



Building Bridges

Autism is on the rise,
but there is support for families
that need help.

BY *Laura Jean Whitcomb*

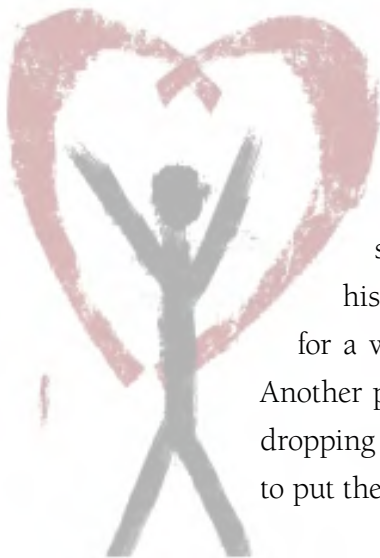
ILLUSTRATION BY *Ken Davis*

It's almost like a girl's night out — but the conversation is a little bit different.

“Kyle pointed and grunted when he wanted something. We never really thought it was a problem until we got to school,” says Brenda Dorr of her son, diagnosed with Asperger syndrome.

Linda LeBlond, a Claremont resident, understands. “Alex stood in one place and cried at the top of his lungs. We'd have to figure out what he wanted. Then, for a while, he only said the middle of a word,” she says. Another parent chimes in with her son's diagnosis and quirk: dropping the last syllable of most words. If the parent is not able to put the child's words into context, a meltdown might result.

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Welcome to an evening with Parent Links, a support group created by parents to help each other with the challenges of having a child on the autism spectrum. Autism Spectrum Disorder (ASD) is a term used for five disorders characterized by delays in the development of multiple basic functions, including socialization and communication: pervasive development disorders, Asperger syndrome, Rhett's syndrome, childhood disintegrative disorder and autism.

The group meets the first Thursday of every month from 6 to 8 p.m. in the Maple Avenue School library in Claremont. Although there are no margaritas to drink or jazz bands playing in the background, Parent Links provides an opportunity



Families have been piecing together support services for almost a decade. The rise of autism has caught everyone off guard, and New Hampshire is struggling to catch up.

for parents to relax, relate and re-energize. Parents snack on cheese and crackers with soda or bottled water, pick up educational information, and share stories and updates while a video about autism plays in the background.

Where to find help

Kim Bonin and Don Carpia met as part of a social thinking group held by

the Claremont School Administrative Unit (SAU), and immediately saw the need for a parent support group. They founded Parent Links in April 2007, and the 12 families that participated have been meeting ever since.

Bonin's son, Justin, was diagnosed five years ago. At the time, there weren't many resources for families with a child on the spectrum. "It was a struggle to find other parents, either in the school district or outside of the school district, going through the same situation," she says. "Parents need a place to go and vent. They need support and guidance from other parents going through similar struggles. The group lets other parents know that they are not alone."

Families have been piecing together support services for almost a decade. The rise of autism has caught everyone off guard, and New Hampshire is struggling to catch up. Autism was considered a rare disability as recently as the 1980s but, according to the New Hampshire Division of Developmental Services, the prevalence of ASD has been rising 10 to 17 percent annually for the past decade. In 2001, when New Hampshire formed a task force on autism, the prevalence for ASD was one in 250; today the Centers for Disease Control and Prevention (CDC) reports that it affects one in 150.

"We clearly are seeing a lot more kids diagnosed in the autism spectrum in the last 10 years, and increasing even in the last five years," says Mark Mills, CEO of Pathways, an area agency that provides support and services to people with disabilities in Sullivan and lower Grafton Counties.

Community Bridges, the area

OUTDOOR ADVENTURES FOR SPECIAL CHILDREN: TRAIL

There's no reason kids with disabilities can't get out and be active. That's the thought behind TRAIL, a New Hampshire nonprofit organization dedicated to teaching individuals with physical and mental disabilities the joy and excitement of playing in the outdoors.

TRAIL (www.trail4kids.org) is based in Charlestown, but none of the activities take place there. "We travel to wherever we can find the best situation for what we need to do in terms of both geography and price," says Al Langlais, founder and program coordinator. Families may drive to Pat's Peak in Henniker for a winter ski/board program or to The Wall in Quechee, Vt., for a fall rock-climbing program. "We don't have any geographic limitations; we accept families from throughout New Hampshire and beyond. Anyone with a special needs child can be on our mailing list to receive information on upcoming events."

Langlais understands the needs of children with disabilities; he's the motor skills specialist for the Fall Mountain Regional School District



and works with kids to improve their gross- and fine-motor function. Through TRAIL, he and his volunteer staff have worked with 75 to 100 families in the past 10 years. "Essentially we try to work ourselves out of a job; we help families learn to enjoy outdoor activities as a family," he says. "Parents of special needs children often feel overwhelmed and isolated, and becoming part of our organization opens up a whole world of new resources and supports to them."

Although many of TRAIL's participants are on the autism spectrum, all disabilities are welcome. "We thrive on the challenge of making whatever we're doing work for everyone who wishes to participate," Langlais says.

agency that covers Merrimack Country, agrees. "When I first started 11 years ago, we'd have one or two kids a year, at most, with autism. This was out of our annual population of 300 kids," says Ellyn Schrieber, director of the Early Supports and Services Program at Community Bridges. "Now we'll see 10 or 12 kids with that diagnosis out of a population of 600 kids." According to statewide data for the first half of the 2008 fiscal year (July to December), 31 percent of the applications for services have been for someone on the autism spectrum.

Janet Correia, an occupational therapist who lives in Grantham, has witnessed the increase. She's worked with New Hampshire and Vermont schools for six years. At one school in 2003, she was working with two children with autism. By 2004, it had increased to three, and by 2005 she was working with four. If the numbers doubled for one school, the math for the Granite State as a whole becomes a bit scarier. According to the 2008 Autism State Profile for New Hampshire, there were 397 (children age 3 to 21) diagnosed with autism in 1999-2000. In 2006-07, there were 1,060.

"Each child on the spectrum will cost \$3.2 million over his lifetime. Now multiply it by 1,000 kids," says Kirsten Murphy, administrative director of the New Hampshire Commission on Autism Spectrum Disorders. "We've got a major problem on our hands."

Plans, but no funds

Overloaded school systems, limited insurance coverage and a lack of trained personnel have prompted quite a bit of activity at the state level. The New Hampshire Commission on Autism Spectrum Disorders — a group formed by the state legislature to review the care, treatment and quality of life of those with ASD and their families — released a report with 43 recommendations in 2008. Now, New Hampshire is the second state in the nation to establish a statewide registry for ASD. The registry not only counts the number of new cases, but also tracks the average

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CATCHING KIDS EARLY: CLAREMONT SAU 6

The Claremont SAU 6 is ahead of the curve in its support of children on the spectrum. Eileen Kane, a Newbury resident, has worked for Claremont or the SAU for more than 20 years as a consultant, contracted service provider and employee. Starting with the 2008-09 school year, her title changed from occupational therapist to autism specialist — an indication that the number of children diagnosed with autism is on the rise and the school system is well aware of the effect it has on the classroom. She estimates that there are 24 children identified through the school system, and a few more that are not yet diagnosed.

On a typical day, Kane works with the preschool program, three elementary schools, the middle school and the high school. "I consult with team members, assist with direct service for social thinking interventions, complete observation, review collected data, assist with behavior

plans, sit in on weekly team meetings, and present in-services, about 10 so far this year," she says. This list doesn't include Kane's direct work with students, the Parent Links group or her educational handouts, making it clear that her busy week means one thing: "I am able to advocate to the specific needs of students with ASD."

The Maple Avenue preschool program for kids with varying disabilities has been evolving for 20 years, says Kane, but now it is expanding to the Bluff School. "We're trying hard to identify kids early," she says. The same is true for Sunapee Elementary, which is starting a program for preschoolers ages 3 to 5 this fall. Terra Geer, co-director of special education, hopes that the program (60 percent typically developing children and 40 percent with special needs) will help all kids, including those with autism.



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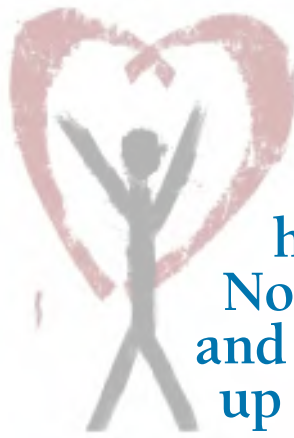
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age at which a diagnosis is made.

“We worked hard to set up arguments for change,” says Murphy, noting that the commission has been renamed the NH Council on ASD. “We meet regularly to continue progress, and eight separate working groups are doing research and proposing program design. It is very consumer driven — the process includes moms who have been waiting for adult services for their children and they’ll work up a program and propose it.”

There’s more in the pipeline, such as an increase of in-home support waivers and improved insurance coverage, but the most immediate change on the horizon is better training for “front line” professionals — the people



“I would ask, ‘How many people know someone with autism?’ Eight years ago, one hand in 50 would go up. Now I ask that question and 95 percent of hands go up in the room.”

working one on one with children and adults with ASD. “We can use technology for online training,” says Murphy. “Using a telemedicine paradigm an aide can check in with a behaviorist using a Web cam. The behaviorist can

observe the child’s behavior and give feedback immediately.”

But a shaky economy means that national donations are decreasing, and federal budgets are getting slashed, including funding for improvements. Pathways is one of 10 area agencies in the state, and provides supports and services to 600 individuals with disabilities. “We have waiting lists. Right now there are 200 people in the state who need services, and funding is not available,” says Mills. This number is projected to increase to 700 people in two years if funding remains stagnant.

Without federal funds, the supports for autism won’t be developed. “Area agencies are putting together proposals to build the capacity and develop those support systems to service a new group of folks,” says Mills, a Newbury resident. “We know the things we have to do, but there’s no money to fund it.”

Pockets of awareness

In the meantime, individuals are creating help at the local level. Grantham’s Correia founded OT in Motion to provide clinical-based occupational therapy (OT) services to children of all ages. Although OT is provided through individualized educational programs (IEPs) at school, the frequency might not be enough for a child. “We’re thrilled that kids get therapy in school, but it’s a toss-up — they miss math to get OT,” she says. “Now parents have a resource outside of the school system.” Four therapists, each with her own specialty, will tackle the needs of kids with disabilities,

NO CHILD LEFT INSIDE: NEHSA

Anyone can ski. Just ask Tom Kersey, executive director of New England Handicapped Sports Association (NEHSA) in Newbury. He points to a woman coming down the slopes in sit-down ski equipment with two instructors. “She is a former world class skier, but hasn’t skied for years because of multiple sclerosis. We showed her the equipment and convinced her to take one run. This is her third run. She’s having the time of her life,” he says.

NEHSA (www.nehsa.org) was founded in 1972 by individuals with disabilities who wanted to enjoy sports. The organization expanded in 1994 to include ski instruction, and now an A-frame lodge at Mount Sunapee is the winter home base for all ages (and all disabilities) who want to learn how to ski or snowboard. Adaptive equipment is provided, and talented volunteers help kids put on their boots, master the “magic carpet” or ride the Clippership Quad lift, and gracefully slalom down the trails in

the South Peak Learning Area.

Kersey, a Newport resident, has been a volunteer with NEHSA since 1996, and executive director since 2005. He notes that during the

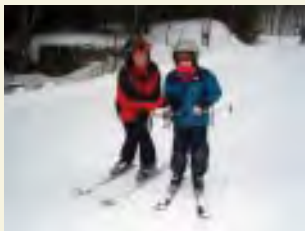


photo courtesy of NEHSA



2007-08 fiscal year, 38 percent of the 5,000 snow sports lessons involved a person on the autism spectrum. “We’ve found that snow sports provide a great activity for these children. Skiing is a personal activity that may or may not involve a group,” he says. “When we give our beginning instruc-

tions to these children it is all about stepping stones and building on very minute successes. As the child gains proficiency, the successes become larger and pride of ownership in the sport develops. Many parents have told me skiing has been a breakthrough activity and, because of the snow sports experiences, their child now will try other new things and excel in other parts of their lives.”

such as improving fine motor skills for a child with low muscle tone to providing classroom coping skills for a child with sensory issues.

There's also a new venue for therapeutic play thanks to Cindy Best, the creator of A.R.T.S. (Adaptive art, Respite & Therapeutic play Services), a nonprofit organization that offers clay classes and art camps for children with special needs. "Art projects are adapted to the child's abilities, taking into consideration each child's challenges," says Best. Parents will share their child's goals, and Best creates individual classes or small group sessions with projects that are designed to challenge the imagination, stimulate speech, encourage interactive play and social interaction with peers. While wearing bandanas and crazy pirate hats, campers sit for morning circle in a pirate ship (social skills), make treasure chests and clay pirate ships (fine motor skills), eat a snack of pirate punch and popcorn, and end the day with an outdoor treasure

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LEARNING TO PLAY: KIDZ PLAY PEDIATRIC THERAPY

When you first pull into the parking lot, all you see is a brown and white industrial building with riveted metal siding. But the exterior doesn't show all the good work happening inside at Kidz Play, a new pediatric therapy center in Concord. The building's 5,000-square-foot is dedicated to kids with special needs, including those on the autism spectrum.

The Kidz Play staff, which includes therapists of all kinds, will meet with a family to develop goals for the child. "We listen to what families are going through," says Janet Wright, MS, OTR, and president of Kidz Play. "We'll start a list — a, b, c and d — of what needs to be done. I might think 'a' is a priority, but 'b' could be more important to the family so we'll work

on that first."

If teens want to start a social group, there's a full kitchen with adjoining conference room space. If toddlers need to work on gross motor skills, there's a swing room — with 15 swings, a ball pit and a scooter board ramp — that is decorated to look like a jungle. A gym room, complete with therapy balls and mats, provides the extra sensory input that children with autism spectrum disorders crave. "I get paid to play," Wright laughs. But therapeutic play has a positive effect on a child who has trouble processing sensory information. "We're all about the child. That really is our passion here — seeing that child achieve their dreams."



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hunt with a map and silly string can-
nons (sensorimotor and gross motor
play). It's a time where kids, no matter
their place on the autism spectrum, can

be kids — and experience therapeutic
benefits while creating art.

Attorney Scott Johnson cre-
ated New Hampshire Education
Law (www.nhedlaw.com) to provide

resources and information about law
topics relevant to education. “I hope
the site provides parents and educators
with a place they can go to obtain in-
formation to help them understand the
law, provide the necessary services to
students with disabilities and without
disabilities, and meet student needs
generally,” the Warner resident says.

Sunapee resident Maria Fair,
who has designed two special needs
pilot programs in Massachusetts and
New Hampshire, now serves as an
educational consultant to schools.
Since many kids on the spectrum are
visual learners, she'll suggest cur-
riculum modifications to incorporate
pictures, such as Picture Exchange
Communication Systems (PECS), to aid
communication. “Using visuals is the
key to learning,” she says. “Once they
have the communication skills, you'll
be amazed at how far they can go.”

And the Family Resource
Connection of the New Hampshire
State Library in Concord has an online
lending library of 5,000 titles (includ-
ing 251 autism titles) related to issues
of concern for parents. Browse through
their online catalog, fill out a “materi-
als request form” with your mailing
information and the books that you'd
like to borrow, click to submit your in-
formation, and six days later the books
arrive in your mailbox. The library
even provides a postage-paid envelope
so you can return your book.

“It's amazing to see the public
awareness of autism,” says Janet
Wright, MS, OTR and president of
Kidz Play Pediatric Therapy Centers
in Londonderry and Concord. “When
teaching a group of new students, I
would ask, ‘How many people know
someone with autism?’ Eight years ago,
one hand in 50 would go up. Now I ask
that question and 95 percent of hands
go up in the room. Most everyone has
a friend or relative on the spectrum.
Five years ago, there wasn't an autism
commission. Now we have legislation.
This speaks volumes of how far aware-
ness has come.”

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A HOME FOR ADULTS: FARMSTEADS OF NEW ENGLAND

Most parents worry less about
their child's future as they reach adult-
hood. But parents of children with dis-
abilities worry more about their child's
future. This was true for Hillsborough
resident Deborah DeScenza. In the
early 1990s, she realized that her son
would not fit into a traditional work
environment and began to think about
where he would like to work.

A farm was the answer, and in
2000 she created Farmsteads of New
England, Inc., a nonprofit that pro-
vides day, residential and respite ser-
vices in a farming environment. Teens
and adults (age 14 and up) visit the
Hillsborough farm for day or respite
services, and 12 adults (age 21 and up)
live on the farm year round. DeScenza
estimates that half are on the autism
spectrum.

DeScenza — a former special
education teacher, program coordi-
nator and consultant—wears both
her professional and parental hat at
Farmsteads of New England. The days
are structured and the activities are
split between groups — one group may
feed the animals, another may run
the farmstand (open nine months out
of the year) while another group may
work on a gardening project. Staff is
on hand to help, and staffing varies



depending on the individual's needs.
(One person may need one-on-one in-
struction while another might be able
to work in groups of four.) “We also
work on life skills,” says DeScenza.
“Residents make dinner, do their
laundry, do the grocery shopping or
go to the library or to the movies. It's
good for parents to know that their
kids have a permanent home.”

It's also good for parents to
know that “there is still help avail-
able after age 21, which is when
most services disappear or you're on
a waiting list,” says DeScenza. “If
you're lucky, you don't have to wait
too long.” And with the increase of
children with autism, there's bound
to be an effect on communities in the
future. Farmsteads of New England
(www.farmsteads-ne.org) plans to ex-
pand this fall, increasing their current
capacity from 12 to 18 and expand-
ing day services to the Epping area.
“It's a struggle to find resources for
adults. As children age, the popula-
tion of adults who have autism will
boom. Farmsteads is preparing for
that need, and parents should know
that there are opportunities out there.
If this is an environment they think
their child would enjoy, we are here
for them.”



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Reverse mainstream

People may be aware of autism, but they may not know what the disability means for a family — and how it might affect them as part of the community. But Community Bridges, a nonprofit agency that supports people with disabilities and their families, is already taking the next step: educating the community. An April Autism Awareness 9-1-1 Registration brought police officers, fire fighters, EMTs and local families together; while a family member filled out a registration form, children met law enforcement and other first responders.

“For families who have a member with autism, safety is a constant concern. People with autism often lack an awareness about danger, and are not able to follow rules about safety that neurotypical people learn and follow with no effort,” says Adra Darling, director of development and outreach. “This characteristic can lead to situations where first responders need to become involved and having them aware that a person with autism is involved can be critically important.” The registration forms go on file with the local first responders, so they’ll know how to handle an emergency in a household that has a family member with autism.

Certain behaviors also make it hard for families to have a normal day-to-day life. “Any special needs situation brings up challenges for families. Some kids with autism can’t tolerate going to a restaurant or the grocery store. So families change their lives for the child; this can create isolation,” says Community Bridge’s Schrieber.

Local businesses — including day care centers, museums and theaters, karate or dance studios — need education about a disability that is growing by leaps and bounds. “Being the parent of a child with special needs, you experience firsthand that there are not a lot of after-school and summer activities offered. Regular extracurricular and summer camp programs are not usually staffed to handle a child with



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sensory, social, emotional or physical issues,” says South Sutton resident Best. “And, honestly, our children get overwhelmed in those situations.”

How to get the ball rolling? According to the annual report of the NH Council on ASD, an awareness campaign, planned for 2010, will create a “state culture” that provides greater acceptance and understanding of ASD. In the meantime, conversations about a child on the spectrum — one family at a time, one business at a time — will encourage understanding at the local level.

“We need to partner with community to integrate these kids into karate or swimming, and give them the same opportunity to participate as their peers,” says Wright of Kidz Play. “A parent could sit down with a summer camp or gymnastic place to let them know about their child’s skills, inquire if extra staff is available to help, or provide strategies for morning circle participation. Give me that glimpse of your child and share that with businesses.”

“It really does happen one person at a time,” says Mills. He notes that Pathway’s Employment Options program works with businesses so they’ll be equipped to hire employees with disabilities. Pathways staff will help a business retool capacity to support people with challenges, provide support for a period of time, then be available for consulting. “This approach could work on a broader scale; families could work with businesses so they are not afraid of a person with a disability or different behaviors. Initial interactions just need to be structured in a positive way. Even as you are out shopping or eating at a restaurant, remember you are educating the community while you are there.” 

Laura Jean Whitcomb, editor of Kearsarge Magazine and Upper Valley Life, is a mother of a child with autism.

Ken Davis is an illustrator and an activist/advocate for those diagnosed with Autism Spectrum Disorders.



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