

The GBArc Beacon

Fall, 2004

An informational newsletter of the Greater Boston Arc

221 N. Beacon St., Boston, MA 02135

Ph: 617-783-3900 Fax: 617-783-9190 Web: www.gbarc.org

GBArc Hosts The Arc's National Convention

Traffic won't be disrupted, North Station will remain open, and no protests are anticipated when "the other major convention" comes to Boston this year. From November 18-20, The Arc of the United States will be holding its most important gathering at the Sheraton Prudential Hotel in Boston. Open to the public, the convention will include much in the way of best practices and new information both for families and professionals.

A major theme of the gathering will be the participation of individuals with disabilities in the arts and public media. Throughout the convention, attendees will be able to see and hear about individuals with disabilities who are making a contribution through the arts. Of particular interest will be two young actors, Jennifer Cunningham (recently on "Kingdom Hospital") and Blair Williamson (recently on "The Guardian"), and the casting director – Gail Williamson – who has helped them find a place in today's highly-competitive entertainment industry.

Hosted by the **Greater Boston Arc (GBArc)**, the 3-day event will feature a wide range of speakers and topics, along with a 50-booth exhibition of suppliers of goods and services of interest to our members. There will also be lots of opportunities for networking with other individuals from across the U. S.

Topics include future planning, fundraising, abuse prevention, education inclusion, housing, legislative advocacy, siblings, aging caregivers, recreation and leisure, religion, and assistive technology, just to name a few. Among the featured speakers and topics are David Pitonyak, Ph. D., who specializes in supporting people with difficult behaviors, who will speak on loneliness, and Ted Schettler, MD, MPH, co-author of *Generations at Risk*, who will speak on environmental factors and disabilities.

And while you're there, take the opportunity to have a night of fun, education and excitement as you join the Arc of Greater Boston for an evening of exploring at the Boston Museum of Science. Ride through the historic streets to and from the museum on one of Boston's Trolley Tour trolleys. Join your friends and make new ones at a reception overlooking Boston's gorgeous evening skyline. The evening includes a light dinner and cash bar. Then explore all the excitement that the museum has to offer, including the Omni Theater. There are over 550 interactive exhibits available that are sure to please every age range, and presentations and shows to make you say "Wow!" Don't miss out on this fun and exciting evening!

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Don't miss this great opportunity for education and networking. Go to www.thearc.org for further details and registration information. If you have questions concerning registration, phone 773-348-3196.

For Volunteer Opportunities, please call Terri Angelone at (617) 783-3900 X20.

Annual Report of the Greater Boston Arc Taken from the GBArc Annual Meeting: June 8, 2004

President's Report

Visioning and having a *vision* has been *the* significant trait of GBArc from its beginning!

GBArc has had a *vision* of a creative revolution of services since it was founded in 1945, 59 years ago, as the Child Betterment Association. GBArc has been motivated by a distinct *vision*, from which many people have benefited. Now we are hosting the National Arc convention for the third time: First in 1954 (50 years ago), again in 1978 (26 years ago), and for the third time in 2004.

The revolution in Special Needs Services started with families gathering together in the 1940's to explore the latest ideas in the learning process, in health care, and in work and training practices. Improving the quality of life is still the focus of attention for the Arcs.

Mass State Law 766 requiring education and training for persons with disabilities was voted into being 30 years ago, and the more recent federal law IDEA (Individual Development Education Act) was patterned on 766. This greater vision speaks to all of us, a new horizon, and we find meaning in grasping the greater vision and quality of life, not only for persons with disabilities, but for all of us, for we all benefit when the quality of life improves for any of us.

We have reason to reaffirm this vision each year when it comes to housing, employment, and health and dental care.

Vision for Housing ~ Most all persons with disabilities now enjoy the greater freedom and stimulation of community living, as compared with institutional life. We think of adequate housing as a basic entitlement. But it languishes without the vision of growth and independence that consumers can successfully achieve. In spite of the opportunity almost half of those recipients of the Boulet Settlement have refused the opportunity to live with peers in an independent setting. We have reason to expand our vision of the entitlement and potential of all persons with disabilities, to confirm that all persons can thrive on independence and peer contact. This is basic to our human endowment.

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Vision for Staff ~ Most staff learn their duties from their own upbringing, but the ability to support and nurture persons with disabilities requires sensitivity and perspective unique to the field. Persons with disabilities need trained staff who recognize individual learning styles. Staff need more training, perspective, and support. It requires perspective and vision in the persons providing care to lead and support consumers without becoming depleted.

Staff Training ~ In the human service field, new direct care staff persons who are motivated and committed are often asked to carry a workload beyond their years or experience, and risk burn out. We need to offer refresher courses and seminars to our committed staff, and pay them an adequate salary for the responsibilities they carry. Direct care staff need a support system. It is great news that a work study bill is developing in the legislature that will identify the hours and commitment that direct care staff are investing, and the limited compensation they receive.

My wife and I were fortunate to meet several of the Social Pedagogues from Europe who were here for a year working in group homes in Massachusetts. They told us what they missed most in their sojourn here was the ongoing training experience they enjoyed in Europe, where they would meet every other week with fellow workers, to swap notes and share the trials and high points as they became acquainted and developed their professional skill. This significant support system helped them mature their commitment to the field as direct care workers, and avoid the isolation and depletion that otherwise can result. We as an Arc have the opportunity to lobby for this advance of a support system of direct care workers, and it will pay big dividends in the quality of life that the people we serve enjoy.

Vision for Employment ~ We are challenged to have the vision to see the motivation and freedom consumers enjoy participating in the work force. The stimulation of the marketplace is enormous. We all continue to learn from friends and co-workers throughout our life. And the same is true for all persons with cognitive disabilities. You just have to see the enthusiasm that exists on the field during Special Olympics to witness the energy and motivation to participate in a meaningful manner in the games. Or to feel the companionship in the workplace when a consumer asks for help in understanding a new task. Companionship is a great learning opportunity that continues throughout a lifetime.

We all continue to learn and grow throughout our lifetime. And the same is true for everyone with a cognitive disability. The capacity to acquire new skills, to enjoy participation in the tasks of living, are found not just in the friendships we develop, but also in the self esteem we develop as we successfully participate in the workforce. And we all benefit from this growth experience in our community. Hard work is ennobling for all of us.

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VISION for HEALTH CARE—Ten days from now is the opening of the Summer Games of Massachusetts Special Olympics. I hope you will all have the opportunity to see the enthusiasm, good health, and happiness that is present on the playing field. Keeping the body in good functioning order is the very best medicine. It is a major learning experience for all of the athletes to perform in public, and to work to do their very best in this peer gathering. This is a vision that keeps growing each year, from the parade on Friday evening through all of the sporting events of this annual festival. We are deeply indebted to the Kennedy's, and all of the coaches and trainers, as well as the athletes for this annual achievement event.

THE TOTAL VISION is WE ARE NOT ALONE—As members of the Arc we have an entitlement born of our commitment to persons with cognitive disabilities. At least _ of 1 percent of the population in all communities are born with recognizable cognitive disabilities. And this knowledge provides us with a perspective and honesty. The honesty of this statistic reveals a phenomenon of the genetic makeup of humanity. And this knowledge gives us perspective on human achievement that we all learn, grow and contribute in our own way.

VISION for the FUTURE--Achievement for all of us is a matter of degree, and a reflection of the maturing of our culture.

C.E.O. Report

We've come a long way in one year and every single program that GBArc provides is getting bigger and better every day.

The Corporate Guardianship Division, Directed by Kim Yen Vu, has concentrated much of it's efforts in the past year on development of new, updated billing procedures, connecting with new clients for the program, and maintaining a high level of contact with existing clients. A new brochure specifically for use as a Guardianship marketing tool is being developed, as is an updated version of the Procedures Manual. And we have hired two part time Guardianship Case Managers this year, both of whom have done a tremendous job in ensuring the rights and responsibilities of their wards are adhered to. We welcome Paul Silva and Carrie Johnson.

The Advocacy and Community Programs and Services Division of GBArc, Directed by Tony Sirignano, has flourished with new and existing projects this year. For example:

- Kids of All Learning Abilities, run by Barbara August, continues to advocate for, develop and ensure implementation of new and existing quality, inclusive after school programs throughout the Greater Boston area. Barbara has developed and presented numerous trainings across

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the state on best practices in inclusion to such well known organizations as the United Way and the Boston Medical Foundation. KOALA is representing "the voice of inclusion" as the program was asked to participate in the development of core policies around quality after school opportunities in the state. These policies will be implemented in educational institutions and organizations in Massachusetts in the coming years. And KOALA continues to foster quality relationships with like minded organizations to provide quality inclusive experiences for youth in Massachusetts. One such partnership with Hostelling International is resulting in a weekend summer vacation for students and their families on Martha's Vineyard in August.

- *Family to Family*, managed by Tony Sirignano continues for it's 4th year in working with the Department of Mental Retardation to provide much needed assistance to families who are part of the Boulet Class Action Suit. Now with 2 years remaining of court mandated funding for housing and/or day programs for persons protected under the Boulet Class, GBArc continues to work closely with the DMR to identify families who are having difficulty with the whole housing process. As the Boston Area Family to Family Support Center, GBArc is making progress working with existing families, some for as long as the past 3 years: Helping parents and siblings formulate ideas for the future of their while at the same time ensuring the needs and desires of the individuals with disabilities are respected and upheld. It's an ongoing process, nothing that could be worked through overnight by any one of us. But for those who are able to see that the lives of their loved ones will be cared for well into the future, and that the input of the whole family was involved in the decision making, the rewards are endless.

Family to Family also continues to provide neighborhood type meetings with small, naturally networked groups, as well as individual meetings and clinical support groups. And back by popular demand, GBArc and the Greater Waltham Arc put on it's second Provider Fair last month, and was a great success as it was attended by almost 50 Boulet and families.

- This year, GBArc took a slightly different route in it's ongoing involvement with the *MDDC/Arc Massachusetts grant* to increase housing options to people with disabilities in the Commonwealth. This year, GBArc has been awarded a \$21,000 grant by the Mass. Developmental Disabilities Council and the Arc of Massachusetts to use as seed money to develop an inclusive living situation somewhere within the 14 communities that GBArc operates. We are working with a Housing Consultant and a steering committee from across the state to develop as close to our "ideal" inclusive situation, which would include both market rate and low income condominiums, for ownership

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and rental, an accessible and attractive common area to be used by all, as well as ongoing adult education classes to benefit folks in the community. We are in the beginning stages of this grant project, and look forward to reporting much more next year.

- *Operation House Call* continues to partner with the Boston University Medical School whereby we offer an orientation to 3rd year medical students every seven weeks around the sensitive issue of working with families who have a child with a disability. This year, under the remarkable coordination of Susan Nadworny, OHC has expanded to work with both North and South Shore Hospitals. Last month, OHC participated in a resource fair at Brandeis University and the Medical Foundation in conjunction with the KOALA Program where GBArc's talents were highlighted to participants. And finally, Operation House Call recently hosted a successful brunch in cooperation with the B.U. Medical School, celebrating the families who participate in the orientation every seven weeks. Each one is truly amazing.
- Donna Rubenoff continues to work with families in need of assistance with Education Plans in GBArc's *Educational Advocacy Program*. Families are referred to Donna who feel dissatisfied with their son or daughters school plan of action, and Donna will advocate on their behalf, going all the way up to mediation if necessary.
- Donna also heads up GBArc's Family Support Program, where for the second year GBArc has collaborated with the Boston Museum of Fine Arts to create a project that exposes self advocates to the museum. Participants of the program explore the museum, choose their favorite pieces of art, and then perform a physical interpretation of the pieces. This year, the program took them to the Esplanade at the Fire King Festival, where participants had an opportunity to perform their interpretations of various artworks with the artists as witnesses. It was a tremendously rewarding experience for all involved. This program has been so successful that Donna is working with other institutions in Boston for similar projects in the future.
- Finally the Silver Stars, many of whom are here tonight, continue to get together every month, with guidance from Tony Sirignano and Donna Rubenoff, to attend social outings of their own choosing. This year events ranged from dinners at local restaurants, to a pottery class in town, to movies and cultural outings. In the coming year, with the blessing of it's participants, we plan to take the Silver to a level of more self awareness with some self advocacy skills development in conjunction with the usual social and recreational outings.
- Summer camp stipends continue to be awarded; this year with over 40 families applying thus far for financial assistance to provide their son or daughter with a summer camp or vacation experience.

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As you can see, GBArc's programs run the gamut from early childhood to adulthood, from educational programs to housing advocacy and support. We continue to provide critical services in the Commonwealth, and are fortunate to have folks on our side with the cause at heart. In addition to the staff named in the program descriptions I just made, I'd like to also send out special recognition to Rose Pessin, our Director of Development and Office Manager. Her undying efforts each and every year in putting together GBArc's fundraising events like the Red and White Ball and the Golf Tournament, which incidentally is being held next Monday at the Blue Hills Country Club in Canton, provides GBArc with almost 20% of it's operation budget. Working closely with Paula Lyons, our Development Assistant, Joe Chandler, GBArc's bookkeeper and Judi Rodger, our receptionist and office assistant, Rose is able to pull in support dollars from places the rest of us dare not even dream about! The GBArc team is wonderful, and it is truly an honor to work with them every day. I thank our staff, our Board of Directors, our members and friends for all you do. Nothing is possible without everyone's support.

GBArc Kicks off Fundraising Campaign for Children's Services

GBArc is happy to announce that it has received a contribution of \$150,000 from the *Ida Bornstein Trust* which will be put to use toward the provision of Educational Advocacy, Family and Sibling Support programs. This generous donation is a tremendous jump start for GBArc's Children and Family Support services Fundraising Campaign, as it puts us at **30% of our goal of reaching \$500,000!** These dollars will be placed in an endowment, where the interest will be utilized annually to cover the cost of our family and children's services, which are critical to our families. This will allow us to continue providing these top quality, essential services for years to come, even as programs are being *shut down around every corner* due to the declining economy.

If you, or anyone you know are interested in assisting us in reaching our goal of \$500,000, please send your donation to:

Children and Family Services Fund
GBArc
221 N. Beacon St.
Boston, MA 02135

Our Children and Families *THANK YOU!*