HELP A LITTLE ONE

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H.A.L.O. Reports

A Foundation for Children with Neurological Impairment

Families weigh heavy decisions at age three

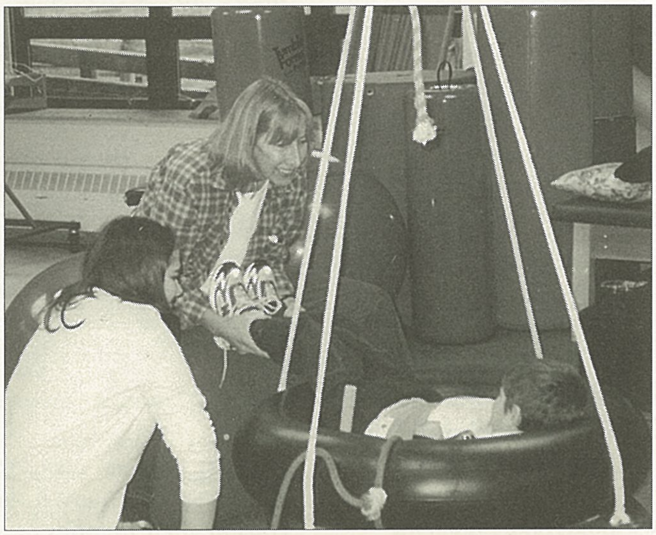
Vibrant leaves garnished the autumn landscape a few weeks ago, but the families of Joey Gordon and Vinoth Kumar were already looking ahead to winter, when they will be forced to make hard decisions for their sons.

Traditionally, parents make school decisions at kindergarten, but Joey has Down syndrome, and Vinoth has cerebral palsy. In Massachusetts, early intervention programs end on the third birthday, when the Department of Public Health transfers responsibility for special needs to the Department of Education.

Over the next few months Arul Kanniappan and Siva Kumar of Canton, and Tom and Kathy Gordon of Norwood will formulate an Individual Education Plan (IEP) with their local school districts, which split tuition bills with the state. The IEP provides a framework for the "free and appropriate" education required by state and federal laws.

How do parents assess the best learning environment for their neurologically impaired child? H.A.L.O. was invited to observe their visit to the Boston College Campus School, a private school for children with multiple challenges.

Principal Donald Ricciato outlined the Campus School basics: up to 47 children, ages 3-21, can be served by the day school, which is learner-centered and focused on communication. Thirty-seven staffers include teachers and assistant teachers (one for every 2 students), three full-time nurses, four one-on-one nurses, and full and part-time physical, occupational and speech therapists. Most classes are 6 to 8 students.



Boston College Campus School gives individualized attention to students with special needs.

Many students use wheelchairs, but use is determined by student needs, not policy, Dr. Ricciato said. Staff members utilize gait trainers, harnesses, standers and other equipment with students to build strength and stamina for vertical positioning, and to increase

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Inside this issue:

Mother writes book about special relationship

One day Dawn Atkinson went through 850 titles on Internet bookseller Amazon.com and couldn't find a single book that addressed her personal experience as a parent of a child with multiple special needs.

"I couldn't find anything written in the past 20 years that explains what it is like," said Dawn, whose son Jacob, 7, has cerebral palsy and other challenges due to oxygen deprivation to the brain during birth. After a lot of soul searching she wrote In This Together to show other parents they are not alone, and to help family, friends and professionals understand what daily life is like.

Dawn's account was drawn from five years of journals and memories. It begins before Jacob – "the child of my heart" – is born, and ends with a touching letter to her son.

". . . If it's true that we all write our own charts before we incarnate into this life,

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Founder's message

Dear Friends,

National news media recently reported the tragic story of Terri Schiavo, a young Florida woman who has been in what doctors describe as a persistent vegetative state since she suffered a heart attack 13 years ago.

Terri had no living will, and her parents and husband have taken opposite stances over the difficult question of whether or not to disconnect Terri's feeding tube— an action that would effectively end her life.

Thorny dilemmas are commonplace to families who have a child with neurological impairment. Whether the child resides in a pediatric facility, or is cared for at home, parents are burdened by painful decisions on their behalf.

For more than a decade our daughter Sarah has been unable to speak for herself. She has been forced to surrender her daily choices and life-altering decisions to us. While her siblings have moved on to college, Sarah remains much as she was when illness robbed her of her abilities twelve years ago. Danny and Julia tap away on their laptops, while Sarah strives to press her cheek to a tiny switch mounted near her face to change her computer display. We can only hope that our determinations have not caused her pain or loneliness.

Unfortunately, thousands of children with neurological impairment share Sarah's predicament. With your help, the H.A.L.O. Foundation will continue to provide gifts to comfort them, and we will continue to fund programs and equipment that enrich their lives and give them a voice. We will empower and console their families by sustaining the Family Circle support group.

We thank you for your kindness and support in this mission.

Sincerely, *Alan Pinshaw*

Coming soon!

www.halofoundation.org

Sounds of music enchant children at Cedarcrest

Melanie Everhard speaks the universal language of music to children at Cedarcrest, a Keene, NH pediatric home for children with complex disabilities.

On Tuesday afternoons the local teacher stimulates the senses with a wide range of musical genres, tempos and vibrations. Children receive one-on-one encouragement or experience small group music enrichment activities.

Response has been so positive, Cedarcrest plans to expand the music appreciation program and purchase instruments such as maracas and tambourines for sensory stimulation.

Cedarcrest is a small, non-profit pediatric facility offering specialized care to children with a variety of disabilities and high-risk medical conditions.

Melanie Everhard shares a guitar with a resident at Cedarcrest in Keene, NH.

Visit Cedarcrest at www.cedarcrest4kids.org or call (603)-358-3384.

School bells ring at age 3 for some children

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opportunities for more eye contact.

How do you evacuate students in an emergency? Kathy Gordon asked as the group toured the second floor. School and fire officials collaborated on a plan that empties the building in less than three minutes, she was told. The younger, smaller students are carried from the upstairs classrooms.

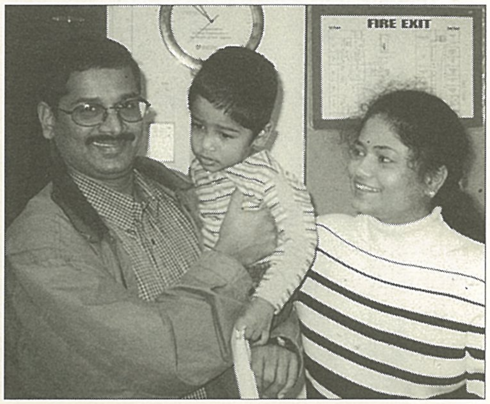
Joey's mother also queried: *Do you have role models for socialization and behavior?* The Campus School does not enroll typical peers, but program specialist Christa Burke-Hill explained that interaction is scheduled with students at a nearby elementary school, and with college student volunteers.

"*Where do students come from?* Vinoth's father asked. *Does everyone have to take a long bus ride?* Students are enrolled from as far as 50 miles away. Accessible buses and vans transport the children, but parents can drive if they prefer. Vinoth's parents seemed relieved. Both families nod when Jill Jones, the classroom teacher for the youngest children, assures them that a gradual transition can be arranged if children cannot tolerate the full 8:30 a.m. to 3 p.m. schedule at first.

A typical day at the Campus School includes toilet training, communication exercises, sensory integration, snacks, free play, naps, music, gross motor activity, and lunch. Occupational and physical therapies and individualized activities are usually scheduled in the afternoon. There is also a fully accessible outdoor playground.

Hugging a happy, screeching Joey in his arms, Tom Gordon said he would like to know what his son is saying: *What does the school do to improve communication skills?* The Campus School's total communication approach guides children from object representations to photographs, then line drawings and communication devices, such as computers, the principal answers. Lessons are also embedded in playtime and in tasks such as a trip to the water fountain. Teachers exchange daily reports with parents in a communication notebook.

The Campus School's recently revised curriculum goals are: (1) Communication and language development; (2) Personal management, or at least recognizing needs and requesting care; (3) Applied academics/ concept development; (4) Socialization and role in the community; and (5) Leisure and recreation.



Siva Kumar, Vinoth and Arul Kanniappan

Why would a family choose the BC Campus School over another program? "We want to bring children to the highest level they can reach," Christa Burke-Hill, the program specialist, answered. "We want them to try to go beyond basic needs, we want them to initiate, to throw humor at us, be silly, and have quality of life, too." Dr. Ricciato emphasized the communication focus, the staff, and the school's culture.

The Gordons and the Kanniappan/ Kumar family left the Campus School with much to think about.

Most public school districts offer integrated preschools, serving both special education and standard students. Benefits include peer role models and reduced travel time. Regionalized special education collaboratives such as The Education Cooperative (TEC) that serves Boston's South Shore communities can provide targeted services in a different setting. Dozens of specialized private schools also offer options.

Joey, Tom and Kathy Gordon

As the families ponder their choices, they will have to decide whether Joey or Vinoth will benefit most from a program that serves similar children, or a classroom where their child could be the highest — or the lowest — functioning student.

Call the BC Campus School at 617 552-3460
or visit www.bc.edu/bc_org/avp/soe/campsch/

Dawn and Jacob: In This Together

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and that we choose who will bring us into the world, then I thank you for choosing me above all others." Dawn writes to Jake. *"It has been my honor and my privilege."*

She needed a new way to think about her life, and was inspired by the book God, Creation and Tools for Life, by Sylvia Brown. It made her believe that Jake chose her to mother him through his time on earth, and that helped her realize she had a special opportunity to learn from her son "without him ever speaking a word."

"I wrote the book first because it is critical to the healing process for parents to connect with some one who has been there. We mothers somehow feel responsible, and we go through anger and grief and guilt," Dawn said in an interview. "You stop grieving about all those missed milestones after a while, but that anger still sits on your shoulder."

Dawn's second motive for writing the book was to share the experience of caring for a child with so many needs.

Dawn was a registrar at a cancer center before Jacob was born. "Now I'm a pharmacist, nurse, advocate, insurance expert and mother." She adds political activist to the list, noting that parents of children with special needs have to fight continuously for services, because they get eliminated when politicians are allowed to forget about them.

There are two types of parents, Dawn said, those who need to be directed by the medical profession and those who collaborate with them.

"I started out being led by the doctors, because I was still in shock. Eventually I realized I am the expert on my son. It's my job to interview the doctors and to tell them what I expect from them, and what they can expect from me," Dawn explained. "With an involved child, your life is not your own. This is my way of having some control over the situation."

Jacob Atkinson

Collaboration has proved beneficial, said Dawn. Jake has been hospitalized just once for illness in the past four years, due to her diligence and consultation with the doctors.

"Dr. (Gregory) Hagan, Jake's pediatrician, says I run a mini-trauma unit at home, but I've learned that if we can avert pneumonia – a big threat to kids like Jake – we can avoid the hospital.

Dawn starts nebulizer treatment and chest therapy at the slightest sign of a cold. She tracks blood oxygen levels and researches drugs recommended for her son. When surgery is an option, she weighs his discomfort against the result. "The doctor's job is to do what is expedient. My job is to do what is most comfortable and best for Jake.

Dawn says she can't do it all alone. Her husband Dave is very caring and supportive of their son, as is her mother and other family members. Dave's daughter Ashley, 15, has learned to put Jacob's needs before her teen wants - a difficult task for a child who was the center of attention for eight years. Four-year-old Jessie, who has never known anything else, has developed sensitivity and compassion beyond her years.

"When we bring a child in to the world, we do so with great expectations. We never expect they will teach us so much about life, love and courage," said Dawn.

Contact Dawn Atkinson at www.dawnatkinson.net

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