



DIRECTIONS

Technology in Special Education

Vol. 6 , No. 8

April 2000

Removing Barriers to Appropriate Supports & Services

(Part 3)

by Susan Lait

In Part 1 of this series, I wrote that parents, school based professionals and independent professionals share a vested interest in working together to achieve appropriate supports & services for children with disabilities. I suggested that you, as parents & professionals, begin the process by requesting your own copies of the federal & state laws, statutes, policies & procedures that establish services for special education children. I proposed that taking the professional's position that we are doing the best that we can do given the current political climate is not good enough anymore. In Part 2, I suggested that **you**, as parents & professionals, take responsibility to advocate for yourselves and the special education children in your care. I presented the dilemma faced by parents & professionals when they realize that their local & state administrations have established barriers to appropriate supports & services. I also suggested that the responsibility of advocacy is too often transferred to parents by professionals. I presented the question to you as a parent or professional, **"What can I do to remove the barriers to appropriate supports and services in a nonsupportive administrative environment"**.

I would like to begin Part 3 of this series by suggesting that you add to your personal library a copy of the January 25, 2000 report released by the National Council On Disability (NCD) titled, **"Back To School on Civil Rights Advancing the Federal Commitment to Leave No Child Behind"**. The NCD is a 15 member independent council appointed by President Clinton which was confirmed by Congress. In their long awaited January 25, 2000 report, the NCD released data as to enforcement and compliance with IDEA. The NCD found that overall, efforts to enforce IDEA over several administrations have been inconsistent and ineffective. NCD found that all 50 states and U.S. Territories were out of compliance to some degree. In a sampling of cases, NCD noted that noncompliance

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Family Center on Technology and Disability Update

We want to welcome the following new members to the Network:

The Assistive Technology Law Center, Ithaca, NY.; Spina Bifida Association of Western Pennsylvania Kid-Screen, L.C.; Michiana Resources, Inc., Michigan City, IN; Cape Organization for Rights of the Disabled, Hyannis, MA

Contact information for Network members can be found on the Family Center website at <http://www.ucpa.org/fctd/netorgst.htm>. We are in the process of updating the network list of organizations to reflect the growing membership in the network.

The Family Center on Technology and Disability Network welcomes you, and hopes that you will find participation in the Network useful in providing services!

Resources

Check the Family Center database of materials for our newest editions at <http://www.ucpa.org/fctd/resourcelibt.htm>.

If you want information about "voice recognition" for students with learning disabilities, check the "question of the week" at the Family Center discussion board at <http://www.ucpa.org/fctd/bbt.htm>. The response to this question contains valuable information on successful implementation of speech recognition programs as well as other on-line resources you may wish to visit. Also, feel free to post your

question(s) for the Family Center's technology expert. Follow the instructions for log-in and take advantage of this wonderful network membership benefit. Note: If you are having trouble accessing the discussion board, please e-mail Sgoodman@ucpa.org.

Questions about the Individuals with Disabilities Education Act (IDEA)? Check www.nichcy.org. If you have specific questions about getting technology in the Individualized Education Program (IEP), you may call an information specialist at 1-800-695-0285.

The following question is posted on the Family Center discussion board: **I have a 6 year old daughter with communication needs, we want to try an augmentative communication device. Where do we start?** Check <http://www.ucpa.org/fctd/bbt.htm> for a comprehensive response to this often-asked question. If you know someone who you think would benefit from an alternative means of communication, check the Family Center discussion board which is highlighting information on AAC this month.

News

The dates that have been selected for the Family Center working conference for its "Outreach to Underserved" initiative are June 23-25, 2000. This conference will be held in Albuquerque, New Mexico.

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DIRECTIONS

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Vendors - We welcome product news. Please include pricing and contact name with press releases.

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Alternative Financing

Part 2

Executive Editor: Susan Goodman, Esq.

Enhancing Access to AT

People with disabilities have continued to look for new funding strategies and models that expand the pool and accessibility of funds while allowing potential AT users to have maximum autonomy in identifying their technology needs and the devices and services that will best meet these needs.

Most people with disabilities do not have the private financial resources to simply go out and purchase the AT they need. Various mechanisms exist by which public policy can, often with little or no direct expenditure of public funds, facilitate and encourage the availability of funds for the purchase and provision of AT. Through loan programs, tax law clarifications, small business development programs, and numerous other means, creative public policy can significantly enhance access to AT. New mechanisms are needed to increase the supply of funds for AT devices and services, but these new strategies must do so in ways that do not require increases in levels of public expenditure. Such new or enhanced funding must not undermine other worthy and pressing policy goals and must not create conflict within the disability community among the advocates of AT, personal assistance services, or similar programs.

To be effective, it will be necessary for new initiatives to increase the available pool of funding for AT and create incentives for the participation

of private funders. Initiatives also must be designed to give the fullest possible scope to the autonomy and self-directed life planning of consumers with disabilities. And finally, such new programs will need flexibility to accommodate rapid change in the nature of available mainstream technology and AT.

Conclusion

The momentum generated by the passage of the Tech Act paralleled America's increasing interest in and use of technology. For this reason, the new millennium brings with it hope for new and better technology and services that will expand universal design and enhance the quality of life of children and adults with disabilities.

Many individuals believe that there is considerably more knowledge and recognition of AT because of the programs and services delivered by the State Tech Act projects. Throughout the hearing process, witnesses repeatedly voiced their support for their State projects. It was felt that the momentum driving much of the demand for AT devices and services is a direct result of information dissemination and advocacy work conducted by these projects. Individuals spoke of the continuing need for research and development that is consumer directed and closely aligned to practice. Repeatedly, individuals marveled at the vast array of devices

that are brought to the marketplace, but also voiced their frustrations about the difficulties of actually obtaining these devices. In addition, inventors and manufacturers are woefully short of capital for innovation. Each year, new regulations are promulgated that further restrict funding and categorize who can access devices and use services, and when they can do so.

Technological devices are not beautiful items to be encased in a protective covering and placed on a shelf where they can be seen but not touched, bought, or used. As stated in this Blueprint for the Millennium, there are several ways to enable individuals to take items off the shelf and put them to use. There is a need for ongoing and expanded activities to provide information about AT devices, services, funding, and resources. This information is sought by individuals of all ages in the community, workplace, school, and home. There needs to be an expansion of funding mechanisms, including public and private partnerships, that will make more dollars available for micro-loans, research and development, and enhanced service delivery. Advocacy efforts could be broadened to ensure that those needing devices and services would be able to find professional support to help champion their causes. There needs to be a systematic effort to increase the numbers of qualified personnel to provide AT services in the schools, communities, and workplaces.

The accomplishments of the past 10

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years are laudable. Individuals who were thought not capable of communicating, moving around their communities, going to school, or working competitively are now participating more fully, thanks to technology. Realistically, however, we have only just begun. This Blueprint clearly outlines the challenge we face in expanding AT and universal design over the next 10 years while responding to the millions of individuals with disabilities who can benefit from these tools.

Endnotes

1. Statistics give ample evidence of emerging trends. According to statistics from the U.S. Department of Health, Health Care Financing Administration, (National Health Interview Survey, Disability Supplement, Washington, DC: U.S. Department of Health, 1994), wheelchair use increased from 1980 to 1994, and hearing aid use increased significantly from 1990 to 1994.
2. The authors of this paper, the Assistive Technology Funding and Systems Change Project, developed and disseminated an information brief presenting criteria to include when developing policy related to AT for this population. A follow-up survey showed that nearly 100 percent of the State directors reviewed this brief and that 20 percent stated that some action had been taken as a result of this effort by the project.
3. National Council on Disability, Study on the Financing of Assistive Technology Devices and Services for Individuals with Disabilities, A Report to the President and the Congress of the United States, Washington, DC: National Council on Disability, 1993. §

Introduction to Technology in Transition

Part 3

Sherrilyn K. Fisher & J. Emmett Gardner

BUILDING A SHARED PERSPECTIVE OF TECHNOLOGY AND TRANSITION

For many students, the goals of technology and transition are intertwined; goals in one area often cannot be achieved without the collaborative planning of both disciplines. For example, for some individuals, the ability to communicate effectively (a skill that cuts across all transition environments) may only be possible through technology; or, access to job site or the accommodations needed to accomplish the job may not be possible without the assistance of technology. In contemplating new and unique transition environments, we may first see the need for AT when a student's transition plan is created. This framework surrounds the student's next environments—occupational awareness and exploration programs, employment, postsecondary opportunities, social networks, the community and independent living (see Blackhurst, Lahm, Harrison, & Chandler, this issue). Within this framework, several commonalities emerge.

Self-determination

In the practice of both fields, the importance of teaching self-determination skills cannot be overstated. How else can we assure

that the personal choices about AT are woven into transition plans? Because technology changes so rapidly, devices fall into disrepair, and environments rapidly change, an individual without sufficient self-determination skills may soon find him/herself without adequate technology to improve his/her life conditions. Just as environments and opportunities change for an individual, so will the technology needed to advance and adapt in new situations. If students leave our watch without the empowering knowledge of personal interests, strengths and needs, combined with the self-advocacy to express these attributes, we will have missed the mark. Articles in this issue by Anderson-Inman, Knox-Quinn and Szymanski, and another by Parette, express similar concerns along with suggestions for capitalizing on the known strengths and preferences of individuals.

Planning for Future Environments

Another piece of common ground between transition and technology can be found in the similarities that exist in legislation regarding AT and transition planning. For example, the requirements in transition planning for long-range services can be a window to the needs for AT services or devices. The article by Blackhurst and his colleagues provides a picture of how future environments can be used to frame technology decisions.

Interagency Planning

Another similarity that the fields of technology and transition share is in interagency planning. Both fields require the cooperation and planning of agencies that will carry on the work after school years are completed. Perhaps the most difficult problem that students and their families face in the transition to adult lives is obtaining services after school. The reason for these difficulties is apparent: while school services are regulated, required, and known, adult services are not mandated. Compounding the perplexing maze of services is the fact that families may be unaware of services to which they may be eligible. In other cases, even though the adult service may be a known entity, the waiting lists are long or services simply are unavailable (Ferguson, Ferguson & Jones, 1993).

Families and Parent-School Partnerships

The relationships that we build with families are pivotal to the success of transition planning. Bruininks, Thurlow and Ysseldyke (1992) reported that families often are the mainstays in a student's life, and in many instances, provide lifelong support. More often than not, this support includes the responsibility of selecting and maintaining technology devices. "Families carry the perspective of past and future from one environment to the next environment; they alone have seen the individual in all of life's settings" (Fisher, 1999, p. 329). The article by Parette points out that families and cultural considerations are central to the planning processes of technology and transition.

Inclusion and Progress in the General Education Curriculum

The Secretary's Commission on Achieving Necessary Skills (SCANS) report (1991) underscored the importance of applied academics for all students, as well as listening and speaking, thinking skills, and problem solving. More recently, the 1997 amendments to IDEA require students to show progress in the regular curricula, with a statement of the support services needed to keep them in the regular curriculum wherever possible. Anderson-Inman et al.'s article demonstrates how AT can be used with great benefit in achieving curriculum and instructional objectives. As we plan toward graduation and the transition to postsecondary education or careers, it is evident that supports offered to achieve these goals should include the AT needed to ensure success in the regular curriculum. The National Council on Disability (Morris, 1992, p. 5) discovered that "...with the assistance of technology, almost three-quarters of school-age children were able to remain in a regular classroom... [and] 45 percent of school-age children were able to reduce school-related services." Recent legislation has not only identified AT as a related service, but has included a statement requiring school districts to furnish supplementary aids and services "...which are to be made available in regular education classes and other education-related settings" that "enable children with disabilities to be educated with their nondisabled peers to the *maximum* extent appropriate." (emphasis added) (20 U.S.C. § 1401(29)).

Even with the emphasis on the regular curriculum, service providers, families and students must be able to extract life skills instruction to meet

individual needs. Recognizing that these needs will differ from needs of other students, the response must involve curriculum adaptation, modifications, and experience in real life settings (Clark, Carlson, Fisher, Cook, & D'Alonzo, 1991; Clark, et al., 1994), which will at times require AT. §

Look for Part 4 in our May issue

FAMILY continued from page 2

Expenses will be paid for those who are chosen to attend. Applications are still being accepted. For an application, e-mail Sgoodman@ucpa.org.

A federal judge in Georgia has issued a favorable decision regarding Medicaid coverage for Alternative Augmentative Communication devices (AAC). The Court concluded that AAC devices should be considered Durable Medical Equipment, prosthetic devices and speech/language pathologist equipment. This is important because items categorized as such may be funded by Medicaid. The court also recognized that close judicial scrutiny is needed concerning the substantive criteria ultimately used to review AAC device claims. A final order will probably be issued this summer. We will keep you posted with more information.

We would love your feedback about the weekly email or input about topics you would like to see covered! Please e-mail Susan Goodman at Sgoodman@ucpa.org. §

BARRIERS continued from page 1

had persisted for many years. In addition NCD found that enforcement of the law had become the burden of parents who too often must utilize Due Process and/or and civil litigation to obtain the appropriate supports and services that their children are entitled to under the law. The statistics in the report reflect that more than half of the states failed to ensure compliance in five of the seven major compliance areas. You can obtain a copy of this report and refer to the compliance status of your individual state on NPND's Web Page: www.npnd.org, NCD's Web Page: www.ncd.gov or by contacting NCD directly at (202) 272-2004.

The above NCD Report provides documentation of a level of noncompliance that is a result of local & state administrative environments which are not supportive of IDEA. The NCD Report also reflects the barriers that have been established to implementing appropriate supports & services. Even though noncompliance on a national scale has been documented by the NCD report, the challenge for me remains the same....how do I share my experiences in such a way that encourages both parents and professionals to advocate for themselves and children with disabilities. I hope that I continue to do this in Part 3 of this series. Prior to becoming a full-time Special Needs Parent, I spent twelve years in service to a government agency. I entered my profession as an idealistic college graduate. Prior to my first assignment, I completed a training period as a recruit. My trainer bestowed a valuable frame of system reality that continues to sustain me

almost twenty years later. I would like to share that approach with you in hopes that it will help sustain both parents and professionals. It went something like this....

The responsibilities of your profession are established in the U. S. Constitution, Federal Law and State Statutes. Know the policies and procedures. Policy & procedure will protect you and the population that you serve. Expect that there may be occasions when a superior or your agency may request of you something that is out of the scope of your responsibilities. Out of the scope means you feel that a requested action may conflict with a written law, policy or procedure. Expect that you may be asked to serve an agency agenda rather than serve as defined in policy & procedure. If this occurs look to the policies and procedures that protect you. Use the appropriate chain-of-command to meet your responsibilities. You are expected to be responsible for yourself and your own actions.

After completing my initial training, I was requested to assume a responsibility outside of the scope of my employment. I was assigned a caseload that required a specific amount of experience and specialized training. Although very uncomfortable with declining my first assignment, I assumed responsibility and approached my superiors requesting that I receive the required experience and training prior to accepting the assignment. Such is the pattern that became the frame for my career and later reflected the values that have served me as a Special Needs Parent. As professionals & parents serving Children with

Disabilities, there may often be occasions when we are asked by our Local & State Education Agencies to accept less than what we feel is defined as appropriate in IDEA. There are occasions when professionals are asked to assume responsibilities for meeting the needs of Special Education Students without the appropriate experience, training, equipment, supports or services. There are occasions when parents & professionals are asked to negotiate as to the provisions provided in IDEA....to accept less than IDEA provides. School administrations may communicate that it is necessary for parents & individual professionals to demonstrate their willingness to negotiate. I have asked myself "why" it is an accepted notion that access to IDEA must be negotiated?

As recently as six months ago, I attended a local & state education agency sponsored parent training that was directed by our state parent training center. In this training, it was recommended to parents & educators that they compare the process of obtaining IDEA provisions to the process of purchasing a used car. It was recommended that parents & educators come to IEP Meetings asking for more or less services than a child needed as their agenda dictated. This approach was suggested in order that each party have negotiating room in which to negotiate IDEA. As I speak to parents & educators across the country, many have received the same advice. As a parent, I have read IDEA. I have not discovered any language that indicates that IDEA and my child's rights are negotiable. Based on this premise, I feel that as a parent, although I remain open to

collaboration, I am not required to negotiate my child's rights and the provisions of IDEA in a manner similar to purchasing a used car. I feel that to require parents or professionals to negotiate as an accepted requirement to obtaining access to IDEA for themselves or children creates a barrier to supports & services. The NOD report appears to reflect the reality of this negotiation frame of mind. This Negotiation Model has translated into some form of noncompliance in all 50 states. Parents & professionals have both asked me, "Will I suffer and will the child suffer if I refuse to negotiate and alienate the school district by requesting supports & services". I am also asked, "Isn't a few services better than nothing when it come to supports & services?" My answer to these questions has always been to ask the following questions which a parent or professional must ask themselves. **First**, do you believe that a child has

already suffered or will suffer as a result of the barriers and delays to appropriate supports & services and has that child been impaired or will be impaired in reaching his/her fullest potential? **Second**, have you as a parent already suffered emotionally knowing that that your child's needs have not been appropriately met? **Third**, as a professional, has your professional experience already been impacted or will be impacted by a lack of specialized training, trained aides, equipment and supports & services, and have you suffered emotionally knowing that you are not able to adequately assist a student in reaching their fullest potential? When my husband and I asked ourselves these questions, we realized that our daughter, our marriage, our family and we as individuals were already suffering. It then became an easier choice to become parent advocates to advocate for our daughter, ourselves and our school based professionals. The NOD Report addresses the

burden that we and other parents have carried for 25 years to advocate for IDEA.§

Part 3 will be completed in our May issue!

Conferences

Date: June 25-27, 2000

ConnSENSE 2000

Mystic, CT,

800-622-9905

Date: June 26-28, 2000

NECC 2000

Atlanta, GA

www.neccsite.org

Date: October 5-7, 2000

SouthEast Augmentative
Communication Conference

Birmingham, AL. Call for Papers
deadline is May 15, 2000. Con-
tact: seac@ucpbham.com

Date: October 17, 2000

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Special Needs Project Book List

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The Special Needs Project is a convenient and thorough source for books on disabilities, including both standard and new releases, with a bibliography on nearly 50 subjects. In addition, SNP publishes a quarterly newsletter with reviews of the best new titles, and information on upcoming conferences. Books can be ordered from: Special Needs Project, 324 State St., Suite H, Santa Barbara, CA 93101. Tel. 800-333-6867, Fax 805-962-5087. E-mail: Books@specialneeds.com.

#6150 Contested Words, Contested Science: Unraveling the Facilitated Communication Controversy. \$27.00 – Paperback. Doug Biklen. Edited By Don Cardinal. Assistive Technology.

Facilitated Communication remains controversial. For those who have followed this particular professional-academic drama, this is the latest word—by the person who has done the most in this country to make Facilitated Communication, in more ways than one, a hot topic. Long an outspoken figure, Biklen has been a lightning rod for bitter criticism of Facilitated Communication. 256 pages, 1997. Special Needs Project also carries this book in hardcover.

#6424 Contested Words, Contested Science: Unraveling the Facilitated Communication Controversy. \$58.50 – Hardcover. Doug Biklen. Edited By Don Cardinal. Assistive Technology.

Facilitated Communication remains controversial. For those who have followed this particular professional-academic drama, this is the latest word—by the person who has done the most in this country to make Facilitated Communication a hot topic (in more ways than one). Long an outspoken figure, Biklen has been a lightning rod for bitter criticism of Facilitated Communication as well. 256 pages, 1996. Available as a paperback (#6150, \$24.95).

#7382 Designing and Using Assistive Technology: The Human Perspective. \$31.00 – Edited By David B. Gray, Louis A. Quatrano, & Morton L. Leiberman. Assistive Technology.

Noteworthy for its holistic view of assistive technology, this book brings together the expertise of researchers, theorists, and practitioners, and personal insights from Assistive Technology (AT) users of all ages, to examine how and why people choose and use various forms of AT. In addition to sharing the latest available findings on design and development, it examines the crucial intangibles of AT, such as judging environmental compatibility, assessing an individual's need for AT, justifying third-party payment, acknowledging public perceptions of AT and measuring life outcomes. 368 pages, 1998.

#6324 Directory of Computer and High Technology Grants: Third edition. \$59.50 – Paperback. Edited by Richard M. Eckstein. Assistive Technology.

Not a general treatise on funding—but an excellent grants reference in this specialized area. 500 foundations profiled, state-by-state arrangement, Internet sources for grant seekers, four outstanding articles target winning grant strategies. The "Directory" identifies qualified funding sources for computer, software, sophisticated office equipment, and technology related grants. Each profile lists the address and areas of support. Geographic restrictions, grant range, and a list of previously awarded grants are included. A fine featured article on grantsmanship by Andrew J. Grant and Suzy D. Sonenberg guides newcomers and on-line veterans to sources on the Internet that provide information about funding availability, proposal writing, and specific foundations. 116 pages, 1996.



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