Building Partnerships to Transform Autism Services

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Since 2003, NEXT for AUTISM has launched an average of 1.5 programs per year, a pace that matched the urgent needs of individuals and families living with autism and our own desire to help grow the field of autism services. As proud as we are of this pace, we could not have achieved it alone. We wanted to go faster, and we also wanted to go far.

NEXT for AUTISM has understood that in order to accelerate change, we had to build partnerships. Rather than reinvent the wheel, we chose to enhance quality services that already existed, particularly for people with developmental disabilities other than autism, and adopt them to meet the specific needs of the autism population with evidence-based strategies. We rely on data to assess the needs, then build on best-in-class solutions to transform the landscape of autism services for people with autism.

Our partnerships involve public and private entities, as well as collaborations among not-for-profit organizations. They succeed in affecting systems transformation, in large part, due to: a high level of commitment at the leadership level of each partner organization; a shared institutional drive towards innovation and a comfort with program iteration; the dedication and professionalism of the found- ing staff at each newly launched entity; and the continued support provided by each partner to the new entities at critical stages of growth.

Large-Scale Partnerships

The NYC Autism Charter School in Harlem opened after several years of collaboration among three key partners: NEXT for AUTISM, which identified the need for evidence-based education for children with autism in New York City, originated the idea for the school, and recruited private donors; the New York State Board of Regents, which issued the charter; and the New York City Department of Education, which operates the school. This public-private partnership resulted in high-quality, evidence-based public education options for families in the five boroughs of New York. Among the innovations were community-based instruction, work internships, and peer mentoring programs. The school has since been replicated in the Bronx, fulfilling NEXT for AUTISM’s wider transform-tional goal – in this case, creating capacity in a large, metropolitan school system to rethink education for children with autism and create two specialized autism schools inside of already existing public schools located in underserved communities.

The Hunter Autism Research Practice & Policy Center (HARPP) at Hunter College has an ABA-certification program for professionals within the City University of New York system and a Masters of Science in Applied Behavioral Analysis opening this year. At the time of HARPP’s creation, ABA was gaining momentum as an effective intervention for autism. Based on research that we had gathered, with commitment from Hunter College at the dean’s level, and funding from private donors, HARPP came to life and since educated thousands of professionals in ABA practices. Once a spe-cial program of the Dean’s office due to its experimental nature, HARPP is now a part of Hunter, its courses offered by the college’s Education Department.

The Center for Autism and the Developing Brain (CADB) was conceived at time when families facing an autism diagnosis often had to coordinate disparate services while simultaneously trying to understand what a diagnosis of autism truly meant for their child and their family. NEXT for AUTISM, whose founders and board members are parents themselves, approached NewYork-Presbyterian Hospital and its partner medical schools, Columbia-Vagelos and Weill Cornell, as partners to address this immediate need for a more rationalized approach. Our vision was to create a family-focused diagnostic and treatment center offering comprehensive and coordinated treatment by clinicians from multiple disciplines. We also sought to build capacity for autism research within a major metropolitan hospital system.

Throughout several years of planning, the partners formulated details that ranged from CADB’s clinical approach, to leadership recruitment, affordability of care, and the bricks and mortar renovation of a dedicated building on the Westchester campus of NewYork-Presbyterian. The outcome was a state-of-the-art center, led by one of the country’s foremost experts in autism, Founding Director Dr. Cath-erine Lord. Since 2013, CADB has served thou-sands of families, and thanks to leadership commitment among the partners, it was able to leverage the hospital’s bargaining power with insurance companies to cover the individualized services which previously may have been challenged. NewYork-Presbyterian’s affiliated medical schools at Weill Cornell and Columbia University also became partners in research, leading to collaborations with researchers from these institutions and others around the world.

Employment Training for Adults with Autism

Project SEARCH – Autism Enhancement, a training package offered to institutions wishing to prepare adults with autism for successful employment, evolved from NEXT for AUTISM’s collaboration with Project SEARCH at the Cincinnati Children’s Hospital Medical Center, an internationally recognized employment training service for people with significant disabilities. We first approached Project SEARCH to adopt its model program for youth tran-sitioning from high school to adulthood. To tailor the already excellent program to students with autism, we worked with Dr. Catherine Lord to develop a comprehensive program enhancement, with clear sequences and goals that target the strengths and challenges of learners with autism. We then invited the TEACCH Autism Program at the University of North Carolina to work with us on the current autism enhancement package.

This three-way partnership resulted first in a high-school to adulthood transi-tion program that operated out of the Center for Autism and the Developing Brain at NewYork-Presbyterian Hospital in further partnership with the Southern Westchester Board of Education Services. From lessons learned and successes in this earlier internship program, the partners went on to develop the current Project SEARCH - Autism Enhancement package, which provides the framework for job and life skills training to adults. To date the package has been implemented nation-ally at sites including Drexel University, the University of California at Irvine, the University of Washington, Sea-