP Sheet. This issue focuses on meeting the needs of children with disabilities and their families, which includes ensuring access to quality health care, providing adequate supports and services, and creating school and community environments where all children are valued and included. While we have made significant advances in disability rights and health care reform, the personal stories shared by families in this issue show we still have a long way to go.

Closing in on his 21st birthday, Dylan Kulish is standing on the cliff of transitioning from special education to the adult services system. "We're in trouble," said his mother Cabrinni.

Even though Dylan has been a client of the area agency since he was three years old and has extensive service needs, there is no solid plan for how he will be supported after May. "Community Bridges wants to do person-centered planning," said Cabrinni, "but in the next breath they say there's no funding."

Cabrinni describes her son as amazing, "He's smart, funny. He's a giant teddy bear. He's a computer genius. When he's stable he's lovely." However, when he is upset and agitated, or as Cabrinni puts it, "wobbly," Dylan's severe behavioral outbursts put himself and others at significant risk.

When he was 17 Dylan had a major psychotic and violent episode. Since that time, the family has been ricocheting from one crisis to the next. Dylan's dual diagnosis of autism and mental illness make it especially challenging to find the help he needs. He has been in and out of Concord Hospital and New Hampshire Hospital. He has been admitted to Elliott Hospital in Manchester and treated at Hampstead Hospital, a private psychiatric facility on the Seacoast. He's gone across the border to McLean Hospital and Massachusetts General Hospital. For most of his hospitalizations, Dylan was discharged with no follow up plan; though, Hampstead did recommend that he be seen by his local mental health center.



Dylan Kulish on graduation day.

Photographer - Cabrinni Kulish-Tobin

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SUSAN COVERT, EDITOR

A COLLABORATIVE EFFORT BY THE

DISABILITY RIGHTS CENTER-NH, INSTITUTE ON DISABILITY, AND NH COUNCIL ON DEVELOPMENTAL DISABILITIES

(Cover story continued)

Through Community Bridges' START program for individuals with co-occurring intellectual disability and behavioral health needs, Dylan received a comprehensive evaluation from yet another hospital that included many recommendations, one of which was community mental health services. For two years Cabrinni waged a campaign to convince Riverbend Community Mental Health Center in Concord to see her son. Because of his dual diagnosis, Riverbend was reluctant to provide treatment. Finally, a few months ago the mental health center agreed to take Dylan on as client. Most of the other recommendations from the evaluation have yet to be implemented.

The severity of Dylan's illness requires supports that go far beyond mental health counseling. He needs constant supervision, including when he is up at night, and for the past several months that would be most nights. Currently, through a contract with the school district, two support staff from the Institute of Professional Practice (IPP) work with Dylan six hours a day, five days a week. Cabrinni believed that START also would be available to help if Dylan went into a crisis. Four months ago, when Dylan attacked one of his IPP staff, the agency called START for assistance. START informed IPP that they wouldn't be able to help, as Dylan had not yet turned 21, and recommended he go to the emergency room. Cabrinni came home, gave Dylan medication to calm him down and called the police who stayed at the house until Dylan was no longer dangerous.

Dylan's IPP services end in May when he ages out of special education services. Cabrinni has no idea how the family will cope. As it is, the stress of caring for Dylan has taken a huge toll. Both Cabrinni and her husband have been injured several times. Cabrinni, who is recovering from a stroke, suffers from severe depression and fibromyalgia. She is exhausted. For five years, she has been asking Community Bridges for funding to send Dylan to summer camp for a few days so she can have some time to herself. She is still waiting. With the exception of one three-day vacation, she hasn't had a break in years. Cabrinni has heard the mantra about using natural supports and she does have neighbors who are helpful and do what they

can, but they are afraid of Dylan and won't stay alone with him. "There's only so much natural support a family can do before they break," said Cabrinni.

In addition to the emotional and psychical stress that Dylan's illness has had on his family, there have been significant financial pressures. While Dylan is covered under Medicaid's Healthy Kids insurance, this program would not pay for his treatment at Hampstead Hospital. His father's medical insurance covered some of the bill, but the family still owes the hospital thousands of dollars. Two years ago, Dylan's SSI support was unexpectedly terminated. Cabrinni has been trying without success to find out why he was cut off and get his SSI reinstated. She said, "I have a few hours Friday morning when I should go try to resolve this at Social Security, but I've been up for the past five nights, and at this point I'm so fried, broken, and twisted I just can't face it."

The family loves Dylan and wants him to keep living at home, but that will only be possible with adequate supports. They would like his IPP program to continue and the recommendations from his evaluation to be implemented. "Without help, we wouldn't last five days," Cabrinni said. Ironically, if help isn't provided, Dylan likely will be placed in a residential program that will be far costlier than the community supports the family is asking for. Stating the obvious, Cabrinni noted, "It makes no sense."



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In Memoriam

Arpiar G. Saunders, Jr.

This issue of the RAP Sheet is dedicated to Arpy Saunders who died November 18, 2014. A gifted attorney and lifetime champion for social justice, Arpy began his career in the Judge Advocate's General Corp of the U.S. Army. Following his military service he joined the ACLU's National Prison Project. In 1976 he moved to New Hampshire to work as Director of Litigation for New Hampshire Legal Assistance where he helped oversee the Laconia State School class action lawsuit, which resulted in the development of a community based service system for individuals with developmental disabilities and the eventual closing of the institution. In the 1990's Arpy was a key member of Claremont Education Lawsuit legal team representing five school districts challenging the



constitutionality of New Hampshire's funding for education. In 1997 the New Hampshire Supreme Court, ruling in favor of the school districts, held that every child in New Hampshire had the right to a state funded, constitutionally adequate public education. Throughout his life, Arpy gave generously of his time and expertise. He served for twelve years on the Hopkinton School Board and for more than thirty years on the Board of Directors for the New Hampshire Office of Public Guardian. He also was on the Boards of Directors for Riverbend Community Mental Health Center and the Disability Rights Center - NH.

New Hampshire is a better place because of Arpy Saunders. His fierce advocacy and gentle spirit will be greatly missed.



CHARTER SCHOOLS AND CHILDREN WITH DISABILITIES

By Bonnie Dunham, Special Education Law and Policy Specialist, Parent Information Center

There are 3 key things that parents of children with disabilities should know about charter schools:

- ◆ Charter schools, also called chartered public schools, are public schools.
- ◆ Children with disabilities have the same right to attend charter schools as do children without disabilities.
- ◆ Children with disabilities have a right to a free appropriate public education (FAPE) whether they are attending a public charter school or a public district (traditional) school; this includes receiving all of the services in the child's individualized education program (IEP).

Charter schools receive public funding, but operate independently. The "charter" establishing each school lays out the school's mission, parent involvement philosophy, program, goals, curriculum, and assessment methods. Charter schools were established under the premise that freedom from some regulations that apply to traditional public schools would allow for greater innovation and that the opportunity to try new educational approaches would provide increased knowledge that would benefit all public schools. There are currently 22 charter schools in the state, including elementary, middle, and high schools. Charter schools typically have

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MEDICAID COVERAGE FOR CHILDREN WITH IEPS

By Karen Rosenberg, Senior Staff Attorney, Disability Rights Center - NH

Question: As part of his IEP my son receives occupational therapy at school to help improve his fine motor and writing skills. I agreed to allow the school to bill Medicaid for this therapy, but now our managed care company says it won't cover additional occupational therapy that the doctor says is necessary for my son to develop other abilities, like tying his shoes and brushing his teeth. These are skills he needs in order to live independently. The managed care company says they are not required to cover "duplicative services." Is this legal?

Answer: The short answer to your question is "No." A New Hampshire law that went into effect in September 2014 makes it clear that the state's Medicaid program, including the Managed Care Organizations (MCOs) that have contracted with the state to operate its Medicaid Program, may not use the fact that a child's school is billing Medicaid for services related to the child's individualized education plan (IEP) as a reason to deny Medicaid coverage for the same or similar medically-necessary services that the child receives outside of his or her school program.

The new law, RSA 186-C:29, clarifies that the related services a child receives as part of his or her IEP are "for the sole purpose of enabling the child to benefit from special education or to receive a free appropriate public education" and are not intended to meet all of the child's medical needs. Further, this law provides, "If a child receives Medicaid-funded services as part of the

child's special education program and also receives the same or similar medical services outside of the child's special education program, the services that are provided outside of the child's special education program shall not be considered to be duplicative provided such services are medically necessary and not inconsistent with federal Medicaid law." (Emphasis added).

The new law provides an additional protection for parents and children with disabilities by making it unlawful for a Medicaid provider, including MCOs or private providers receiving any Medicaid payment, to require a parent to provide the child's IEP as a precondition to decide whether the child may obtain Medicaid coverage for medical services outside of the child's special education program. Upon making a request, the state Medicaid agency or MCO is entitled to receive a list of the related services in the child's IEP that are eligible for Medicaid reimbursement. However, neither the state Medicaid agency, MCOs or Medicaid providers may use the fact that a child is receiving Medicaid-covered related services as part of his or her IEP to deny coverage for medically-necessary services even if they appear to be identical to services the child receives at school.

If you have questions about the new law or believe your child has been denied Medicaid coverage for medically necessary services, please call the Disability Rights Center-NH toll free number 1-800-834-1721 or email advocacy@drcnh.org

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WE FOUND HOPE – NOW WE NEED A PROMISE

By Amy Girouard, LICSW and healthcare advocate, Graduate of the NH Leadership Series Class of 2013-14

Hope and promise were two words that I never would have used when my daughter Ally was diagnosed in 2007 with Angelman Syndrome. She was not quite a year old and I thought her life was over before it had started. Angelman Syndrome (AS) is a severe neurological disorder characterized by profound developmental delays, problems with motor coordination and balance, and epilepsy. Individuals with AS do not develop functional speech. (For more information visit the Foundation for Angelman Syndrome Therapeutics website at www.cureangelman.org)

AS affects Ally's ability to do many things that other children do with ease. She was five before she walked and she still requires help to get dressed. Ally, who is considered nonverbal, uses a communication device to let us know what she needs and wants. While she understands what is being said, her ability to engage in reciprocal communication is limited which often causes her intelligence to be questioned. This is one of the more frustrating aspects of AS. Ally is intelligent, funny, persistent, and loving. Her effervescent smile and personality capture hearts and open minds. People are drawn to Ally in a way that I never thought possible.

This is especially true at school. Ally is a second grader at Beaver Meadow School in Concord where she is fully included in the general education setting. She has the proper supports to help her succeed in the classroom; for example, her worksheets are on an IPAD instead of requiring the use paper and pencil. Ally is allowed to make mistakes and learn from them. At school Ally is learning about addition, subtraction, spelling, reading, and friendship.

The most heartwarming part of being included is the friendships that have happened. Ally now has friends who worry if she is not in school and who celebrate when she is there. Beaver Meadow fosters a true sense of community for Ally and we are forever grateful for that gift. This experience has given us hope for Ally's future. We hope that she will continue to have teachers and aides who believe in her potential and receive the supports she needs to be included both in school and in her community.

Unfortunately, the promise of a bright future ends at the end of the school day. After school Ally is at home where she receives support from a nurse's aide (this is funded through Medicaid). Due to Federal and State laws, her

aide is only able to provide care and support within our home. The focus is on meeting Ally's medical needs; her aide is not allowed to support her to participate in after school programs, sports, or in any activity that takes place outside of the home. The Federal Centers for Medicare and Medicaid are working to change this, but it is a slow process. For more than three years we have been fighting to find a way to include Ally in our community. She is on our Area Agency's waitlist for in-home supports, but no one can tell us when the funds will come through. It is extremely disheartening that there seems to be no system that can help Ally obtain a full life outside of school.

Ally loves being a part of the crowd and learns best when surrounded by her peers. For Ally, there are no other children around after school. She is looking out from behind a glass door that she cannot open while other kids in her class are at after school programs, joining sports teams, and going on play dates. For children without disabilities, this is where the real friendships are made. These kids enjoy the camaraderie of working on a team for that goal and know how good it feels to hear friends shout when you nail a backflip at gymnastics.

True inclusion goes beyond being part of a classroom. Communities, schools, and governmental agencies need to work together to break down the barriers to full inclusion. Ally and others like her have so much to offer. Let's open that glass door so that children like Ally have the promise of a future filled with every day experiences, friendships, and hope.

Post Script – Just as this issue was getting ready to go the printers we received an update from Amy Girouard. "It has taken us 3+ years to secure an after school program for Ally and it looks like we, as a community, have done it!" The family has been working closely with Community Bridges and NHTI to find a solution. Ally will be attending an after school program two days a week; the program, which takes place on the school grounds, is run by YMCA. Ally will receive support from an NHTI student who is pursuing a career in early childhood education. The YMCA will be supervising the student.



Friends

Photographer – Amy Girouard



SWIFT ACTIVITIES IN THE GRANITE STATE WHERE ALL MEANS ALL!

By Maura Hart, Ph.D., NH LEA Facilitator, SWIFT and Mary Schuh, Ph.D., Director of Development and Consumer Affairs, University of NH/Institute on Disability

The SWIFT Center, a national education initiative, with funding from the Office of Special Education Programs, provides academic and behavioral supports that make it possible for **all students** to be educated in their neighborhood public schools alongside their grade-level peers.

What do we mean by all students? Students who are struggling readers, gifted, living in poverty, students with disabilities, high achievers, culturally and ethnically diverse students, and those with the most extensive needs. Just imagine a busy, vibrant school filled with classrooms where students with a wide range of abilities are working and playing together and engaged in meaningful learning. A school where special and general education silos are eliminated and resources are provided so that all students have the supports they need to succeed. In this school, all adults (teachers, aides, administrators, and support staff) share the responsibility for teaching and supporting student learning and families and community members are integral and valued partners in the process.

Research has found that several components need to be in place in order to effectively meet the needs of ALL students; these include: administrative leadership, a multi-tiered system of support, family and community partnerships, an integrated educational framework, and inclusive policies and practices. SWIFT (Schoolwide Integrated Framework for Transformation) is committed to creating powerful inclusive learning opportunities for students and teachers and promoting active, engaged partnerships among families and community members.

In collaboration with the New Hampshire Department of Education, SWIFT is currently working with four school districts (SAUs 13, 60, 64, and 81) and providing ongoing technical assistance to eight partner schools in the Granite State. One of these schools, Charlestown Primary School in the Fall Mountain Regional School District, is developing a school culture focused on equity and excellence in education for all students. For the first time, children with significant disabilities in Charlestown are fully included in their neighborhood school and enrolled in age appropriate general education classrooms. The school district has shut down its self-contained "school" that had served many students with disabilities.

Brenda Olson, a third grade teacher at Charlestown Primary, reflected on the first week of school. She was pleased with how well all the students in her class were doing and found that the student who had come from a segregated program was much more capable than what was documented in his IEP. Charlestown's principal, Chris Young, had anticipated this and asked that the planning teams for recently transitioned students meet to review and revise the IEPs for these children to reflect their new inclusive environment. The district also provided a stipend for teachers in inclusionary classrooms and special educators who had worked with transitioning students to meet for a full day prior to the beginning of the school year. The focus for the planning day included discussion about the teaching methods and accommodations that would best meet the student's educational needs, as well as how to make sure that these children would be fully included in all aspects of the classroom communities to which they now belonged.

The implementation of the SWIFT Framework is changing lives and helping schools to be places where children learn in a community that values the contributions of each and every student! In 2015, the New Hampshire Department of Education will be inviting new schools to participate in the New Hampshire SWIFT initiative. If your school community is interested in becoming a SWIFT implementation site, please email Maura Hart at maura.hart@unh.edu

For additional information about the SWIFT Center visit their website at <http://www.swiftschools.org/> and like SWIFT Schools on Facebook.



In SWIFT schools everyone is included.



YOU ARE NOT ALONE

Support for families with children who have special health care needs

By Terry Ohlson-Martin, New Hampshire Family Voices

Did you know that more than **one in five** families in our country has at least one child with special health care needs? These families have children with physical, developmental, behavioral, and emotional health care needs and represent a wide range of conditions including autism, cerebral palsy, developmental delay, intellectual disabilities, depression, learning disabilities, and epilepsy. My family is one of these families.

When my son was born, some 34 years ago, I would have sworn I was the only parent of a child with special needs. Although I soon discovered I wasn't alone - finding help wasn't easy. While he is no longer a child, I am still a parent and I remember well the difficulty of trying to figure out how to access services. Diagnosis of special health care needs presents families with a myriad of issues. Our families typically experience greater economic stress due to high out-of-pocket medical expenses. We also face a steep learning curve when confronted with the task of navigating multiple and complex systems of care. While there are more supports now than when I started out, I recognize that there is still nothing "easy" about finding the help your child needs. You need to start somewhere and that's where New Hampshire Family Voices can help.

New Hampshire Family Voices is a Family-to-Family Health Information and Education Center established to provide the tools and information that families need to make informed decisions. We are a family run program and know New Hampshire systems and services from first-hand experience. We've been there. We can explain how things work and tell you who is supposed to do what. We are here for the long haul and available to answer your questions as you live, love, and grow with your child.

For New Hampshire families who have children with special health care needs, the Department of Health and Human Services also provides additional supports through Special Medical Services and New Hampshire Partners in Health.

Special Medical Services (SMS) includes health programs and services for children from birth until age 21 who have, or are at risk for, a chronic medical condition, disability, or special health care needs. The services



Photographer - Dan Habib

offered through SMS are provided at no cost to families and include, but are not limited to, a Nutrition, Feeding and Swallowing Program, Neuromotor Clinic Program, Child Development Clinics, and Care Coordination. SMS also makes referrals to a variety of medical specialists and connects families to New Hampshire Family Voices and New Hampshire Partners in Health.

New Hampshire Partners in Health is a community based, statewide program that is free for families who have a child under the age of 21 with a chronic physical health condition that is expected to last 12 months or longer AND that either affects the child's ability to function daily or requires frequent and intensive medical care. The role of Partners in Health is to advocate, access resources, navigate systems, and support families to manage the chronic health condition of their child.

New Hampshire Family Voices, Special Medical Services, and Partners in Health all strive to assist families, their children, and the professionals who serve them. Give any of us a call, I promise – you're not alone.

For more information call or visit our websites –

New Hampshire Family Voices

www.NHFV.org

800-852-3345 ex 4525 or 271-4525

Special Medical Services

<http://www.dhhs.nh.gov/dcbcs/bds/sms/>

800-852-3345 ex 4488 or 271-4488

Partners In Health

<http://www.dhhs.nh.gov/dcbcs/bds/sms/pih/index.htm>

800-800-656-3333



THE RIGHT TO PARTICIPATE IN EXTRACURRICULAR SCHOOL ACTIVITIES

By Julia Freeman-Woolpert, M. Ed., Disability Rights Center - NH

Full inclusion in a school community extends well beyond the walls of the classroom. Participation in school sports, clubs, and activities are important to a child's education and development. Extracurricular activities encourage fitness, promote teamwork, build social skills, support community involvement and, perhaps most importantly, lead to friendships. Many schools recognize that *fully* including students with disabilities in all aspects of school life benefits the entire student body. More than ever, students with disabilities are joining sports teams, playing in the school band, serving on student council, and volunteering with service clubs. They are participating in field trips and attending school dances, plays, pep rallies, and other after school activities.

Providing an equal opportunity to participate in extracurricular school activities is not only the right thing to do, it's also a legal right under Section 504 of the federal Rehabilitation Act of 1973 (Section 504).

Section 504, which guarantees civil rights for people with disabilities, covers any program or activity that receives federal assistance, including public and charter schools. Under Section 504, students with disabilities have a right to

equal access to and participation in extracurricular school activities. Schools are required to provide a student with a disability the same opportunity to benefit from the program or activity as other students and to provide reasonable accommodations. A student who uses a wheelchair cannot be excluded from a field trip because the school did not arrange for accessible transportation. A school club cannot exclude a student because he or she needs the support of an aide to maintain appropriate behavior during meetings.

However, Section 504 does not require schools to make fundamental alterations to the programs or services, or change the basic nature of the activity. For example, in putting together a competitive team, the school may use selection criteria to choose team members, as long as these criteria are not discriminatory. The student cannot be excluded based on disability if he or she is otherwise qualified for the team. An athlete with diabetes who tries out and makes the basketball team cannot be excluded from participating because she needs assistance with glucose testing.

The federal Individuals with Disabilities Education Act (IDEA) also provides protections. IDEA stipulates that each student's IEP must contain a statement of the special education and related services and supplementary aids and services that will enable a child "to be involved in and make progress in the general education curriculum... and to participate in extracurricular and other nonacademic activities." The IEP team must determine what specific aids and services are needed to support the student's participation in extracurricular activities and include these in the student's IEP. Supplementary aids and services include things such as transportation, staff assistance, extra time to learn a skill, adaptive equipment, or training for personnel.

If you have questions or believe that your child is being denied the right to participate in extracurricular activities, please call DRC at 1-800-834-1721.



Photographer - Dan Habib

Full inclusion happens inside the classroom and out.



FEDERAL HEALTH REFORM EXPANDS PRIVATE INSURANCE COVERAGE OF SERVICES FOR CHILDREN WITH DISABILITIES

By Carol Stamatakis, Executive Director, NH Council on Developmental Disabilities

The Affordable Care Act (ACA), frequently referred to as ObamaCare, provides families of children with disabilities access to services through private insurance that in the past often were not covered.

Under the ACA, states are required to establish minimum "essential health benefits" that must be included in all individual and small group (currently 50 or fewer employees) insurance plans, including all plans sold on the Health Insurance Marketplace, also known as the Exchange. Plans that were in existence on March 23, 2010 are an exception. These can be "grandfathered" and do not have to comply with most of the ACA rules and regulations, as long as their costs and benefits do not change substantially. Insurers must notify consumers with these policies that they have a grandfathered plan. In addition, some non-compliant individual and small group policies have been extended as a result of a federally authorized transitional policy. The essential health benefits for each state are subject to change in the future.

All policies offered on the Exchange must be compliant and provide essential health benefits that include items and services within 10 categories. A category of particular importance to families of children with disabilities is "rehabilitative and habilitative services and devices." Historically, health insurance plans covered rehabilitative services, such as physical, occupational, and speech therapies, to help people recover abilities that they had lost due to an accident or illness. However, plans generally did not cover comparable habilitative services that help individuals with disabilities develop or maintain skills, such as speech or fine motor movement. Other categories of essential health benefits are pediatric services, including dental and vision care, and mental health and substance abuse services, which must comply with federal parity protections and provide coverage that is generally comparable to coverage for medical and surgical care.

Each state defines the details of its essential health benefits through the adoption of a "benchmark plan." New Hampshire's benchmark plan includes services mandated by State law that are important to families of children with disabilities, including early intervention services, hearing aids, and autism therapy (as required by "Connor's Law"). Many of the State law protections were a direct result of advocacy by people with disabilities and their families. Full details on the New Hampshire Benchmark Plan and specific benefits can be found at <http://www.cms.gov/CCIIO/Resources/Data-Resources/ehb.html> and <http://www.nh.gov/insurance/lah/index.htm>.

Unfortunately, self-insured plans governed by federal law are not required to provide the benefits required by State law or the essential health benefits applicable to individual and small group plans under the ACA. Large employers (those with 50 or more full-time employees) are not required to include essential health benefits in their plans. One option for families who have employer provided plans that do not cover needed services, such as Applied Behavior Analysis for autism, is to purchase a separate child-only plan through the Exchange that includes these benefits.

In addition to services included in the essential health benefits, the following ACA provisions are applicable to most policies and provide important protections for children and adults with disabilities:

Coverage of preventive health services without cost-sharing - The following pediatric screenings are available without co-insurance or co-pay, even for those who have not met their deductible:

- ◆ Autism screening for children at 18 and 24 months
- ◆ Behavioral assessments for children
- ◆ Developmental screening for children under age 3
- ◆ Hearing screening for all newborns
- ◆ Depression screening and alcohol and drug use assessments for adolescents

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MY CHILD IS BEING BULLIED. WHAT CAN I DO?

By Julia Freeman-Woolpert, M. Ed., Disability Rights Center - NH

All children deserve to grow and learn in caring and supportive settings. What happens in a child's early years is critical to healthy emotional development and to success in adulthood. Sadly, students with disabilities are more likely than their peers to be bullied or harassed. Much has been said and written about bullying in recent years and there are now a variety of programs to address bullying in schools. However, bullying still occurs and sometimes schools look the other way.

Every year the Disability Rights Center – NH (DRC) receives calls from parents whose child is being bullied and the school is failing to address the problem. Occasionally, a staff member is the one doing the bullying. Some parents are hesitant to confront the school, fearing that their involvement will result in retaliation. Others conclude the only way to stop the bullying is to seek an out of district placement. It is important for parents to know there are steps they can take to protect their child.

Federal and State law offer protections for students with disabilities from bullying and harassment.

New Hampshire's Pupil Safety and Violence Prevention Law (NH statute, RSA 193:F) was enacted to protect children from bullying and cyberbullying that occurs in schools and at school sponsored activities. The law also applies to bullying that occurs in non-school settings if the bullying interferes with the student's education or disrupts the school's operations. The law requires school districts to have a policy prohibiting bullying and protecting students that includes procedures for reporting, notification to parents within 48 hours, and an investigation within 5 school days. The policy also must prohibit retaliation and include disciplinary consequences for the bully, when these are necessary to reduce the risk of future incidents.

Bullying due to a disability is a violation of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act. The US Department of Education, Office for Civil Rights (OCR) has issued a series of letters to public schools providing detailed guidance on addressing bullying and harassment. In its letter issued on October 21, 2014, OCR states that bullying of a student with a disability on the basis of the disability is a violation of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act. If the school knows, or should know of such bullying, Federal law requires the school to take immediate and appropriate action to

investigate the issue, and to take steps to end the bullying, eliminate the hostile environment, prevent its recurrence, and remedy its effects.

What about bullying and special education? OCR makes it clear that there are protections under the Individuals with Disabilities Education Act (IDEA) and Section 504 for students with disabilities who are bullied on *any* basis (not just on the basis of a disability). The school should convene an IEP team meeting to address any changes in the student's needs, and determine what is necessary to provide the student with a meaningful educational benefit. OCR recommends convening the team if the student's needs have changed, if the bullying affected the student's educational services, or if additional services are necessary. The school must take appropriate steps to ensure needed changes are made promptly.

Examples that a child has been negatively affected by bullying include a sudden drop in grades, an increase in emotional or behavioral problems, and increased absences. If the school's investigation indicates that bullying based on disability created a hostile environment or affected the student's ability to receive an education, the school has a legal obligation to address the concerns related to the student's special education and related services.

There are steps you can take if your child is bullied

1. Know your rights. Call DRC if you need more information or advice about your situation.
2. Don't wait! If bullying is hurting your child, address the problem right away.
3. Get a copy of the school's reporting and complaint process, and use it. Read it carefully, follow the steps to file a complaint, and make sure the school adheres to its own policies.
4. Document the problem. Take good notes on what your child or others tell you is happening, the effects of bullying on your child, what you have asked the school to do, and what the school's response has been. Keep copies of anything you send and all related paperwork. If things don't get better, this record will be important in resolving the problem at a higher level.
5. Call an IEP team meeting to look at whether your child's needs have changed due to the bullying, and what modifications to the plan and/or placement need to be made to assure your child receives FAPE.
6. File a complaint with Office for Civil Rights. For information on the complaint process - <http://www2.ed.gov/about/offices/list/ocr/complaintprocess.html>

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a specific areas of focus, in New Hampshire these areas include: the arts; science, mathematics, engineering and design; arts and technology; classical studies; service- and community-based learning; individualized and strength-based instruction; Montessori approach to learning; career-prep; college-prep; underperforming and/or at-risk students; Orton-Gillingham approach to literacy; and distance/e-learning.

RSA 194-B is New Hampshire's charter school law; it includes information about the procedures for charter schools, the funding mechanisms that support them, and specific requirements that apply when a child with a disability enrolls in a charter school. Under RSA 194-B, the State Board of Education is responsible for granting new public school charters and must ensure that charter schools meet the requirements in the law. Charters are renewed every 5 years; their renewal can be jeopardized if student assessment scores or other performance measures are poor. In response to the Federal Elementary and Secondary Education Act, the New Hampshire Department of Education has a "profile" for each school district and city or town; each charter school also has its own profile, which includes performance or assessment data. For more information see - <http://my.doe.nh.gov/profiles>

While a founding principle of charter schools is freedom from many regulations governing public schools, charter schools must abide by all of the Federal and State special education laws and all civil rights laws. Charter schools must be non-secular and have open enrollment, which means they are open to any New Hampshire student who is of the age and/or grade(s) served by the school. If a charter school has more applicants than the school is approved to serve, the school must hold a lottery to determine admission. When a parent enrolls a child with a disability in a charter school, the child and the child's parents retain all rights under Federal and State special education law, including the child's right to be provided with a FAPE and to receive all of the special education and related services included in the child's IEP. (It is important to note that these same rights do not apply when a parent chooses to enroll his/her child with a disability in a private school.)

Charter schools are schools of choice; only a parent can decide to enroll his/her child in a charter school. For a child with a disability, the IEP team can neither place a child in a charter school nor can the team block a parent's decision to enroll a child to a charter school. When a student with an IEP is enrolled in a charter school, the child's resident school district conducts the IEP team meetings and must invite a representative of the charter school to the meeting. The school district in which the student resides remains responsible for implementing the child's IEP. The services in the child's IEP are to be provided, with the cooperation of the charter school, and in the least restrictive environment. IEP services for students attending charter schools may be provided in a variety of ways including: 1) at the charter school by staff from the resident school district and/or by personnel contracted by the resident school, 2) by the charter school under a contract with the resident school district, 3) at a public school in the resident district, and/or 4) at the service provider's location. If a child with a disability needs transportation to and/or from the charter school (including during the school day) to receive special education and/or related services, transportation should be included in the child's IEP and it must be provided by the resident school district.

The NH Bureau of Special Education's FY 2013 Memo #10 answers many questions about charter schools and students with disabilities, including questions related to funding and the provision of special education and related services. This memo may be found at:

http://www.education.nh.gov/instruction/special_ed/documents/fy13_memo10_chartered_public_school_funding.pdf



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REQUESTING MEDICAID COVERAGE FOR AUTISM SERVICES UNDER EPSDT

By Rebecca G. Whitley, Staff Attorney, Disability Rights Center

The Centers for Medicare & Medicaid Services (CMS) recently provided guidance related to Medicaid coverage for beneficiaries with Autism Spectrum Disorder (ASD). CMS makes clear that medically necessary autism treatment for Medicaid eligible children must be covered in accordance with the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) provisions of the Medicaid Act.

What is EPSDT?

EPSDT is Medicaid's mandatory comprehensive health program for children under the age of 21. EPSDT requires states to cover medical services when necessary "to correct or ameliorate" any physical or behavioral conditions. Unlike the adult Medicaid program, EPSDT requires coverage of all medically necessary services that could be covered under federal Medicaid law. States are not required to pay for services that are not medically necessary. States like New Hampshire that contract with managed care organizations (MCO) to provide health insurance for Medicaid recipients must also ensure that MCOs comply with EPSDT's coverage requirements.

Does Medicaid cover ABA?

Intensive Applied Behavioral Analysis (ABA) is an evidence-based treatment associated with positive outcomes for children with ASD. New Hampshire law mandates *privately* funded group health insurance plans to cover ABA for individuals up to age 21 who have been diagnosed with Pervasive Developmental Disorder and Autism. While ABA is not included in New Hampshire's Medicaid State Plan, CMS's recent guidance on ASD specifically references ABA, speech and language therapy, occupational therapy, and physical therapy as Medicaid-coverable treatments for children with ASD and makes clear that medically necessary autism treatment must be covered in accordance with the EPSDT provisions of the Medicaid Act.

CMS identifies several Medicaid benefit categories that may be used to cover autism treatment under EPSDT (preventive services, services of other licensed practitioners and therapy services). CMS's guidance confirms that ABA must be covered by Medicaid under EPSDT when medically necessary to correct or ameliorate a particular individual's ASD and no alternative treatment is appropriate or available for that individual.

How do I access coverage for ABA when medically necessary for my child?

To access coverage for ABA for a child, families and providers must first request prior authorization from the appropriate state contractor, MCO, or MCO contractor. Because ABA is not currently in New Hampshire's State Medicaid Plan, the request for prior authorization must be submitted according to the EPSDT provisions and detail the medical necessity of the therapy for the particular child. For Medicaid beneficiaries under the age of 21, New Hampshire defines "medically necessary" as "*reasonably calculated to prevent, diagnose, correct, cure, alleviate or prevent the worsening of conditions that endanger life, cause pain, result in illness or infirmity, threaten to cause or aggravate a handicap, or cause physical deformity or malfunction, and no other equally effective course of treatment is available or suitable for the EPSDT recipient requesting a medically necessary service.*"

The EPSDT request for prior authorization should be as specific as possible (e.g. 30 hours a week of ABA) and reference EPSDT and the standard for coverage described above. Additionally, the request should include any applicable diagnostic evaluations, a letter of medical necessity from the child's treating doctor, and any other documentation supporting the medical necessity of the requested service at the requested level.

If the child has Fee-for-Service Medicaid (i.e. the child's Medicaid is administered by the New Hampshire Department of Health and Human Services), the EPSDT request for prior authorization must be submitted through KEPRO, the State's contractor for Medicaid utilization management.¹ Before submitting the EPSDT request for prior authorization, families and providers should review He-W 546, New Hampshire's EPSDT rule.² In particular, Section 546.06 of the rule provides detailed instructions about what must be included in an EPSDT request for prior authorization based on medical necessity.

There is a different process for EPSDT requests for prior authorization when the child has Medicaid through one of the state's two MCOs, Well Sense or New Hampshire Healthy Families. Well Sense contracts with Beacon Health Strategies, LLC, to manage behavioral health

services and New Hampshire Healthy Families contracts with [Cenpatico](#) to manage behavioral health and specialty therapy services.³ The EPSDT request for prior authorization based on medical necessity for coverage of ABA must be submitted through either Beacon or Cenpatico.

Can I appeal a denial or limited authorization of ABA?

Despite the strong federal EPSDT provisions to protect children's health, state Medicaid programs (including state-contracted MCOs and MCO subcontractors) do not always comply with the law. Medicaid agencies may attempt to provide limited authorization or deny access to particular healthcare services for children and youth. Medicaid recipients have a right to appeal any denials, limited authorizations, or termination of treatment that they believe is medically necessary. Appeals may be filed with the New Hampshire Department of Health and Human Services' Administrative Appeals Unit (AAU). For more information on appeals to the AAU see "*Fair Hearing Rights Under Medicaid*," <http://www.drcnh.org/medicaidhearings.html>

If the service coverage dispute is with a MCO or MCO contractor, you must first follow the MCO's appeal process. If you are not satisfied with the result of the MCO appeal, you may request a fair hearing before an impartial hearing officer at the AAU. For more information on MCO appeals, see "*Know Your Rights: New Hampshire Medicaid Managed Care Health Plans - Your Right to Appeal or File a Grievance*," available at www.drcnh.org/MMCappealsgrievances.html.

If you have specific questions or concerns regarding Medicaid coverage for autism services, feel free to contact the Disability Rights Center - NH at 1-800-834-1721 to schedule an appointment with one of our intake attorneys.

¹ See <https://nhmedicaid.kepro.com/> for more information.

² He-W 546 can be found at: http://www.gencourt.state.nh.us/rules/state_agencies/he-w500.html.

³ See <http://beaconhealthstrategies.com/> and <http://www.cenpatico.com/> for more information on the MCO subcontractors.

(Continued from page 9)

Pre-Existing Conditions - Insurance companies are prohibited from denying, limiting, or charging more for coverage due to pre-existing conditions. The only exception is grandfathered individual policies.

Young Adults up to age 26 - Children can now stay on their parents' health plans until age 26, whether or not they are full-time students.

End of Lifetime Coverage Caps - Insurance companies can no longer impose lifetime or annual benefit caps. However, insurers may still cap specific individual benefits in a calendar year.

The New Hampshire Department of Insurance maintains a hotline (1-800-852-3416 and email consumerservices@ins.nh.gov) for consumers and provides information through their web site at <http://www.nh.gov/insurance>.

Open enrollment for individual plans for 2015 began on November 15, 2014 and ends February 15, 2015. These dates apply to all individual health insurance plans, regardless of whether they are purchased through the Exchange. New Hampshire residents buying individual market coverage will not be able to buy 2015 coverage or change their plans after February 15, 2015 unless they have a change in circumstances, such as marital status, employment, or having a child. The best source of information about all provisions of the Affordable Care Act is the website maintained by the U.S. Department of Health and Human Services at - www.healthcare.gov

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IOD TRAINING & EVENTS



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PBIS Universal Team Training: Getting Organized to Implement PBIS!

This daylong retreat will help school district teams with implementation of PBIS and will include time for individualized team-self-assessment and planning.

- Date:** March 26, 2015
Presenters: Joanne Malloy, Ph.D.
Time: 8:00am - 3:00pm
(Registration begins at 7:30 am)
Location: Holiday Inn, 172 North Main Street, Concord, NH
Cost: \$199 individual,
\$99 member of a group 3 or more

RENEW Facilitator Training Institute

Two day institute about the Rehabilitation for Empowerment, Natural supports, Education, and Work (RENEW) model and process. *Approved by the NH NASW for 14 Category 1 Continuing Education Units.*

- Date:** April 1 -3, 2015
Presenters: Joanne Malloy, Ph.D., Jonathon Drake, MSW, Heidi Cloutier, MSW, and Kathy Francoeur, M.Ed.
Time: 8:30am - 3:00pm
Location: Holiday Inn, 172 North Main Street, Concord, NH
Cost: \$399

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PBIS Behavioral Support Team Training

Participants will explore evidence-based interventions using case examples from area schools and will design interventions for their school, with a focus on progress-monitoring and sustainability.

- Date:** April 7, 2014
Presenter: Kathy Francoeur, M.Ed.
Time: 8:00am - 3:00 pm
Location: Holiday Inn, 172 North Main Street, Concord, NH
Cost: \$119 individual,
\$99 member of a group of 3 or more

NEGC Annual Meeting

Join the New England Genetics Collaborative (NEGC) at their Annual Meeting to receive updates on research and projects taking place around the region.

- Date:** April 9-10, 2015
Location: Hilton Garden Inn, 100 High Street, Portsmouth, NH
Cost: Free



LEGISLATIVE COMMITTEE STUDIES SPECIAL EDUCATION SERVICES AT CHARTER SCHOOLS FOR STUDENTS WITH DISABILITIES

By Christopher Rueggeberg, Policy and Planning Director for the New Hampshire Council on Developmental Disabilities

In its 2014 session, the New Hampshire Legislature passed HB 1128 - *An Act Establishing a Committee to Study Issues Related to Students Receiving Special Education Services While Attending a Chartered Public School*. The HB 1128 Study Committee issued its final report on November 1, 2014.

The HB 1128 Study Committee members included Senator Nancy Stiles, and Representatives June Frazer, Mel Myler, and Jeffrey Harris. The committee was charged to study issues related to services mandated under Section 504 of the Rehabilitation Act of 1973 and special education services for students who attend a chartered public school. This included looking at whether the funding and provision of special education services afforded children with disabilities an equal opportunity to enroll and fully participate in a chartered public school and to receive all the services in their individualized education plans.

The HB 1128 Study Committee received testimony from charter school administrators and teachers, parents of children attending charter schools needing special education services, special education directors, the Parent Information Center, the NH Department of Education, the NH Council on Developmental Disabilities, the Disability Rights Center-NH, the NH School Boards Association, the NH School Administrators Association, the NH Association for Special Education Administrators, an attorney for special education, and a student attending a charter school.

The HB 1128 Study Committee found that:

1. Services for students with disabilities enrolled in New Hampshire's public chartered schools were inconsistent; the provision and quality of services varied from school to school.
2. The delivery of services appeared to be dependent upon the level of communication between the charter school and the Local Education Agency (LEA).
3. There were instances where LEAs did not invite a charter schools to participate in the Individual Education Planning (IEP) meetings for students who were enrolled in their charter school. Other charter schools reported they had excellent communication with the LEA and worked collaboratively.
4. Public chartered schools valued support from the LEA.

5. Further study regarding funding issues is needed to ensure children with disabilities enrolled in charter schools receive a Free and Appropriate Public Education (FAPE).
6. In some instances, the confusion about the role of the LEA and the lack of LEA authority to monitor charter schools caused strained relationships between LEAs and charter schools regarding the provision of special education services.
7. Some LEAs and charter schools disagreed on special education services for students enrolled in the charter schools, including how and where services should be provided.
8. LEAs expressed concerns about whether the requirement for a FAPE is being met for the student attending the charter school.
9. Further study is needed in order to understand better the issues for children requiring special education or 504 services who attend public chartered schools and to ensure these students receive needed supports and services.

The HB 1128 Study Committee recommended introducing legislation for the 2015 session to establish a yearlong commission to conduct an in-depth study of the issues identified by their committee and further recommended the commission members include representatives from the organizations who participated in their hearings. Study Committee chairwoman Representative Mary Heath filed the legislation and is the prime sponsor for *HB 126 - establishing a commission to study issues related to students receiving special education services while attending charter schools*.

Better information concerning the level of services that charter schools provide for students with disabilities is necessary. The NH Department of Education was unable to provide the HB 1128 Study Committee with statistics on the number of students with disabilities who attend charter schools. The testimony during the study committee meetings came primarily from charter school administrators and charter school parents who were satisfied with the special education services that charter schools provide. *If the legislature votes to establish a commission to study charter schools, it will be critical that commission members get a complete picture of how New Hampshire's charter schools are addressing the needs of students with disabilities. This includes hearing from parents and students who feel that services can be improved.*

Christopher Rueggeberg can be reached at 603-271-2336 and Robert.Rueggeberg@ddc.nh.gov

RAP Sheet

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