

BETWEEN.....THE LINES

Summer 2006

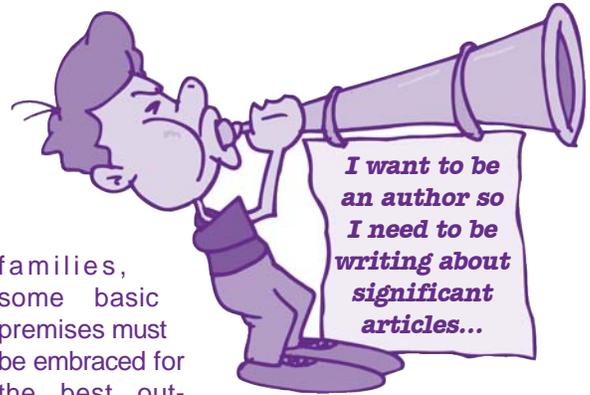
COLORADO DEVELOPMENTAL DISABILITIES COUNCIL

Typewriters as Liberators

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The reoccurring seeking of a typewriter in the lives of individuals who are non-verbal is worthy of some note—some serious note. There exist many stories about people living on the back wards of institutions, sharing a room in a group home, on the Alzheimer's wing, or simply living at home with family, in which a typewriter has been the focus of interest; of seeking. Most of the time the seeking for the typewriter is ignored by everyone with the exception of the person who has no voice; who is doing the seeking. The assumption is that this person has nothing to say—the typewriter is just a toy. However, recently some all too rare individuals with minds like parachutes (i.e. open) have paid closer attention to the typewriter user and even encouraged the use based on the positive assumption that the person does have something to say. This concept could sound like simple reporting of routine information to some readers, or if the reader happens to be a person who had no way to communicate previously, these concepts are revolutionary. Sue Rubin, a person with the label of autism and a facilitated communication user, states, "Before I could talk I wasn't a person/was retarded." In a parallel form, a Brazilian peasant working in literacy with Paulo Friere wrote, "Before I could read I was not a man." Clearly the access to written expression as well as being able to read the written word are associated with personhood and being a human—disability present or not.

Before the use of typewriters (or any other more sophisticated form of assistive technology) is explored by persons with communication difficulties and their



families, some basic premises must be embraced for the best outcomes. Having high expectations, being open-minded, creative, and willing to follow the lead of the person with communication differences is critical. There must be a belief in personhood; that this person has thoughts and feelings to share—communication that goes beyond a 'yes-no' board to choose whether to wear red or green that day or to eat macaroni and cheese or hot dogs. The ability to see the world from another's view is equally critical to the meaningful use of assistive technology. Dropping personal agendas, professional training, and preconceptions is essential. The following diametrically opposed views of a young student and his teacher illustrate the student's concept of high expectations and the ability to follow his lead rather than a predetermined agenda with low expectations. The student states,

"I want to do more with facilitated communication and not stupid questions. I want to be an author so I need to be writing about significant articles... I like the scientific approach to learning and need to learn more about it."



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Newsletter



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On the other hand, the educator responsible for the development of the curriculum, materials accessed, as well as content matter, states.

“I guess it gets frustrating for me to have to spend so much time on an area that I don’t perceive as being a strong point for him. Writing English papers, is that going to ever be a piece of his life? I don’t think so. But there are a lot of other things he has strengths in. That’s what I’d like to focus on.”

In other words, the segregated ‘adaptive-functional’ approach that may use a workbook on making change and base the curriculum on field trips to fast food venues, because that is what the educator was trained in and thinks is important, is missing an opportunity by not tapping into the most obvious resource—the students’ interests. The same concept holds true in the pursuit of accessing assistive technology. Why would one program in the use of the word “bathroom” as the first one for a preschooler to use, rather than their favorite activity, person, or pet?

We have much to learn about individuals who experience life and communicate differently than ourselves. However, the positive piece is that there are more and more listeners and more and more people

who formerly had no voice from whom to learn. Donna Williams, who has put her thoughts to text in her book Nobody Nowhere, offers much for us to listen to.

❖ “When I was ten a typewriter was left in my room. I smelled it, licked it and tapped at the buttons. I felt its texture and the sound it made when touched, its shiny surfaces and its rough ones.

❖ By the time I was eleven, I had typed lists of words running down the page and the words jumped back at me with imagery and feel to them in a way written words that had come from other people, never had. These had come from my own context from somewhere within me, beyond my conscious mind. The typed lists had pattern to them. The words written had a relationship between them... there was hurt and anger and beauty in those lists.

❖ By the time I was twelve, those lists had begun to look like poems. By thirteen, those poems were waterfalls falling out of my fingers.”

Kluth, P. (1998). The impact of facilitated communication on the educational lives of students: Three case studies. Doctoral dissertation. Madison, WI: University of Wisconsin-Madison, Special Education Department.



Open the Technology Door and the School Door Opens



Amy Gips, Phillip DiMattia and James Gips, researchers at Boston College, have documented exciting evidence that introducing assistive technology to students can result in the students being given access to the regular curriculum in their neighborhood public schools. Providing the assistive technology may also result in cost savings. It is important to consider the education of students who need special education supports in broader terms than the financial costs, since positive educational outcomes have long-lasting benefits for the students and our society. Nevertheless, the evidence of financial as well as educational benefits bolsters the argument for inclusive education practices.

The research results are for two students; Michael, a high-school student in Massachusetts and Amanda, an elementary school student in New Jersey. Before Michael and Amanda were introduced to communication technology neither was able to communicate, and they were attending segregated schools for students with disabilities. Since they weren't in their neighborhood schools, considerable amounts of money were being spent on transportation, tuition and teacher salaries.

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Until she had access to Camera Mouse, she had been attending a private special education center since preschool. At ten years old, Amanda "...learned to read and write using the Camera Mouse and is being educated with the other children in her town."

I Love My Child, But...

Jim Sinclair, founder of Autism Network International and who started an annual conference—Autreat—"for and by other autistics," was featured in a story on NPR's All Things considered on June 26, 2006.

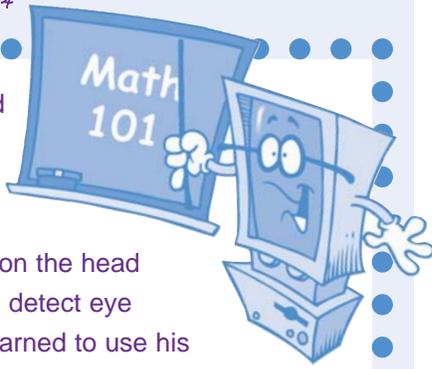
Excerpts:

"What the rest of the world needs to know about autism is that it's not something that can be separated out from the person, it's part of the person," explains Sinclair. "And so you cannot meaningfully say I love my child but I hate the autism.

"That's like saying I love my child, but I hate that she's a girl and I'd like her to be a boy instead. So when you're saying all of these things about how terrible it is that you've lost a child and how much your child is a disappointment to you, and how much that you wish you had a different kind of child, we're hearing that. And what we're hearing is that you don't want us and you want someone else instead."

<http://www.npr.org/templates/story/story.php?storyId=5488463>

Michael was introduced to EagleEyes, technology developed at Boston College, which uses electrodes placed on the head and around the eyes to detect eye movements. Michael learned to use his eye movements to move a mouse pointer on a computer screen in order to activate communication software. After he learned to use the technology his teachers decided that he "...had the cognitive and communicative ability to be mainstreamed into a regular classroom." He graduated from his neighborhood public high school in 2003.



Amanda learned to use Camera Mouse, which uses a video camera to track head movements. Using Camera Mouse, Amanda learned to use her head movements to control a mouse pointer in order to access communication software. Until she had access to Camera Mouse, she had been attending a private special education center since preschool. At ten years old, Amanda "...learned to read and write using the Camera Mouse and is being educated with the other children in her town."

Not only did assistive technology allow these students to be successfully educated and included in their local public schools, but also both school districts realized financial benefit. For less than the costs of tuition and transportation the school districts were able to pay for training teachers and students to use the technology, and to support the students in their neighborhood schools.

The article, "The Effect of Assistive Technology on Educational Costs: Two Case Studies," appears in [Computers Helping People with Special Needs](#), 10th International Conference, ICCHP 2006, Linz, Austria, July 11-13, 2006, Proceedings Series: **Lecture Notes in Computer Science, Vol. 4061 Sublibrary: Information Systems and Applications, incl. Internet/Web, and HCI** Miesenberger, K.; Klaus, J.; Zagler, W.; Karshmer, A. (Eds.) 2006, XXIX, 1356 p., Softcover. ISBN: 3-540-36020-4. The book is not available through the Auraria Library in Denver, however, and costs \$150. Please contact the Colorado Developmental Disabilities Council if you would like a copy of the article.

Ten Things Every Child with Autism Wishes You Knew

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Some days it seems the only predictable thing about it is the unpredictability. **The only consistent attribute—the inconsistency. No question: autism can be baffling.**

And though once thought "incurable," that notion is crumbling in the face of ever-increasing knowledge. Every day, individuals with autism show us that they can overcome, compensate for and manage many of its most challenging aspects. Understanding their needs can have a tremendous impact on a child's journey towards productive, independent adulthood.

Autism is a "spectrum" disorder, but core elements exist. Here are **ten things that every child with autism wishes you knew:**



1. I am first and foremost a child. I have autism. I am not primarily "autistic."

My autism is but one aspect of my total character. Like you, I am a person with thoughts, feelings, and many talents. **I am still unfolding; we don't yet know what I may be capable of.** Defining me by one characteristic runs the danger of setting up an expectation that may be too low. If I get a sense that you don't think I "can do it," my natural response may be: Why try?

2. My sensory perceptions are disordered.



The ordinary sights, sounds, smells, tastes, and touches of everyday life that you may not even notice can be hyperacute and downright painful for me. I may appear withdrawn or



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belligerent, but I am really just trying to defend myself from a world that is intrusively loud, blindingly bright, offensively smelly, difficult to navigate. **My brain cannot filter the multiple inputs** and I frequently feel overloaded, disoriented and unsettled in my own skin.

3. Please distinguish between won't and can't .

It isn't that I don't listen to instructions. It's that I can't understand you. When you call to me from across the room, I hear: “*^#@, Billy. #\$\$&*.” Instead, come speak directly to me in plain words: “Please put your book in your desk, Billy. It's time to go to lunch.” This tells me what you want me to do and what is going to happen next. Now it's much easier for me to comply.

4. I am a concrete thinker. I interpret language literally.

When you say, “**Hold your horses, cowboy!**” what you really mean is “**Please stop running.**” Don't tell me something is a “piece of cake” when there is no dessert in sight and what you really mean is, “This will be easy for you to do.” Idioms, puns, nuances and sarcasm are lost on me.

5. Be patient with my limited vocabulary.

It's hard for me to tell you what I need when **I don't know the words to describe my feelings.** I may be hungry, frustrated, frightened, or confused, but those words are beyond my ability to express. Be alert for body language, withdrawal, agitation or other signs that something is wrong.

6. Because language is so difficult for me, I am very visually oriented.

Show, rather than tell me how to do something. And show me many times; **patient repetition helps me learn.** A visual schedule is extremely helpful. Like your day planner, it relieves me of the stress of having to remember what comes next. It helps me manage my time—and meet your expectations.

7. Focus and build on what I can do rather than what I can't do.

Like you, I can't learn in an environment where I'm constantly made to feel that I'm not good enough or

that I need fixing. Trying anything new when I am almost sure to be met with criticism, however “constructive,” becomes something to be avoided. **Look for my strengths and you'll find them.** There's more than one right way to do most things.

8. Help me with social interactions.

It may look like I don't want to play with the other kids on the playground, **but I simply don't know how to start a conversation or enter a play situation.** Encourage other children to invite me to join them at kickball or hoops; I may be delighted to be included.

9. Try to identify what triggers my meltdowns.

Meltdowns and blow-ups are even more horrid for me than they are for you. **They occur because one or more of my senses has gone into overload.** If you can figure out why my meltdowns occur, they can be prevented. Keep a log noting times, settings, activities, people. A pattern may emerge.

10. Love me unconditionally.

Banish thoughts like, “If he would just...” Did you fulfill every last expectation your parents had for you? I didn't choose to have autism. Remember that it's happening to me, not you. **Without your support, my chances of successful, self-reliant adulthood are slim.** With your support and guidance, the possibilities are broader than you might think.

I promise you—I'm worth it.

This article has been condensed from its original version. It can be viewed in its entirety at www.ellennotbohm.com. © 2005 Ellen Notbohm

Ellen Notbohm is author of [Ten Things Every Child with Autism Wishes You Knew](#), a ForeWord 2005 Book of the Year Honorable Mention winner and recipient of iParenting's 2005 Media Award. Her new book, [Ten Things Your Student with Autism Wishes You Knew](#) will be released in September 2006. She is also co-author of 1001 Great Ideas for Teaching and Raising Children with Autism Spectrum Disorders, winner of Learning Magazine's 2006 Teacher's Choice Award, and a regular columnist for Autism Asperger's Digest and Children's Voice.. For article reprint permission, to learn more or to contact Ellen, please visit www.ellennotbohm.com



ASSISTIVE TECHNOLOGY PARTNERS:

Providing Essential Services for People with Disabilities and Their Families

What is Assistive Technology?

Assistive Technology (AT) refers to any item, piece of equipment, or product system that is used to improve functional capabilities of individuals with disabilities—including evaluations and follow-up trainings. AT includes a wide range of options from simple, inexpensive devices like adapted pencil grips that enable individuals with limited hand mobility to write, to sophisticated computer systems that enable people to



communicate more effectively. Assistive Technology Partners (ATP) promotes awareness of current and new technologies by hosting open houses at its facilities, distributing newsletters, and maintaining a website <http://www.uchsc.edu/atp/>.

What does ATP do?

ATP conducts regular trainings for people with disabilities at its downtown Denver location at the corner of 18th St. and Pearl, as well as in various locations throughout Colorado. Most of the training sessions are free to participants and cover a wide range of technologies.

In addition to offering training throughout the year, ATP, in partnership with the Colorado Department

of Education, sponsors an annual conference, the 'Collaborative Assistive Technology Conference of the Rockies'. The 2006 Conference was held on June 8th through the 10th. During the conference, ATP modeled its Adapted Home—an assortment of the various technologies that are used to facilitate independent living in every room of the home.

Is it possible to borrow AT equipment? ATP and the Colorado Department of Education have worked together to develop a loan bank of equipment and technologies that may be borrowed by ATP trained public school assistive technology providers (SWAAAC teams) or early childhood experts (also trained by ATP) specializing in AT. The loan bank has over 1,600 items ranging from door handle grips to sophisticated software programs that promote literacy development. The purpose of the loan bank is to create a 'try before you buy' opportunity to make sure that a particular item is best suited to the individual's development. ATP further facilitates the process by partnering with the Colorado State Library courier system to transport the devices safely and cost-effectively.

In addition, ATP's WESTAC (Western Slope Technical Assistance Center), located in Grand Junction, Colorado, is conducting a pilot AT loan project for people with disabilities of all ages. These items are available for loan to individuals receiving services through SWAAAC teams, DVR (Division of Vocational Rehabilitation), and Mesa County Workforce Center. (These loans are limited to this area of the state and not available statewide.)

ATP currently is working with other agencies and



interested parties to develop ATMatch, an on-line exchange bank through which people could donate or sell AT equipment. Both individuals and agencies frequently store equipment that is no longer used due to growth, maturation, and other transitions. ATMatch is a service to facilitate the transfer of these devices to people who can benefit from them. Fall 2006 is the targeted implementation date.

Is there financial assistance for AT products?

Numerous funding resources exist in Colorado. However, no single entity holds all of this information so that an individual can efficiently identify appropriate financial assistance. ATP is developing an on-line information center that would help people with disabilities and their families locate funding sources for AT equipment and devices. The goal is to have this funding information resource in place by fall 2006.

ATP is also designing a feasibility study on the need for a low-interest loan program for AT. The study should begin in June and be completed by fall 2006.

Currently, most insurance providers will pay for some forms of assistive technology for individuals with disabilities. ATP works closely with most major insurance carriers, Medicaid, and Medicare to pursue funding for evaluations, recommendations, and follow-up training.

The loan bank has over 1,600 items ranging from door handle grips to sophisticated software programs that promote literacy development.

What kind of training does ATP do?

ATP provides regular trainings for interested individuals and agencies/ organizations, conducts customized trainings across the state upon request, and trains people seen in its clinics to use AT. ATP also trains Vocational Rehabilitation counselors in Denver and at its WESTAC office, in addition to training Workforce Center employees.

ATP also provides college coursework in assistive technology. ATP received a grant from the U.S. Department of Education to provide advanced training in AT to 60 graduate students over a period of five years. The students come from the fields of education and occupational, physical and speech therapy; each receives 18 credit hours in advanced AT training and a stipend for their year of study.

How does ATP work with other agencies?

ATP facilitates the Assistive Technology Coalition, a unique collaboration of state agencies and organizations serving individuals with disabilities. Membership includes representatives from the Department of Education, the Division of Vocational Rehabilitation, the Office of Workforce Development, the Department of Public Health, the Legal Center for People with Disabilities and Older People, the University of Colorado Denver/Health Sciences Center, and Colorado WIN Partners. The Coalition serves as the

The technology ranges from software that enlarges images on a computer screen, large-print keyboards for people with low vision, power-adjustable tables to permit wheelchair access, and talking software for people with learning or vision disabilities.

advisory committee to Colorado's State Assistive Technology Program. Equally important, the Coalition collaborates on activities to minimize duplication of effort, and maximize opportunities for individuals and families to access and obtain AT devices and services. The Coalition was instrumental in the establishment of WESTAC, and is seeking support to replicate a similar center in the southeastern part of the state. An important goal of the AT Coalition is to educate policymakers and state leaders about how AT usage can positively impact the economy. A step toward this goal is to explore expansion of the current AT Loan Bank to a Statewide Loan Bank that would be accessible to people of all ages and residents in all areas of the state.

In addition to training Vocational Rehabilitation counselors, ATP has consulted with the Office of Workforce Development and DVR to analyze the need for AT equipment at statewide Workforce Centers, and has installed more than \$250,000 of AT equipment in 17 centers to date. The technology ranges from software that enlarges images on a computer screen, large-print keyboards for people with low vision, power-adjustable tables to permit wheelchair access, and talking software for people with learning or vision disabilities.

What kind of research does ATP conduct?

ATP has received several federal research grants. The RERC-ACT (Rehabilitation Engineering Research Center for the Advancement of Cognitive Technologies) is the nation's first Center of Excellence for conducting research and development of AT for individuals with cognitive

disabilities (including disabilities resulting from traumatic brain injuries and Alzheimer's disease). Twelve universities and a number of private companies throughout the US are involved. The funding for this research comes from the National Institute on Disability and Rehabilitation Research, the US Department of Education, and the Coleman Institute for Cognitive Disabilities.

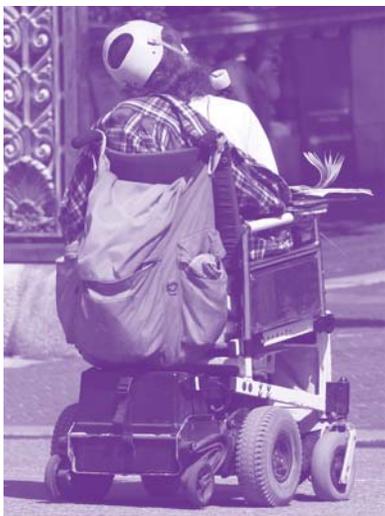
Another RERC project is the REC-TEC study that is designed to identify what recreational technology would motivate people with disabilities to adhere to an exercise regime. And finally, the RERC-WTS project is research on wheelchair transportation safety. The goal is to develop minimum safety standards that wheelchair manufacturers should use to help protect wheelchair users in vehicles.

What if I need help finding the right AT for me or for someone I know?

ATP provides a wide range of services for people with disabilities from infancy into the senior years. Services include assessing a person's AT needs, recommending technology to meet those needs, and training the person and family members in the use of the technology. The ATP facility has a wheelchair seating and positioning clinic, a sleep positioning lab, a computer lab for assessing computer access technology, augmentative/ alternative communication services/ evaluations, and AT evaluations to access employment opportunities.

ATP is located at the University of Colorado at Denver Health Sciences Center, School of Medicine. Assistive Technology Partners conducts research and provides services to enable people with disabilities to become more independent in their everyday lives. For additional information about ATP and its activities and services, please call 303-315-1280, toll-free 800-255-3477, or TTY 303-837-8964, or go online to www.AssistiveTechnologyPartners.org.

—Lorrie Harkness, Tech Act Coordinator,
Assistive Technology Partners



Technology Tidbits

Number of people per mobile line in the United States: 2
[Cellular Telecommunications & Internet Association (Washington) November 2003]

Number of people per sauna in Finland: 2.5
[Embassy of Finland (Washington) November 2003]

Number of the 158 used hard drives purchased for an MIT study this year that contained recoverable data: 129 [Simson L. Garfinkel, Massachusetts Institute of Technology (Cambridge) April 2003]

Minimum number of credit-card numbers the hard drives contained: 6,650

Year in which "idiot," "fool," and "nitwit" were removed from Microsoft Word's thesaurus: 2000
[Microsoft Corporation (Bellevue, Wash.) February 2002]

Ratio of applicants to slots for DigiPen Institute's degree program in video-game design and computer animation: 10:1 [DigiPen Institute of Technology (Redmond, Wash.) June 1998]

Percentage change since 1999 in U.S. sales of hardcover books for adults and children, respectively: -12, +13 [Association of American Publishers (N.Y.C.) September 2001]

Number of U.S. schools that use E-rater, a software program that reads and grades student essays: 95
[Educational Testing Service (Princeton, NJ., 2001)]

Number of these schools that are colleges or universities: 9
[Educational Testing Service (Princeton, NJ., 2001)]

Number of years between the invention of the first photocopier technology in 1938 and the first commercial-copier sale: 21
[Jonas and Nissenson, Going, Going, Gone] January 2000

Average annual number of copies produced per American six years later: 52
[Jonas and Nissenson, Going, Going, Gone]



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