

Building on Possibilities

Deeply rooted in the founding philosophy of occupational therapy is the firm belief that using our hands to create has a therapeutic value

By Calista Hendrickson
with Stephanie Lesser



Carlos' transfer steps, made from cardboard and PVC tubes, allow him to independently move back and forth between his wheelchair and the floor.

There remains a basic truth to the idea that an individual derives satisfaction and a sense of empowerment from creating a tangible object.

And I am reminded of this as I coordinate a collaborative program between the Adaptive Design Association (ADA), a Manhattan-based nonprofit organization, and the New York City Department of Education. In this case, however, it is therapists themselves who are experiencing those therapeutic benefits firsthand.

They are making all kinds of low-tech, affordable adaptive equipment for children in New York City, following a model of the Perkins School for the Blind in Watertown, MA—the school that educated Helen Keller.

Think, Plan, Build

As the supervisor of OT in New York City's District 75 (special education) schools, I am constantly aware of the enormous need our children have for all kinds of individualized adaptive devices to help them achieve their educational goals. Commercially available items meet some of these needs, but all too often we need a customized design to address their particular disabilities.

Thanks to Alex Truesdell, executive director of ADA, we are learning to "dream large" and tap our creativity to come up with solutions to benefit our students. ADA's mission and Truesdell's years of experience in this field inspire us to optimize our interventions and take charge of problems at hand.

Truesdell first founded the Creative Construction Project in 1998. It replicated key elements of the adaptive design services she had implemented at Perkins in 1987. Perkins is recognized internationally as a leader in the education of children who are blind or deaf-blind.

In April 2001, Truesdell established ADA as a 501(c)(3) nonprofit organization under the name Adaptive Design Association. She uses the term "adaptive design" to describe practical, affordable, custom-fabricated equipment and modification.

Building on the success of the Perkins model, ADA is proving that people within a child's circle of support can create effective adaptive equipment at a very low cost by using common materials such as corrugated cardboard, wood, plastic, fabric, foam and basic electronics.

ADA also incorporates Appropriate Paper-based Technology (APT) into its work, using pieces of pasted paper and card to strengthen and finish cardboard-based equipment. Bevill Packer, who developed APT in Zimbabwe almost 25 years ago, was featured in a March 1997 issue of *ADVANCE for Occupational Therapists*.

ADA offers training in adaptive design and construction, builds child-specific adaptive equipment and advocates for a proliferation of adaptive design services. In order to maximize its ability to

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reach children with disabilities in New York City's five boroughs—its current service area—ADA has been working closely with the New York City Department of Education (DOE) to raise awareness of the tremendous need within the system for adaptive design services. This relationship began in the spring of 2000, when the DOE signed ADA to provide adaptive design training to therapists working in New York City public schools.

To date, more than 300 of the 1,000 DOE therapists have attended introductory training; 22 have received intermediate training; and 10 therapists participated in a yearlong advanced training course funded in part by the New York Community Trust.

These therapists—along with the other professionals, parents and volunteers trained by ADA—have made hundreds of pieces of adaptive

equipment. Projects include customized chairs, floor seats, footrests, activity trays, communication systems and pre-vocational jigs.

An Exercise in Problem-solving

Carlos, a second-grader with spina bifida who attends a public school in Brooklyn, used to sit in his wheelchair all day. His physical therapist, Judy Loebel, knew he had the upper body strength to transfer himself from his wheelchair to the floor and back up again. After attending a day of training at ADA she began to think of a way for him to do so.

Loebel contacted ADA, after which Truesdell visited the school to measure Carlos's wheelchair and build a mock-up of what would become a set of durable, lightweight transfer steps.

A few weeks after Carlos began to use his steps, Loebel wrote to ADA saying, "I just wanted to let you know that Carlos's steps have been even more successful than I imagined. He's getting out of his wheelchair on a regular basis." The steps were indeed so successful that a second set of durable, lightweight steps was made for Carlos to use at home.

In the summer of 2004 the DOE sponsored six sessions of training at ADA for 12 additional OTs and PTs. Collaborating with Truesdell and Antoinette LaSorsa, ADA's fabrication director, they designed and built 21 pieces of customized adaptive equipment for children with disabilities at their schools.

The projects included a sensory activity center, another set of transfer steps and an adaptive chair for a first-grader named Todd



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NYC Department of Education therapists measure cardboard during an advanced summer training program at the Adaptive Design Association.

who, as a little person, had never been able to sit at the same level as his classmates. Sitting in his new adaptive chair, Todd is now able to see eye-to-eye with his peers for the first time. "The more you come to ADA, the more the creative side of your brain gets exercised, and the more ideas you have," said Betty Alpern, OT, of her experience with adaptive design. "It's a great exercise in problem-solving."

Adaptive Equipment that FITTs

Another team of therapists decided to take adaptive design one step further. After participating in ADA's advanced training program, OTs Agata Gately and Jane Rutt, and PTs Dianne Scully and Meghan Stark, felt that the students at their school, PS 138 in East Harlem, would benefit greatly from a small on-site adaptive design team. With the approval of their school's principal, Jacqueline Keane, the women christened themselves the "Fabrication of Individualized Technology Team" (FITT) and got to work designing and fabricating customized adaptive equipment for their students, in collaboration with ADA.

On a series of visits to the seven satellite school sites of PS 138, FITT assessed the need for customized adaptive equipment. The number of "essential" projects the team came up with is astonishing: 60 child-specific pieces of equipment and 93 programmatic pieces, for a grand total of 153 projects.

During an informal discussion I recently had with FITT, they shared their experiences with adaptive design and their hopes for its future. Jane Rutt, OT, had been exposed to adaptive design and APT while working on community-based technology teams in Kenya. She had made some items from cardboard while she was there and said, "When I learned that there was a place in New York City where they were doing adaptive design, I was very excited to become a part of it."

An adaptive design project always starts with a problem that needs to be solved. The adaptive design team assesses a child's need and then brainstorm with the student, teachers, aides and clinical team. Rutt said, "Every day we see unique needs that can't be met commercially. We ask ourselves, 'How we can solve the problem quickly, affordably, and effectively? Can we do it out of cardboard? What other materials and techniques make sense?' That's what we try to accomplish."

Agata Gately, OT, designed and built a "hug box," a long, foam-lined box, to provide self-initiated deep pressure input based on

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sensory integration theory and Temple Grandin's work. Meghan Stark, PT, said, "After Agata made the hug box, we realized the design could also be a ball/car chute and a step stool. The kids in wheelchairs could roll a ball back and forth from one lap tray to another. So one piece of equipment generates ideas for new items."

"We try to address things that are going to be appropriate for a child's education plan," Dianne Scully, PT, said. "We ask ourselves, 'How can we better service and educate this child? How can we increase their access to things and include them in the group, or help them calm themselves so they can participate in an activity, or provide them with a chair so they can sit at the table with everybody else?' Adaptive design helps to integrate children into the whole educational environment. That's what we try to keep in mind when we're coming up with projects."

Scully related a specific experience.

"As therapists, thinking of better ways to address the needs of children helps us to expand our expectations of what a child can do. The ADA approach takes away limits that you may be imposing without realizing it. I built a chair with the intention of positioning a child better, and with better positioning he became more communicative. He verbalized more; he reached for things more; he became more social; and I said, 'Wow, this kid wants to do so much more—let's figure out how to make that possible!'"

Another important element of adaptive design is empowerment. There is an immediate satisfaction that comes from developing a solution to a problem and being able to act on it now. And the fact that adaptive design materials are inexpensive and easy to work with helps to keep the ideas evolving. You can build a piece of equipment and, if it's not quite right, it is easy to adjust and change. One's own sense of self-efficacy is enhanced by knowing how to go from start to finish.

Looking Ahead

We are also starting a new program in our district to integrate adaptive design practice into our schools. As a pilot model, we have two therapists and a shop teacher in our occupational training center in the Bronx working as a team with older students transitioning to the workplace. They are learning how to finish equipment.

Some of this work, including papering and painting, is being incorporated into job training for our students. They will be improving fine-motor skills and developing job skills while helping to complete pieces of adaptive equipment for their peers and classmates. This program provides them with the opportunity to experience meaningful work and share in the therapeutic value of hands-on activities. The building of equipment becomes a community effort of therapists, teachers, staff and students. As the momentum builds and the excitement grows, we are hoping to see adaptive design workshops sprouting up all over because the need is great and the benefits are enormous.

I am, once again, reminded of Mary Reilly's inspiring quote: "Man, through the use of his hands, as they are energized by mind and will, can influence the state of his own health." ■

Resources available at www.advanceweb.com/ot or upon request.

Calista Hendrickson, OTR/L, is the OT supervisor for District 75 (Special Education schools) of the New York City Department of Education. She can be reached at chendri@nycboe.net. Stephanie Lesser is a program associate of the Adaptive Design Association. She can be reached at stephanie@adaptivedesign.org.