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H.A.L.O. Reports

A Publication from the Help A Little One Foundation

H A L O
HELP A LITTLE ONE

INSIDE . . .

Founders message

H.A.L.O. explores the options

Over the summer our daughter Sarah came home for several day-long visits. Homecoming is no simple matter: Sarah travels by wheelchair van, and must be accompanied by a nurse to take care of her tracheostomy tube and G-tube — that's a gastrointestinal tube for feeding and medication.

Gayle and I, and our daughter Julia and son Daniel, were grateful for the opportunity to feel whole again. Sarah only occasionally makes a sound or seems to respond to a voice or touch, but we hope she knows on some level that this place of sunshine, dachshunds and parakeets will always be her haven of love.

The hardest part is saying good bye. We'll never know if Sarah's departing tears these last few visits are cries for home and family or merely symptoms of exhaustion or over-stimulation. While her body is growing tall, and her raven hair frames an angelic face, Sarah's condition is unchanged and irreversible.

We attend to her physical needs and we hope our frequent visits provide the support and stimulation she requires.

We founded the Help A Little One (H.A.L.O.) Foundation to ensure quality of life for children with neurological impairments. H.A.L.O. continues to search out facilities that help children reach their potential.

Recently we met with experts at the acclaimed May Institute about the scope of brain injury in both children and adults in this country. We learned our medications and treatments are light years ahead of Third World countries, but many facets of neurological impairment continue to be mysteries.

We have also been introduced to a model program for community interaction at Children's Extended Care Center, an affiliate of Children's Hospital in Boston.

Our thanks goes to the Baglieri family for sharing Charlie's story with us. This family's journey has a smile at the end. We recognize not every family's experience with the heart-wrenching process of committing a child to a chronic care facility will be the same.

As we explore the options, we discover more opportunities to help. We consider all requests, from backpacks to family support programs, teddy bears and television sets.

We thank you for your support in pursuing this mission.

Sincerely yours, Alan Pinshaw

A Foundation for Neurologically Impaired Children

H.A.L.O. Foundation
1330 Boylston Street
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(617) 423-HALO

May Center teaches living, learning strategies to children

The number one killer and disabler of children in the United States is not AIDS or cancer, it is brain injuries, according to experts at The May Institute, headquartered in Randolph, Massachusetts.

As many as 7,000 children may die of brain injury in a given year, and 30,000 may become permanently disabled, according to a report co-authored by Ronald C. Savage, Ed.D., and Gary F. Wolcott, M.Ed., of The May Institute.

Many more children are affected by subtle, yet life shattering effects years later when "broken connections" from brain injuries fail to kick in at the appropriate development stage, the report said.

This has resulted in misclassification of children as mentally retarded, learning disabled and behaviorally disturbed, and caused much anguish for them, their families and teachers, said Savage, director of Haverhill Health Systems/The May Institute.

As the provider of a comprehensive network of schools, group homes and services to people with developmental disabilities and behavior disorders, the May Institute has taken a lead in helping educators and physicians identify this invisible condition that impacts thinking and behavior. Unfortunately, the symptoms mimic many other conditions.

The Institute opened the May Center for Education and Neurorehabilitation in Randolph last year to fill a void in competency-based treatment of children and adolescents with brain injuries. About 70 percent of the students live at the center.

Director Rita Gardner said the May Center's unique methods teach children the skills they need to maintain appropriate behavior and learning attitudes at home, at school and in unfamiliar situations.

"It is not our goal to keep kids, but to return them to their communities," Gardner said. Already, four of the first 44 students have been reintegrated into their home schools with much success. Other students have been relieved of protective helmets and other gear as they have learned to control destructive impulses.

The May Center is believed to be the only facility in the world producing such dramatic outcomes. Teams from Denmark and Mexico have already consulted to reproduce the program in their countries, according to Gardner.

An extensive waiting list has already developed, as word spreads about the school's exciting results. Since student tenure is tied to progress, the May Center cannot readily predict when slots will open up, so the Institute administrative offices are being moved to create room for more students, Gardner said.

While a student is enrolled, the May Center staff works closely with families and school systems. Once the student returns to his community school, the staff regularly evaluates his progress. Early intervention is key to averting "hopeless" situations, Gardner said. The most challenging students are those who have been underserved for years, she explained.

The Savage/Wolcott report outlines three areas where injured children may experience problems: *thinking and communication skills,* such as memory, organization, decision making and concentration; *feelings and actions,* including self esteem, self-control, age appropriate behavior; and *sensory motor controls,* for balance, coordination, spatial coordination and speech.

For more information contact The May Center, 35 Pacella Park Drive, Randolph, MA 02368.

CONTRIBUTIONS ARE ALWAYS WELCOME!

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"Into the Community" sparks awareness, friendship

How do you improve quality of life for children with multiple handicaps and complex medical needs? How do you increase awareness and tolerance amongst their peers?

Would you believe a project called "Into the Community" at a pediatric nursing home in Groton, Massachusetts?

For the past three years, eight residents at Children's Extended Care Center (CECC), a subsidiary of Children's Hospital in Boston, have been making friends and enriching classroom culture in the Groton Public Schools, under the auspices of a grant funded by the Massachusetts Department of Education.

CECC support staff push the participants' wheelchairs a half mile to the school complex, and stay with them in the "regular ed" classroom 100 percent of the seven or eight hours they attend each week.

Since the visiting children have very restricted communication skills, the support staff enables them to be part of the class: guiding a pencil through unresponsive fingers; pushing calculator buttons in math; pointing to pictures for selection of an "answer." The staffer also explains unfamiliar behaviors to the class, and helps the visiting child to reach out.

All the teacher has to do in this voluntary program is provide a framework that includes the students with disabilities. The age-matched classmates just have to be themselves.

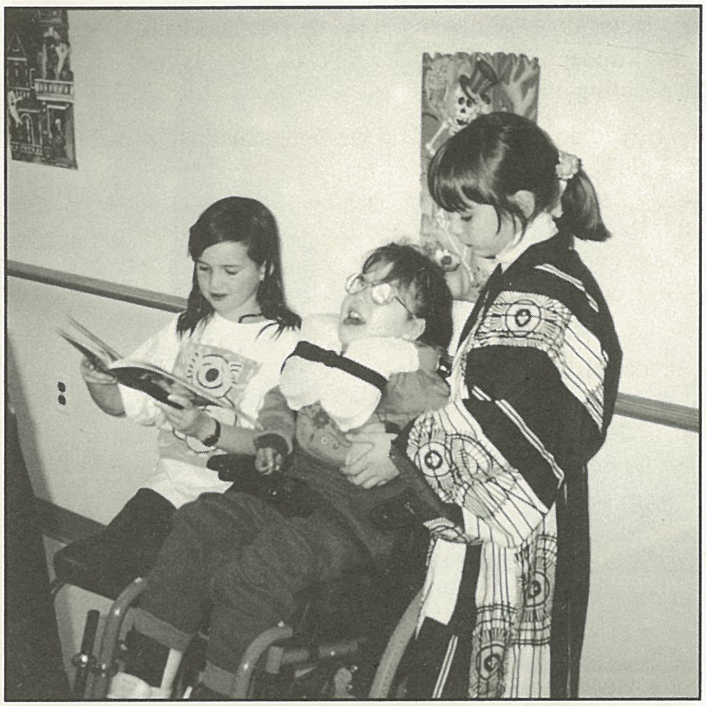
"Before this project we used to have field trips, but it was difficult to get people to relate to groups of kids with disabilities," said Beth Atkinson, "Into the Community" coordinator. Field trips failed to develop relationships, she said, and the social interactions weren't natural.

Third Grade Teacher:

"I see . . . sincerity, care, concern, affection in their eyes and manner when they are talking to Matt."

"The biggest thing here is quality of life. Our kids live in a static environment," Atkinson said. "The kids have their families and the people who work here — paid people. Some develop friendships, but the "kid connection" has been missing."

Nine-year-old Catie H. is one example of how the "kid connection" has been made. For three years she has participated in recess, lunch, music, gym, math, reading, spelling, library and field trips with third and fourth graders at Florence Roche Elementary School.



Campfire Girls visit Catie H., center, in their Halloween costumes. They are Catie's classmates at Florence Roche Elementary School.

Catie uses a wheelchair and does not walk or talk. Atkinson said she has demonstrated happy behavior, alertness and makes an effort to participate with her peers. She is a sought-after partner in gym and her classmates have clearly accepted her.

The third graders at Florence Roche created their own report cards for Catie, giving her top marks in categories such as "happiness" and "friendship" and noting her enjoyment of music and her effort in gym.

The CECC staff was proud when classmates in Campfire Girls included Catie in their activities. But they recognized the real success of "Into the Community" when the classmates showed up to visit Catie at CECC during vacations.

Atkinson happily taught the children a protocol for visiting a child who may be unavailable at times due to a strict schedule of feedings, medication and therapies. Another outward sign that "Into the Community" is achieving its mission has been the public school request to take part in a CECC special education class.

Additionally, Atkinson has created opportunities for other CECC participants to invite a few public school classmates and their families to join them in a CECC pool party with their immediate family.

Not every CECC resident needs or wants "Into the Community." Atkinson's team and the public school teachers

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Children with disabilities motivated to reach out at CECC

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review the results after a one-month adjustment period. Does the CECC student sleep or cry during class time? Is poor health affecting attendance?

"We try to do things based on the right situation for each child. This is not 'politically correct' inclusion. It's individual," said Atkinson. She recalled one instance when staff felt an invitation to join a public special ed student in his adaptive gym class was a step in the wrong direction. When they observed the two children in wheelchairs happily interacting, they reversed their opinion.

An older resident, "David," persistently indicated he did not want to return to a high school class. The staff and family were confident he could benefit from high school experience, but they found placements at a flower shop and a bowling alley where David could work on the same skills.

Outside evaluator's report:

> *She wasn't sure how she would would feel seeing Matt with a bunch of 'normal' kids....She said she was moved almost to tears . . . one of the boys came up to her and asked her if she was Matt's mom. "Matt is one of my best friends."*

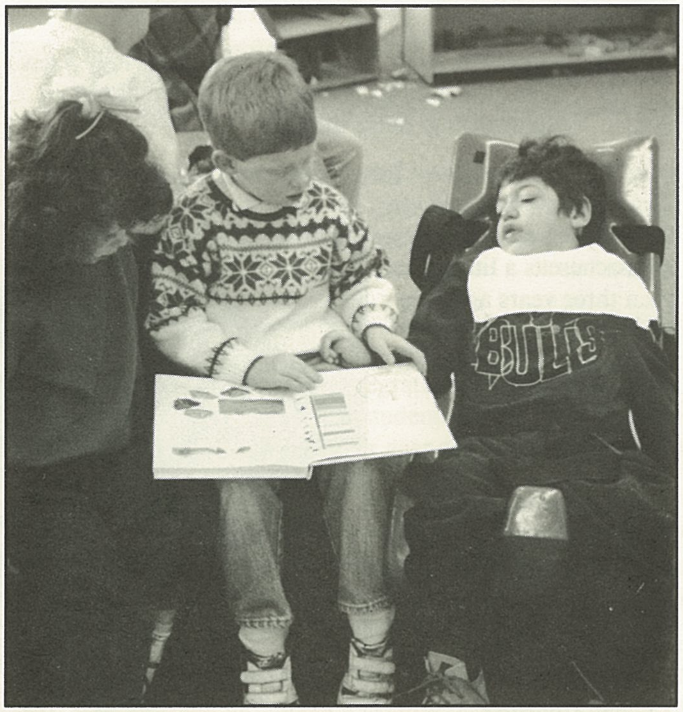
"CECCers are trying to learn how to respond to and interact with people and things in their environment," Atkinson said. Schools are natural settings, but the workplace is appropriate, too, she said.

Schoolroom or workplace goals for CECCers include:

- Initiating and responding to social actions;
- Maintaining longer periods of alertness;
- Improving visual and/or auditory awareness;
- Developing a reliable yes/no response;
- Addressing the goals of each Individual Education Plan in the more generalized setting.

"Into the Community" has exceeded expectations, according to Richard Murphy, CECC director of education. Feedback collected by an outside evaluator has been overwhelmingly positive, he said. The children from CECC gain social skills and become more motivated; the teachers and "regular ed" students become more sensitive and involved; parents have an opportunity to view their child in a more capable role. Also, the relationship with the public school district is being solidified.

"Into the Community" now receives more requests for participation than it can handle. The grant funds three-part time assistant teachers, but the demands of one-on-one support staff, the maintenance of the rigorous in-house Special Education program at CECC, and the health of the children limit participation.



Classmates at the Florence Roche Elementary School share a book with Matt, who is a resident at Children's Extended Care Center.

Murphy gives Atkinson the credit for the eager waiting list: she recruits teachers, conducts orientations, trains support staff, interviews participants, reports to parents monthly, facilitates, documents and evaluates the project. She also conducts a bi-monthly forum.

CECC support staffer:

> *"At first Al did not really respond to interactions from peers . . . now he's very social . . . he smiles, uses his voice . . . he likes being where the action is."*

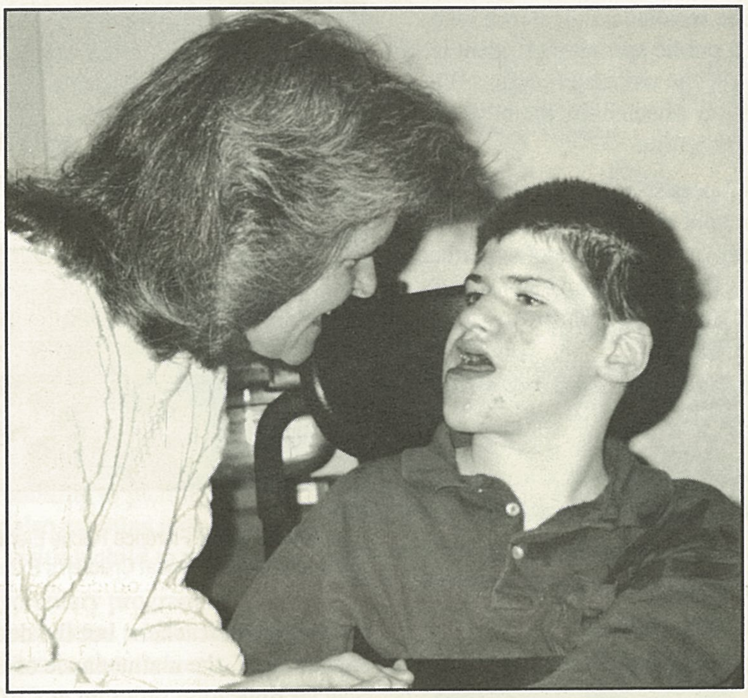
CECC provides 24-hour skilled nursing care, in-house special education programming, physical and occupation therapy to 69 people between the ages of 3 and 33. "Into the Community" participants were volunteered by their families.

Contact Beth Atkinson at Children's Extended Care Center (508) 448-3388

Conversation with a mother: 'It's a hard place to come to'

The journey from Metheun to Billerica is only a few miles, but it took Charlie Baglieri's family about eight years to make the trip.

Charlie, who turns 12 on November 11th, moved from home to New England Pediatric Care in Billerica, Massachusetts a little more than three years ago. He has a seizure condition, delayed development and mental retardation, according to Kathy Baglieri, his mother.



Kathy and Charlie Baglieri

"I never wanted to send Charlie away," Kathy said. "I wanted Charlie to be with me. He is my son and I love him."

Kathy said she discovered Charlie's conditions when he was three weeks old. She looked away from the gurgling baby for a few minutes during dinner preparation only to find him stiff and white-faced in the throes of a seizure when she turned back.

"I was so scared," she remembered.

Husband Michael, Kathy, and the kids, Brenda, now 19, and Michael, now 20, teamed up to care for Charlie at home. Kathy took on the majority of care, because she did not work outside the home.

The family found medical and emotional support at Children's Hospital. The seizures occurred many times a day, but medication controlled most of the outward symptoms.

The staff helped Kathy deal with feeding difficulties and therapy. Support people came to their home. Kathy speaks appreciatively of Dr. Leslie Rubin, Charlie's doctor during those years. "He gave us all his phone numbers and helped us whenever we called," she said.

Charlie became involved in early intervention programs. When he was five months old he spent several hours each day at the Professional Center for Handicapped Children in Andover. Later programs provided respite for Kathy and skill development for Charlie.

When Charlie was about eight the situation worsened.

"I noticed that when he came home from school, sometimes he seemed different. Not unhappy but, you know, not interested and aware.

"I was also on the verge of getting very sick. Charlie was having problems at night. Several times I thought I would lose him, when he had seizures. Sometimes I had to call a neighbor to get us to the hospital. (Michael works third shift.) It got worse.

"I finally knew we were going to have to have nurses around the clock," Kathy recalled grimly.

One of Charlie's special education teachers at public school suggested the more extensive day program at NEPC. When Charlie switched, Kathy said she observed dramatic improvement. "He became more responsive and showed his emotions more.

"I realized for him to grow and develop, he had to go there," she said.

The decision to seek residential placement at NEPC was somewhat easier after that.

The Baglieris and their doctors completed mountains of paperwork and testified before such government agencies as the Department of Public Health, Department of Mental Retardation, and Department of the Blind, before the state Medical Review Team would certify Charlie for residental placement. The trips into Boston were physically and emotionally exhausting.

"But I know that Charlie thrives on the structure and the daily routine at school. He has therapy, meals, classes and hygiene," Kathy said. She is also pleased that Charlie is active a good part of the day, and has the occasional opportunity to swim or ride horses.

"I could never handle these things now, because Charlie is so big," she said.

"The staff has always made me feel comfortable here,"

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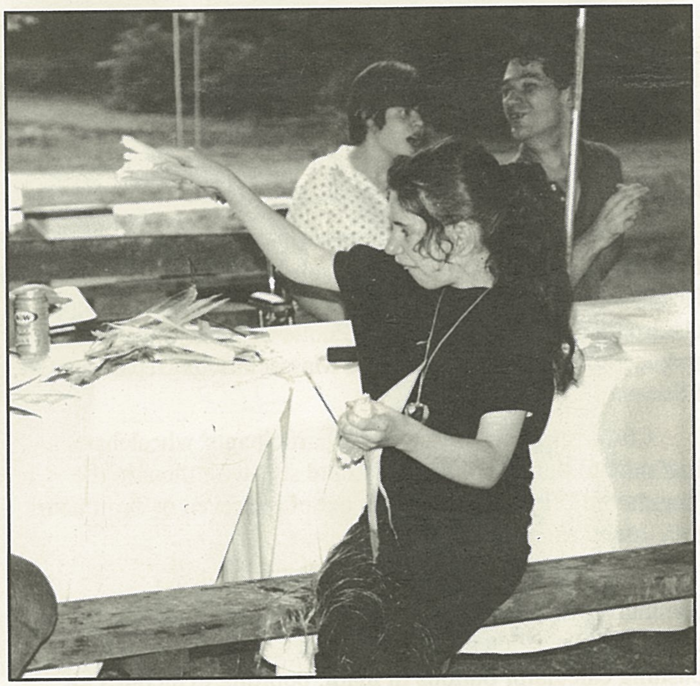
Kids just want to have fun

New England Pediatric Care in Billerica, MA provides a variety of community experiences to students. Above, N.E.P.C. staff and residents enjoy a ride at Canobie Lake Park in New Hampshire. From left, Chris Redmond, Lynn Mertz, Ken Underwood, Bobby Schurian and Veronica Barradas.



Shelley Draper shucks corn on an N.E.P.C. camping trip, while Kim Bruno and Michael Rousseau look on.

Kathy and Charlie

(Continued from page 5)

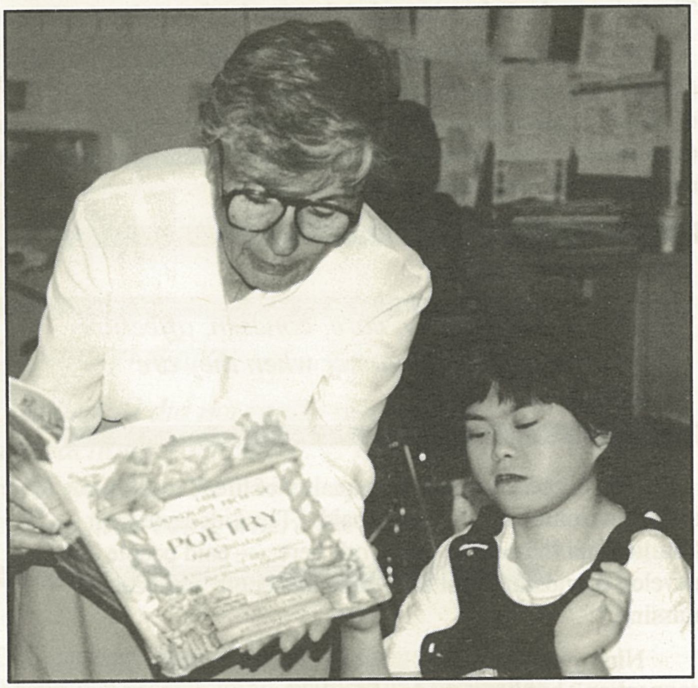
said Kathy. "I am Charlie's mother, and I have the last say, and there is never any question about it."

Charlie validates the family's decision when he shows recognition of them and when his home visits flow comfortably every Saturday, Kathy said.

Charlie also appeared happy and at ease when Kathy dropped in to say hello during cooking class one Friday. Although the five wheelchairs were lined up facing into the kitchen area, Charlie struggled to turn his head at the sound of his mother's voice. He glowed with delight when she planted a kiss on his cheek.

"It's not like we've forgotten about Charlie," said Kathy. "He has two families now. Our family and his family at school."

"It's a hard place to come to," she said of having to visit her son in a nursing home. "I understand when other families find it difficult. I wish my son didn't have to be here. But I think it's the best thing that ever happened to Charlie."



Heung Ngo looks at a book with Margaret Hart, a volunteer who rarely misses a weekly visit with residents at New England Pediatric Care.