

H.A.L.O. Reports

A Publication from the Help A Little One Foundation



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Founder's message

Meeting new challenges every day

Nothing remains static these days. The world is a changing place. It is imperative that we all continue to learn and grow to meet new challenges presented in the form of medical advances, technological improvements, and a thriving, or not so thriving, economy.

Our daughter Sarah, the inspiration for the Help A Little One Foundation, continues to live at New England Pediatric Care. She has had a relatively healthy year. Her new challenge has been presented by her caregivers: adjusting to a vertical standing position, using a special positioning device. Vertical positioning is important for proper bone development, to prevent spinal deformities, and, to the degree Sarah is aware, to give her a different perspective on the world.

In this issue of H.A.L.O. Reports, we recognize the need of social service agencies to accommodate the changing medical needs of children in their care. In the last ten years - even five - medicine has advanced to a point that individuals with complex medical issues can be released to the home. Unfortunately, some children have no suitable home. The Massachusetts Department of Social Services is training foster parents to manage medical care for these children in the foster home environment.

Young people today are being made aware of complex social issues in their schools, places of worship and in their extra-curricular activities. At Framingham High School in Massachusetts, teenagers who are not required to perform community service nevertheless are donating their time to improve relations between children in the regular classrooms and those with special needs, many of whom might not have attended public school a decade ago. Not surprisingly, all the participants in these Unified Special Olympics programs are expanding their horizons.

The Help a Little One Foundation is also looking to expand its horizons. To date, we have focused on direct, tangible gifts to children with neurological impairment, mostly residents in pediatric nursing homes.

At a recent meeting of administrators of New England pediatric homes, Gayle learned of several programs that would be of direct and continuing benefit to residents, if funding could be provided to train the staff at the homes. H.A.L.O. is exploring these and other options which may make it easier for families to support their children in nursing homes. We invite your suggestions on new directions in support of the H.A.L.O. Foundation mission.

Thank you for your continued moral and financial support. Best wishes for a happy, and perhaps less rainy, summer.

Sincerely yours,

Alan Pinshaw

A Foundation for Neurologically Impaired Children

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Foster care for children with medical needs

In early June, the Boston Globe newspapers carried a story about a father who admitted to beating his three month old baby within an inch of its' life.

Not only did the Massachusetts Department of Social Services have to remove the child from its home, but once the hospital released the baby, workers had to find a foster home that could deal with the complex medical issues resulting from the assault.

Case managers find homes not only for abandoned or abused children, but those with behavioral problems, severe birth defects, victims disabled after near-drowning incidents or critical illnesses, or in need of special care which families are unable or unwilling to supply after long-term hospitalization.

In a network of 6,300 foster care homes across Massachusetts, DSS has developed a pool of almost 75 foster homes to care for children with complex, multiple medical issues. Since the early 1990's there has been a great influx of children with medical needs, due to changing hospital policies, the use of drugs and domestic abuse.

"Kids being discharged from hospitals today have far more acute and complex issues than even five years ago. We have to find homes to deal with these issues, as well as the kids," said DSS Foster Care Manager Pat Autori.

She estimates about 250 of the 10,000 children in foster care in Massachusetts right now require a high level of medical care. DSS developed a pilot program in 1990, and is implementing a full-fledged medical foster care program now.

"Originally we had four specific homes in a pilot program where the parents were trained in medical issues. We established a different budget and staffing pattern, where a foster parent is provided with nurses or other staff required for the child's round-the-clock care, in addition to the nursing hours paid by Medicaid," said Autori. "One of our parents has three full time nurses, at least one of whom has been with the home for five years.

"It has been an incredible success. These foster parents attend the hospital discharge for the child, and get trained by the staff. Most take courses and training on their own initiative, to increase their skills to meet the child's needs."

Autori said the person who manages a medical foster home has to expect and handle crises and deaths. The pool of medi-

cally skilled foster parents is low, but with staffing support one home can handle as many as six children with varying medical needs. One of those children could fail to accept a liver transplant, or die from full-blown AIDS. Another child might need emergency respiratory assistance.

When the hospitals first began discharging children with tracheostomy equipment in place, the medical foster parents had to be trained to care for the tube and its complications. Today everything is far more complex, Autori said. "These people are to be praised and supported. Our area officers supervise the cases, but the parents nurture and provide daily care to these children. Without staffing support at these (medical) homes a foster parent would be alone, and unable to deal with this.

Many of the medical foster parents may have raised their own children with special needs, and know how to advocate for them. Their assessments and medical record keeping may be the first compiled for a child. The community hospitals come to respect and welcome medical foster parents as active partners in the child's care, said Autori.

Our foster parents are people who want to give these kids quality of life in a home setting rather than in a hospital. Typically they find us, we don't have to find

them," said Autori. "We see a phenomenon that with increasing experience, our parents become more competent and better advocates. In return we get more comfortable placing children with a higher level of acuity.

How long does a child stay in acute medical foster care? Autori said the agency's goal is to reunite children with their biological parents, or place them in a more permanent situation: guardianship, adoption or kinship. But some medically-involved children are difficult to place. One foster parent has had the same three children for three-and-a-half years, Autori said. Some foster parents adopt the children placed in their care. Whatever the ultimately resolution — including the occasional placement in a long-term nursing home — the foster parents work to ease the transition.

How long do medical foster parents last in the job? Autori says most foster parents go on and on, creating a positive reality for children who need it, for 20 or more years.

If you are interested in becoming a foster or adoptive parent or medical foster parent in Massachusetts, call the Department of Social Services recruitment line at 1 800 KIDS-508 or 1 800-543 7508.



Special teacher was "called" to teach special kids

Fate was dropping hints to Kelly Doolan long before she discovered her life's work as a teacher of disabled children.

It probably started when none of the neighborhood kids would share a seat on the school bus with a girl with Down Syndrome. The girl's devastated mother called Kelly's mother, who asked Kelly to sit with her once in a while. It turned out to be every day.

"She was so happy, so grateful, she would say thank you every day, in her own special language," said the 23-year-old teacher at New England Pediatric Care in North Billerica, Massachusetts. "We didn't see each other in classes, but at lunch she would smile and hug me and kiss me. I was only in fourth grade, but I felt loved."

Kelly said she may also have been prepared for the needs of the disabled by her relationship with her only cousin, Pete, who is autistic.

"My aunt and Pete lived in the duplex over my grandparents. Pete had no speech, and would make scary noises and rock wildly out of control. It would scare my brother and me, although now I know from college courses that he was probably struggling to communicate (and) the rocking was his way of trying to calm himself down."

Once Kelly advanced to Pittsfield (MA) High School, Fate was a bit more direct. Kelly and three other standard curriculum students were inadvertently assigned to a Special Education homeroom. The other students had moderate to severe physical and developmental disabilities.

Kelly was accustomed to interaction with special individuals, and developed a rapport with "special" students. One boy began to spell daily on the blackboard: I Love Kelly.

A girl with emotional problems began to respond well when Kelly would brush her hair, lovingly, consistently every morning at school.

"During study periods the teachers would let me work with these kids. They knew me, trusted me."

Kelly decided to become a teacher, based on her successful work with students, but "the only subject I was good at was history. I never even thought of Special Education."

At Westfield State College she prepared for a secondary school teaching career. She had a tough experience teaching Sociology to seniors at Westfield (MA) High School, where her youthful appearance often caused her to be mistaken for a student, and the small age difference made it



Teacher Kelly Doolan coaxes a smile from Brian M. Liberacki, a day student in her class at New England Pediatric Care, a residential nursing facility for children in North Billerica, Massachusetts.

difficult to establish authority.

However, Fate decreed that she would also be assigned to a cooperating teacher with an "inclusion" Civics class which included seven special needs students.

"I thought Civics was kind of boring, so I took the basics of the course, and made it fun for me, too. I earned amazing respect and attention from this low-level, hard to handle class. The teacher and the principal were impressed.

"I visited the Special Education Department at the school, and knew then and there, this was the work for me."

In the middle of senior week festivities before graduation, Kelly interviewed at New England Pediatric Care, which operates a school for seriously impaired pediatric residents and day students.

"I fell in love from day one," said Kelly. "One of the kids was sitting there in his wheelchair, looking at me. He was smiling and giggling. He couldn't communicate verbally, but I asked him 'Do you think I'm funny?' Head shake,

yes.

"He was staring at my shoes. I've been a dancer all my life — I teach aerobics after work for the staff at NEPC — so I started tap dancing. The other kids got curious. I think they knew I was not going to stay a stranger. From that day, I knew this was the place for me."

Always a happy person, Kelly spent a satisfying first year as a teaching assistant. Her friends were mildly critical that she would take a "lesser" position than she might have had in regular education.

"But right from the start I saw it as a great learning experience for me. These kids were going to teach me how to laugh, how to learn things. The staff has been an inspiration to me, sharing, teaching, helping me.

"I think I can make a difference here. I can see the potential in these kids. . . . I have never regretted my decision," Kelly explains.

Kelly took courses and "learned the

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Framingham teens grow by coaching Special Olympians

Every Tuesday from January to April, 13 Framingham High School students coached Barbieri Elementary School's Unified Bowling Team for the Special Olympics of Massachusetts.

Unified means half the students on each four-member team had special needs, and half were in the standard curriculum. *Coached* means the teens volunteered about 75 hours, including two full Saturdays, deferring heavy course loads, sports and social activities, to do something worthwhile.

Special educator Dale Bekesha, one of four teachers who organized the program, said it was a rousing success for the 36 grade schoolers who participated.

"The special needs and standard curriculum children melded together, learned to tolerate each other and cheered each other on," she said. "Some of the 'special' kids turned out to be better at bowling than the others, and that made everyone realize we are all individuals with different strengths."

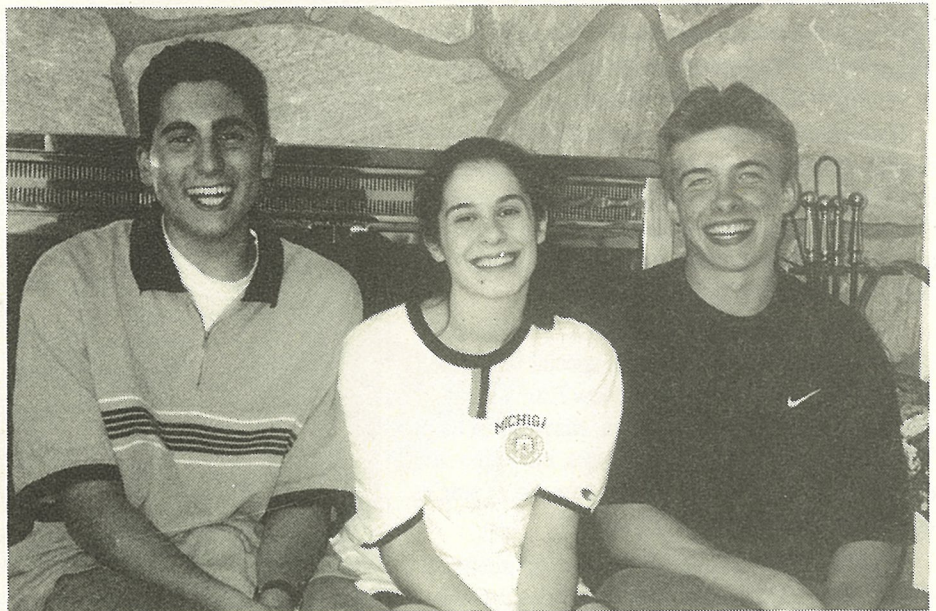
Beyond that, the teen coaches said they learned that volunteering means not only giving, but also receiving and learning.

"I volunteered because I felt I should do some community service. I don't mind working with kids, and I like bowling," said junior Jon Moody. "But beyond the fun, I learned how to be more patient, with both the 'special' and 'not special' kids. I also learned sometimes you have to be stern to get them to listen."

Jon is captain of the FHS volleyball team, hoping to make the Varsity Soccer team in the fall, and a member of the National Honor Society. He would like to become an architect. It is important to broaden your experiences, he said, and that same message is important to the younger children.

Jessica Tubman said she expected the volunteer experience to be something she could list on a resume, but she learned a lot about appreciating the moment, and being grateful for small happinesses. "The kids always smiled, they enjoyed just being there bowling. Where we might feel knocking down nine pins was good, they'd be jumping and shouting Yesssssss! if they knocked down three."

Jessica, also a junior, plays volleyball and for the United Soccer Club, is an active



Framingham High School students coached a Unified Bowling team for the North East Regional Special Olympics in Massachusetts. Among them, from left, Michael Bekesha, Jessica Tubman and Jon Moody.

member of the FHS student government and National Honor Society. She studies flute at the Longy School of Music, and participates in the United Synagogue Youth group. She plans to go into business.

"The 'not special' kids worked together with the 'special' kids," said Mike Bekesha. "I learned that nobody should be excluded."

Mike, also a junior, said more teens should volunteer in the Special Olympics because they could learn that everyone has strengths and weaknesses. Mike participated in both the Harvard Model United Nations and the Massachusetts Bar Association Statewide Mock Trial Association this past

year. He plans to become a lawyer.

Robert Johnson, president and chief executive officer of the Special Olympics of Massachusetts, said the genuine benefit of unified sports programs is long term.

"Relationships are established as on any other team, and extend beyond the field, gym or bowling alley. Participants gain or renew appreciation of each other. Unified sports bring people together and teach them that just because an individual has special needs in one area, it doesn't mean that all levels of performance are affected."

To learn more about Unified Sports and Special Olympics team, contact Bob Johnson at (978) 774-1501.

Fate fingered Kelly early on for special ed

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ropes" from her head teacher Teresa McMahon. The different gadgets and teaching toys, the sensory stimulation techniques, the auditory techniques were overwhelming at first.

"I was nervous about trach(eostomy) tubes, mist machines. I was afraid I would forget to strap a seat belt on a wheelchair.

"But I saw that that every (teacher) I worked with were the eyes, ears and voice for these children. They were so protective of them, and I strived to be like that. To

know the kids well and keep them safe."

Kelly has great praise for the nursing, teaching and therapeutic staffs at NEPC, for their care of the children and their ability to make her understand and integrate care into the classroom.

Kelly is now working towards a master's degree in moderate to severe special education at Fitchburg State College. Being involved in this program allows Kelly to obtain teaching status at NEPC, where she has her own class of seven students.