

H.A.L.O. Reports

A Publication from the Help A Little One Foundation



**A Foundation
for Children
with Neurological
Impairment**

INSIDE . . .

*The Federal
government
mandates that
children with
disabilities
must be tested.*

*Educators at
NEPC explain
how they do it.
Page 2*

*Some families
care at home
for children
with multiple
disabilities.*

*When they
need a rest, the
Lisnow
Respite Center
is one
solution.
Page 3*

Founder's message

H.A.L.O. is family-centered

Dear Friends,

Family is one of the most important words in any language. It is defined in many ways by many agencies and public bodies. A family can be biological, adoptive, legal, social or religious. It can be distant or close, divided or blended, happy or dysfunctional, broken or whole.

In the best and broadest definition, family is the group of people who love and support you unconditionally.

Since 1993 the Help A Little One Foundation has been helping to maintain family life for children with neurological impairments. Our original mission continues to provide family-like touches at holidays and every day for children whose families often cannot be present in their lives. Our two-year-old Family Circle program is blossoming into a family resource for emotional support and information.

In past newsletters, we have tried to highlight dedicated volunteers and professionals who become "family" to our special children. H.A.L.O. Reports has also featured stories about swimming and horseback riding programs, camping trips tailored to accommodate wheelchairs and service dogs who expand the horizons for children who may never experience camp, Little League or Girl Scouting.

This issue looks briefly at the perplexing issue of federally mandated testing of children with cognitive impairment. It also features an example of a respite center that prevents emotional and physical burnout in families who care for their children at home.

Our hope is that you will continue to be aware of the existence and needs of children with neurological impairment, and our efforts to help them reach their potential.

As always, we thank you for your continued support in this endeavor.

Sincerely yours,

Alan Pinshaw

A Foundation for Children with Neurological Impairment

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Children with disabilities learn in "baby steps"

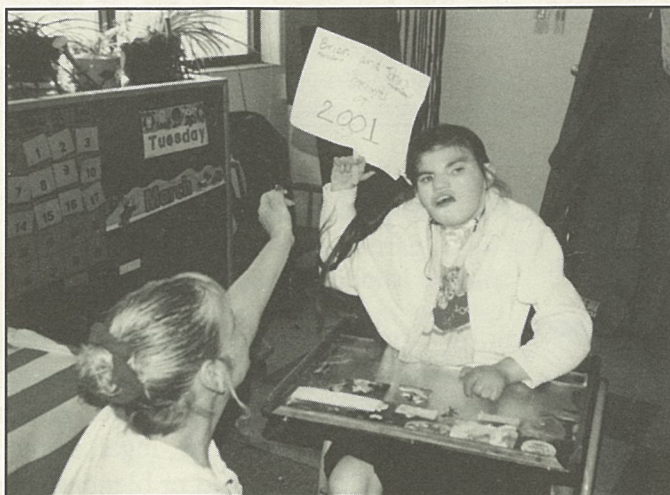
Boards of Education are embroiled in a debate about testing America's students. The federal Individuals with Disabilities Education Act (IDEA) requires that children with special needs and disabilities have equivalent testing. All states were to have "alternate assessment" tests in place by July 2000. We asked special educators at New England Pediatric Care in North Billerica, MA to put testing in perspective.

Our kids take baby steps,"

said teacher Brian MacDonald, on measuring learning for children with disabilities.

"If you come here (to New England Pediatric Care's classrooms) expecting to change their world, you'll be frustrated as a teacher. But if you go in and see where your kids are and get a feel for what they are capable of doing, then you can give them options, see if they open up," he said. "And every once in a while they will have that moment when it all POPS! When you can see they learned something."

The problem for Brian and all teachers of children with disabilities is how to demonstrate progress when many students are non-verbal and have multiple disabilities. NEPC held an "open house" to show parents the portfolios and videos assembled in



Becky participates in a mock election at New England Pediatric Care

the first year of mandated assessment.

Teacher Laura Mahoney said reactions were mixed. Some families were pleased that there was an opportunity to view their child's progress. Others, she said, questioned the point of testing, since their child's cognitive skills are limited.

"I may not agree with everything about MCAS (the Massachusetts standards testing program) but what I like about it is that it gives these kids credit. They have the same rights as others to education," said Laura. "This insures that there is a purpose to school, that the students are learning and not doing meaningless activities."

Brian adds that testing students forces him to be fresh and creative.

"We have to look at ourselves and analyze

what we are doing and if our students are achieving their goals," he said. "The kids aren't here to be baby sat."

Brian teaches seven students in the 15 to 20 year age group. Two qualified chronologically for the state's Grade 10 tests. Their intellectual development levels vary.

"Basically the Department of Education broke down the "strands" of knowledge it defined for standard curriculum students and offered some suggestions on how to assess the skills of children with special needs on those same areas," he said. "Our students' skills fell far below those levels, so we broke everything down further — to things like, paying attention, responding to stimuli, recognizing differences in color, texture and environment."

He said the key is to

define a task that the student can understand or appreciate in science, math or literature, and use it as a tool for assessment. For instance, Brian uses a software program called "Living Books." His students listen to a story, view it on the screen, and interact by signaling for a new "page" at the appropriate time. They strike an electronic "switch" to indicate a preference or respond to his questions.

By observing and even video-taping the students' tracking abilities and responses to a "Living Book" Brian was able to use technology to prepare an assessment on the English Language Arts experience for students Richie and Mike.

"I try to get my kids as much access to technology as possible," said Brian. "My theory is that everyone deserves the right to alter their own reality. We make choices every day. My kids don't get many opportunities to change anything or even express their preferences."

"By using technology, mostly switches, they can grow. Richie, for instance, uses switches to "read", to change colored lights and to select and play music he enjoys."

(Continued on back page)

The Lisnow Center is a loving home away from home

A tapestry of hand-prints hangs above the entrance to the Michael Carter Lisnow Respite Center in Hopkinton, Massachusetts. It was created by sixth graders whose letter read: "if you ever need a hand, give us a call."

This is the philosophy of the Lisnow Center — giving a helping hand to families who care for a child with disabilities. Webster's New School and Office Dictionary defines **respite** (*res'pit*), *n.* as a pause or temporary cessation of anything. The Lisnow Center provides a pause so families can rest, get a haircut, go to their other child's baseball game or recital, or visit with friends.

The Center was created by two special education teachers who are also great friends, Mary McQueeney and Sharon Lisnow. They experienced firsthand the challenges of caring at home for a child with multiple disabilities. Sharon's son Michael — for whom the Center was named — was born 16 weeks prematurely, causing blindness, severe cerebral palsy, and other chronic medical issues that caused him to pass away in 1996 at the age of 10.

"Michael showed me the need for respite care," said Sharon. "I loved him dearly, everyone did, and he taught me so much; but sometimes I was so exhausted from doctors appointments and paperwork and his care, I needed some time to myself," she said. Unfortunately, she discovered that even when she had social service funding for a few hours of respite care, it was difficult to find caregivers with any consistency.

"I was constantly training new people on how to care for my son," Sharon said, "and once I did that, the thing I most wanted to do was relax and do nothing but lie on the couch. But I didn't feel comfortable with



Directors Mary McQueeney and Sharon Lisnow, standing at rear, join in after-dinner activities at the Lisnow Center.



The "Helping Hands" tapestry.

them in the next room."

So Sharon and Mary set out in 1994 to create a center where individuals with disabilities and chronic medical conditions could come for care with regularity. They convinced the Archdiocese of Boston to give them a dilapidated 164-year old house on land in the center of Hopkinton for \$1, and invested their hearts and souls in rousing a community to offer respite to challenged

area families. Two special supporters — one a contractor — helped bring their dreams to reality. They designed an inviting and efficient Victorian-style home specifically for the services they wanted to provide.

The Center provided 37,728 respite hours last year (2000), free of charge to 109 families. The previous year 26,633 hours (valued at \$333,000) were allotted, all through scholarships. Only four clients could be served when the Center opened in 1997, exactly one year after Michael Carter Lisnow passed away.

Nearly half of each year's annual budget is raised through pledges in support of the Respite Center Team running the Boston Marathon. The Lisnow Center is one of only 15 approved Boston Marathon charities. Mary and Sharon both run the grueling 26.2 miles, joined by friends and client family members.

Programs at the Center include day care (newborn to four years old); after school care for children four to eighteen years old; Monday over-

(Continued on the back page)

The Lisnow Center: "We make it a place they want to be"

(Continued from previous page)

night respite, and two weekend group respites per month. These programs are all privately funded and provided by a staff of twenty-three: three teachers, one registered nurse, one licensed nurse and a highly trained support staff. The Center also provides a five-day-a-week adult day care program (ages 22+) which includes a structured education program and job coaching eight hours a day.

All the clients live "at home" but visit the Lisnow Center on a regular schedule. Some are mobile, others are non-verbal or have tracheostomies, g-tubes (for feeding), oxygen and complicated medication regimens. Disabilities include cerebral palsy, seizures and Down Syndrome.

"Respite is one of the critical factors in allowing parents and whole families to stay together," Sharon said. "We are here to relieve the strain on the families, I think the difference in a successful family-based respite center is that we make it a place they want to be."

Sharon said the Center is really a home away from home. "Respite doesn't work unless it's a place the individual wants to go to, and where the family feels comfortable leaving . . . their child. We really do give them a great time, and have a great time with them. They come happy and leave happy because we know them as individuals, and because they know we care."

Sharon and Mary recognize the need for expanded hours and services, but are moving slowly forward, unwilling to give any less than the best possible atmosphere. Full 24 hour/7 day a week service is the goal, but not until more staff can be certified to handle the complicated equipment and client needs.

"In view of the nursing shortages we know we need to provide even more solutions. Families are hurting," Sharon said. As a stopgap measure, the Center helps families get more comfortable with their child's care by answering questions and providing additional training with equipment such as g-tubes.

The townspeople have been overwhelmingly supportive of the Lisnow Center. Girl Scout troops run a baby food drive and supply all the food needed for the entire year. Others provide laundry detergent and paper goods, make repairs, and work on the lawn and plantings. Schools and churches send community service volunteers to help out.

In return, the Lisnow Center offers a 1.5 hour program teaching disability awareness to community



Everyone learns life skills such as meal preparation

members in a non-threatening way.

The Lisnow Center serves a limited number of families in Massachusetts. Respite care is also available through pediatric nursing centers, individual providers licensed by the state and in group settings.

How do you test a child with disabilities?

(Continued from page 2)

Laura Mahoney teaches children 11 to 14 years old, also with very limited cognitive ability. She tested nine students for the Massachusetts Comprehensive Assessment System.

"My students' goals are different than students in standard schools. I use a lot of sensory stimulation to assess their awareness of people and activity in the room," Laura said. "For instance, we are supposed to test math skills. None of my children can count by themselves. So every day the aides and I count out loud to the date of the month, then clap. On June 15th we count to 15, then clap. We assess whether the students are aware of the counting, notice or join in. We repeat this type of exercise regularly."

"We also work with a Velcro thermometer to 'measure' temperature. These students respond to

touching, feeling, hearing. It is a stretch, but it is a way of assessing progress toward the (state required) Individual Educational Plan set up for each student."

Special educators all note that teaching methods and assessment are very subjective when working with children with special needs. They need to look for learning cues and be aware of medical issues, sleep cycles and medications.

NEPC Director Ellen O'Gorman and her Director of Education Jennifer McDonough both praised their six teachers for their innovative assessment work.

"Twenty-three of our 48 students were tested this year," Jennifer said. "The teachers worked long and hard to create appropriate assessments for their students and were very creative. I am pleased and proud of the way we implemented the testing."