Matching Individual Needs with AT Options

Re-published with permission from Family Center on Technology and Disability
Technology Voices – August 2009
“The parents of the profoundly disabled kids I help, as well as other children whose disabilities are less severe, regard computers as a means to an end for their child, the end being increased equality and integration with society,” declares RJ Cooper. “So does the school district. The kids, however, regard computers not as a part of their life but as life itself.” Often, he notes, a computer represents a child’s first and ultimate lifeline to the world. Without it, learning, communication, and/or socialization might not be possible.

“In the case of AAC (Alternative and Augmentative Communication), I’m not teaching these young people to speak; I’m teaching them a new way of speaking. It’s almost like teaching them a foreign language versus a language they were born to. After sufficient practice, the goal is not to translate their thoughts into the new language, but to use the new language alongside their thinking,” he points out.

Finding Megan

RJ works with the full spectrum of children with disabilities, from those with emotional disorders and learning disabilities to those who are severely and profoundly disabled. Most of his efforts, however, are dedicated to children who are the most disabled. Megan was such a child. Megan had no face.

“At a trade show in Atlanta years ago I had passed by a booth run by two parents. Their daughter was with them. Megan was probably 11 years old then. As I walked past the booth I realized that her face was very ‘different’. Upon further inspection I realized that she didn’t have a face. She had two tiny slits for her nose. The rest of her face was just skin. Her face was very difficult to look at. I’ve since been exposed to many disabilities but I met Megan early in my career and thus her appearance put me off. Three days of the trade show passed. I saw her many times.”
Each time he caught a glimpse of Megan he reminded himself, “I should go to her parents’ booth and at least try to do something.” Yet each time he approached the booth he procrastinated. “Finally, on the last day as the show was closing down, I said, ‘I have to do this or I’ll never forgive myself.’”

RJ introduced himself to Megan’s parents. “They told me they had seen me all weekend working with kids and wondered if Megan was going to get a chance to work with me too. But they were not going to bring her to me because they had been rejected too many times before due to her appearance. I said to them, ‘I’ve looked at her for three days and I’d like to try to help.’ I then asked, ‘What else is going on with Megan beside the physical deformity?’” They replied, ‘We don’t know if there is anyone in there. She doesn’t exhibit much behavior.’ I invited them to my booth before I broke the booth down so we could experiment a little.”

It turned out, he explains, that Megan was in there. “She was very physically disabled but, I discovered, she could push her left cheek against a button. Using auditory information only, she was able to time the switches and hit the switch without prompting. During her first session with the computer she was able to make some simple selections about what she liked and disliked. This was very exciting for me. I was the only one there, along with Megan and her parents.”

He declares: “I have long said that if anyone comes to me with a need I’ll find something for that child or create something.”

**That Magic Moment: Contact - Then, What Next?**

For RJ Cooper there is almost always a magic moment when he is working with a child, that split second of epiphany when the child begins to understand what is being asked of her and how to respond. It’s the moment, RJ says, “when the child emerges from the dark.”

That initial moment of contact, he explains “is an epiphany for everyone involved, especially the child but also for the special needs directors, doctors, parents and other professionals in attendance. It’s very dramatic.”

Unfortunately, however, that moment is just a moment. For RJ Cooper the major question becomes, “How can that moment be sustained after I leave?”
That’s a question for which he still has no answer, he admits. “Because of the way I conduct my workshops I meet lots of kids for short periods of time, 30 minutes per child. What I unfortunately lack is the luxury of longitudinal guidance and observation.”

He continues to hope, however, that parents will contact him to let him know how their children are doing and whether they’ve been able to sustain the breakthroughs they made with him. He has concerns about the fidelity of implementation of the techniques he has introduced and would like to know that those who work with the child on a regular basis are following through on his recommendations.

The Challenge of Building an AT Industry

RJ Cooper believes that society has been slow to embrace assistive technology in all environments – home, school, and the workplace. When asked why he thinks that is, RJ responds with an anecdote. “In 1986, I recall having a campout with an occupational therapist friend of mine near the University of Utah, where I was attending. He and I, as far as we knew, were the only people in Utah doing anything with computers and special needs. I asked him, ‘When is this stuff going to catch on?’ With a poker face, my OT friend replied, ‘When you can buy the equipment at Radio Shack.’ Little did I know how prophetic that response would be. Even today you cannot walk into any retail store anywhere in the world and find any hardware or software directly related to special needs or AT. It has never caught on. I don’t know if it ever will.”

Adding to the problem, he says, is the lack of AT instruction at colleges. “Even graduate level courses in AT have failed to catch on,” he notes. “There are only 5-10 post-grad courses in AT nationwide and it has been that way for at least 10 years. In a growing field you’d expect to see more post-grad-level courses, but that has not been the case.”

In his travels, RJ has seen a pattern of bias against technology designated as “assistive.” “I think there may be a stigma about any devices that are associated with special needs. I’ve had parents, usually fathers, say to me at baby expos after I’d explained my special needs based roots, ‘My kid is not special needs.’ They shut down. There is a real stigma.”
Thirteen years ago, he recalls, “I had an infant daughter. I saw that my equipment, which was designed for kids with her level of cognition and physicality, might be useful for her to get a head start. My colleague and I took that equipment to every able-bodied baby expo in the country.

“I always had two booths in order to be very visible. We made the same big buttons that we use in AT buttons and had very easy to understand software running on large monitors, hoping that mothers would wheel up their babies, who ranged in age from two months to three years old. Their children would be able to whack at the buttons and fun things would happen on the computer. We were certain this would be a big crossover hit. I invested several tens of thousands of dollars toward this effort with, as it turned out, zero return. Once again I was left scratching my head and wondering, ‘Why can’t this cross over?’”

The Stuff of Champions

Although many experts extol the need for a team approach when considering the AT needs of a child, RJ feels that “when the chips are down it is usually a single individual who emerges to champion a child’s AT cause, not a team.” He adds, “When parents say, ‘I’m not happy with my school district. What can I do to get things going?’ I always respond the same way: ‘It takes one person, and you never know who that one person will be. You never know who will take your child’s AT career to task!’ The folks at the district said they were going to adhere to your child’s IEP. Unfortunately, the success of this approach involves dependency on the good will, experience, proficiency, and even what AT equipment they have been exposed to and have in their inventory, of the people on the IEP team. But when that one person emerges, things start to move, most of the times, forward!”

That person, he explains, can be an OT, SLP, an AT specialist or a special education director - “but for some reason one individual emerges out of the fray to become the prime mover.” This individual, RJ says, attends the conferences, subscribes to the journals, searches online and experiments with AT tools. “These individuals go way beyond the call of duty. They make something happen. They take immediate action and and keep pushing until something works.”
Such an individual emerged recently, he says, when RJ was working with a nine-year-old girl named Paige. “Her parents invited me in to work with her in front of school personnel after seeing me work at a United Cerebral Palsy event three weeks earlier. It was summer, so the only person to attend, of those who had been invited, was the Special Education director. With just the five of us there, I suggested that we postpone the session to a date in the near future when we could get the OT and the PT, the SLP and the Special Ed. teachers in the room at the same time so I could demonstrate the techniques Paige’s parents saw me present and liked. The Special Ed. director rose to the occasion. She said, ‘No, Well, we’re all here, and you have your equipment. I’d like to see what you can do with her now. I rigged Paige up with a switch and assigned her tasks that were clear-cut. Paige fulfilled every assignment. Her Special Ed director was visibly moved. Right there, right then, she became that person, the one individual who will be Paige’s staunch advocate.”

Early in his career RJ says he made an effort to spot these potential “heroes.” Now, however, “I try to hook up parents and professional staff with local resources, which I’ve catalogued throughout the nation. I learned that I can’t arrange the appearance of a hero like Paige’s Special Ed director. Usually, they emerge on their own out of the blue. When they do it’s always a happy surprise.”

He cautions parents, however, that whether the hero is singular or plural, an individual or a team, there is a time limit attached.

“This summer I participated in a summer camp workshop in Alabama for the University of Alabama. Things were going well with the technology training. The staff was open to new ideas. I told a mother whose child was a camp participant, ‘You have a great staff working with you this year.’ She did a double-take. She asked, ‘What do you mean this year?’ I replied, ‘In a couple of years or so you will have to work with an entirely new team because these people won’t be there for you. They will have new kids and as your child grows you are going to have to find new people to do as great a job as your current team.’ I was immediately sorry I said that because her face just fell. It brought back to her how difficult it was to assemble the current team. I had to remind her that she would have to do it again, and again and again.”

Start with Success but Not with Quiet
In his workshops, RJ emphasizes that he chooses activities he is certain the children can perform and enjoy. “I want the kids succeeding almost instantly and then I’ll nudge them a little further toward the goals that others have for them.”

Some, he remarks, “believe that my approach can be effective only in a quiet, no-distractions environment. That is a fallacy. The fact is that life is busy and full of distractions. I try to get the children into a real-life environment as quickly as possible, whether it’s a special day environment or community environment or the workshop environment. Whatever the environment, I don’t try to avoid distractions. I try to reduce them at first but then I want to have the child in an environment that’s as natural as possible.”

Such an environment, he says, often includes interaction between the children and audience members. “Many of the kids enjoy visiting with the audience. If increased socialization is one of the goals pre-established for them (and it almost always is), I’ll encourage them to spell out the word ‘friend’ on the computer, using their best abilities (cognitive and physical) and then I’ll walk the child to someone special in the audience and warmly interact. The audience loves this and so do the kids.”

“Necessity is the Mother of…”

RJ says he has found that “people are very adaptive when there is no other choice. That is, someone that has options, such as a person with RSI (Repetitive Strain Injury) will always choose the ‘best’ (easiest, fastest, etc.) technology. However, someone with fewer options, such as a quadriplegic, will adapt to that technology that best suits their needs, even if it’s slow or challenging.”

Adaptations for special needs are not limited to the computer or AAC devices. Popular consumer items also fall into the category of assistive technology. And the items that do are those that are popular with mainstream society. RJ states, “We have seen, of late, digital music players, recorders, cameras, camcorders, and phones, to name just a few. I note that parents tend to ask for adaptations for those items that are already popular with able-bodied persons. And they are ‘trend’ oriented, also!”
The next popular technology trend, he predicts, is the digital camcorder followed by video capability in phones (the latest iPhone just incorporated this feature). “The video camera itself has gone completely digital and is in the realm of affordability. A year ago I could not have said that.” Within the past year, he notes, at least three companies have made video cameras in a digital format with the same filming capacity - two hours - as regular video cameras. You have seen TV shows showing funny or captivating video. These were all shot with regular video cameras. But the age of the *digital* camcorder is almost here and when a person can whip out a pocket sized camcorder, video online and on TV will boom!

“And those are the type of requests I get for adaptations, whatever is popular in the mainstream. Within the past year, we started adapting digital still cameras and recently added digital camcorders to our inventory of adapted consumer products. We look at what people want – even it’s only for one person – and adapt. I had an individual who wanted a dog feeder adapted for her daughter recently. She wanted her daughter to be able to give her dog a treat. So I purchased several electric dog feeders, chose the smallest and adapted it for single-switch.”

“Whatever the trend is – whatever people want to do – guides me. I don’t wonder, ‘What else can I invent?’ I am always surprised at the ideas people come up with but cannot do anything about it because they lack the means to bring to reality. The truth is that not many manufacturers of off-the-shelf technology are responding to individual requests or needs. However, if you call someone like me something will be done about that idea within a week.”

“What Do You Want Your Child to Do That He Is Not Doing Now?”

“With each parent that accompanies their child during my popular Roadtrip visits around the country, I always start by asking: ‘What is it that you’d like your child to do that she is not doing now?’ Most parents, and even professionals, are somewhat taken aback by this seemingly simple question. Evidently, no one has been this direct with them, so they may lack a quick response. Sometimes I’ll have to make a suggestion to get them started.”

Once started, however, parents can often make a significant contribution during the brainstorming process. One parent, RJ says, knew exactly what he wanted from the
outset. He contacted RJ with a specific request: He wanted his son Philip to be able to operate his computer by using the big toe on his right foot.

The parent envisioned a box with 10 buttons on it, each the size of a quarter. And each would be operated by Philip’s right toe. All buttons would be connected to computer functions, like moving a cursor. Other buttons would take Philip to a website or other web destinations.

The parent initiated the process with an email. Remembers RJ: “I asked him to give me a day. Twenty-four hours later I had created what he needed. The box I created had 10 buttons, square rather than round. I said to him, ‘I’m shipping this out today.’ He asked what he owed me. I replied, ‘Nothing. Let’s see if it works first.’

A week later the parent informed RJ that the device was a success. He also sent photos showing RJ the equipment in action. “I was leery about whether Philip could memorize the position of these 10 buttons which were placed outside his range of vision. But Philip’s dad made a graphical legend for him located within Philip’s view so each button’s function was visible to Philip. Philip loved that contribution. Together his dad and I made something that Philip could use that week!”

Later, RJ recalls, “The dad came across my track ball on my website and suggested using that. He bought one. They used it for two weeks before Philip went back to the little button box.”

“User Control is Paramount”

To RJ, both computer, and consumer technology such as the iPod, is useful in a special needs environment only if the child controls it. “If the child is only on the receiving end, either the technology hasn’t been investigated enough, or the parent/professional is still searching for a good control method (choice or position of a switch). Even though the kids may like the technology, I personally want more from it. If the kid is not controlling the equipment it’s just another way of Mommy singing to the child.”

In his direct work with children, RJ touches on all aspects of AT. “But I usually must focus on communication and/or academic goals because I only have 30 minutes with each learner and I have to make something great happen within that time.
frame. Recreational use of the AT for purposes of relaxation (TV, music...) or to play a game is not as practical during my sessions as pushing the child outside of his comfort zone on the computer, that is, getting him to do something today that he didn’t do yesterday. I don’t discount recreational use of the computer. It is very important. Both uses of AT, computer (communication/academic), and recreational (TV, music, games, etc.) are equally important.”

The upside to the popularity and proliferation of devices like the iPod, RJ observes, “is that with the iPod and the Wii we have a stimulus. Before the iPod we had no real stimulus for letting special needs kids have, create or control their own music in the real world. The current trend has created the needed stimulus. Parents email me and ask, ‘How can I get my child to participate in Xbox 360 games?’ This development, he remarks, has stimulated parents and sometimes teachers to investigate options.

Remember, he cautions, “the recreational aspects of AT usually involves parents much more than professionals. When I use the expression ‘trend’ I use it on a popular level. The trend to have a child on the Xbox 360 creates a stimulus for the parent to ask, ‘How can I have my special needs child participate in it? She loves watching her brothers play it but she’s not doing anything. What can we do?’ This creates a stimulus on the part of the parent to do something to involve their child in that trend.”

Whatever technology trends finally emerge for special needs children, though, RJ Cooper insists he’ll judge their usefulness as he did during the 1980s: Will they help a child to do more today than yesterday?