



DIRECTIONS

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Family-Centered Decision Making in Assistive Technology

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Part 1

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Throughout the country, school teams increasingly are adopting culturally sensitive family-centered practices in planning for assistive technology (AT) for children with disabilities. Over the past two decades evolving research has revealed the importance of considering family and cultural issues when planning AT interventions for children with disabilities and their families. This paper presents an overview of selected family and cultural issues, and suggests ongoing questions. The potential for interactive multimedia in helping teams and families make AT decisions is reviewed. The paper concludes with a description of a newly available interactive CD-ROM designed to provide to both families and professionals basic information on augmentative and alternative communication decision-making, including an overview of relevant family and cultural issues.

This article is the first in a series of special invited AI manuscripts from leaders in the field of special education technology. JSET has invited experienced researchers and practitioners to share their current projects and speculate on important trends for the future. This forum will provide a distinct opportunity for sharing ideas and generating new directions for research and practice in special education technology.

During the past two decades, the role of assistive technology (AT) in providing appropriate educational programs for children with disabilities has grown on tremendously. The Technology-Related Assistance for Individuals with Disabilities Act of 1988, P. L. 100-407, established a national funding mechanism for comprehensive state systems of AT service delivery. That legislation also provided the impetus for the subsequent federal mandate



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under IDEA (P. L. 101-475, The Individuals with Disabilities Education Act of 1990) that AT must be considered when developing individualized education programs (IEP) for children with disabilities. Subsequent reauthorization of IDEA (P. L. 102-119, The Individuals with Disabilities Education Act Amendments of 1991) specifically identified AT as a service to be provided in the IEP as appropriate.

Importantly, each of these federal mandates has emphasized enhanced family participation in special education decision-making processes. Generally regarded as best practice for some time, the inclusion of families in all processes affecting AT service delivery to children with disabilities is now legally mandated (Inge & Shepherd, 1995; Judge & Parette, 1998).

A frequently used approach to include families in decision making is to invite and facilitate dynamic family participation on IEP and Individual Family Service Plan (IFSP) teams. On the best of these teams, professionals and family members participate as equal partners, working collaboratively in pursuit of a common interest (Dunst & Paget, 1991). The active participation of family members may be especially important when AT devices are being considered by decision-making teams (Ainsa, Murphy, Thouvenelle, & Wright, 1994; Beaver & Mann, 1994; Parette & Brotherson, 1996; Parette, Hourcade, & VanBiervliet, 1993). Given that such typical AT-related goals for children with disabilities as greater independence or enhanced communication skills have significant implications for home as well as

school, significant involvement of the family in these service decisions becomes even more critical.

FAMILY ISSUES AND AT DECISION MAKING

Inclusion of family members during team AT decision making provides the comprehensive perspective necessary for selecting the most appropriate AT devices for children with disabilities. Important factors typically considered by the team in this process include such traditional considerations as child characteristics, AT device features, and service system concerns, as well as such less traditional issues as family concerns and cultural factors (Parette & Hourcade, 1997). A number of previously developed AT program development guides for professionals and family members discuss many of these issues (Parette & VanBiervliet, 1990, 1991a-c). More recently, CD-ROM training materials have been designed to provide in-depth information regarding the relative importance of a range of family issues during AT decision-making processes (VanBiervliet & Parette, 1999).

While some family issues receive significant attention as teams make decisions about AT; other equally important family issues may not be adequately addressed. For example, Parette and Hourcade (1997) examined state practices related to augmentative and alternative communication (AAC) decision making. They found that, while family preferences for particular AT often are considered at least to some extent, many other important family issues (e.g., increase in parental responsibility for

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implementing device; increase in stress; financial resources required) frequently were not considered by teams. Given the increasing emphasis on family-centered service delivery in special education, the potential disregard of significant family issues is a matter of significant concern (Darling & Baxter, 1996).

Importance of family values

Effective team planning for AT requires that the unique qualities of individual family values be incorporated into any decisions (Simpson, 1996). Incorporating family values helps professionals (a) build more collaborative relationships, (b) understand the extent of participation desired by the family, and (c) separate out cultural differences from personal preferences or lack of understanding (Lynch & Hanson, 1992b). Program dissonance occurs when values of professionals differ from values held by families and those differences are not successfully addressed, thus negatively impacting the potential outcomes of any program decisions.

Shift in family roles

The inclusion of AT in a home represents a significant change for many families. Providing AT for students with disabilities requires new role behaviors on the part of the children, and new interaction patterns between those children and other family members (Giacquinta & Lane, 1990). Criteria that help determine whether such a change is positive or negative for a family include: (a) family member receptiveness to the AT device, (b) family willingness/ability to implement the AT, (c) availability of support resources, and

(d) compatibility of the overall family system with the AT (Gross, Giacquinta, & Bernstein, 1971).

Rogers (1983) additionally suggested that another important factor is the family's perceived need for AT. Not all families will be receptive to provision of AT; particularly if changes in routines and such additional stressors as repeated training sessions are introduced (Hourcade, Parette, & Huer; 1997).

The potential for abandonment

Failure to consider family factors and to involve families in meaningful ways during AT planning may result in abandonment of devices that are prescribed by teams. AT abandonment refers to the observed phenomenon wherein the AT is simply discarded and not used (e.g., Batavia, Dillard, & Phillips, n.d.; Batavia & Hammer; 1990; Parette & Angelo, 1996; Phillips, n.d.). Abandonment of any assistive technology device has far-reaching implications, including: (a) exacerbation of the effects of disability experienced by the child (Brody & Ruff, 1986), (b) excessive personal and financial costs for families (Luborsky, 1993), and (c) inefficient (if not wasteful) use of finite service system resources (Bradley, Parette, & VanBiervliet, 1995).

Importance of information, training and supports

Integral to family acceptance of AT is the provision of appropriate information, training, and related supports to ensure the success of the device in the home setting (Parette, 1997). Families repeatedly report that

they have needs for AT information in such diverse areas as range of devices available, features of devices, maintenance requirements, cost, funding, teaming issues, and training required (Angelo, Kokoska, & Jones, 1996; Behrmann, 1995; Carey & Sale, 1994; Derer, Polsgrove, & Reith, 1996; Parette & Hourcade, in press; Wehmeyer, 1999). A truly family-centered AT assessment process should result in the identification of those AT devices and services most needed by the child and his or her family (Parette & Brotherson, 1996). The most effective determination of child and family needs results when professionals conduct culturally sensitive interviews and other information-gathering approaches with families, and provide families with comprehensive information about supports services. The end product of an effective assessment process is a unique set of recommendations based on the family priorities for AT.

Of particular importance to many families is the need for information and training that is user-friendly and accessible (Parette, Brotherson, Hoge, & Hostetler; 1996). In analyzing family preferences for training related to AAC devices, Parette et al. (1996) reported that families prefer to have information and training provided using support groups. They also noted that families want information that is easy-to-understand, and delivered in flexible, family-friendly formats.

For example, some professionals utilize a lecture/presenter/demonstrator approach in which they orally transmit information to participants who are captive audiences for large blocks of time. Large quantities of printed materials may be presented to

participants, who are then expected to leave the presentation site, read the information, make inferences about content related to their needs, and implement the necessary strategies with their children. The assumption is that simply receiving information about or being observers of demonstrations of AT will then translate into parents and other family members then being effective teachers or trainer for children with disabilities. Such an assumption may be inaccurate, as family members generally are not trained to be teachers, nor do they always wish to take on such a role. Nevertheless, all too often current approaches to delivering information and training are based upon this implicit assumption.

Families prefer to receive information and training from family members who have already had experiences with a particular type of AT. They may also want to see families/children using an AT device being considered by the team. They also prefer discrete information relevant to their needs, information that is easy to read or implement. Finally, they often request ongoing supports (e.g., demonstrations, technical assistance, an empathetic listener) while they are attempting to implement the information/training received (Parette et al., 1996).

Much of this discussion, however, assumes that parents are willing and able to participate in their children's education in AT. However, as suggested earlier, families may be anywhere along a continuum of involvement, ranging from little or no interest in participating to total involvement in their children's education. Family willingness to participate may be influenced by a range of

factors, including: (a) family values, (b) cultural influences, (c) AT enculturation (i.e., the degree to which families have been influenced by outside forces regarding the importance of AT; or their past experiences in using AT-related equipment), and (d) other forces (e.g., awareness of the use of AT devices by others, media coverage of AT; etc.). Other family issues that impact on family willingness to use AT include (a) stress experienced by the family (Angelo, 1997; Brinker, Seifer & Sameroff, 1994; Parette & Angelo, 1996), (b) degree to which the AT might alter family routines (Angelo, Jones, & Kokoska 1995; Parette & Angelo, 1996), (c) amount and nature of AT training required by or provided to the family (Angelo, 1997; Angelo, Jones, & Kokoska, 1995), and (d) involvement of immediate and extended family members (Angelo, 1997; Angelo et al., 1995, 1996). Greater attention to such factors can greatly facilitate the effectiveness with which teams conduct AT planning and decision making.

Since developing a collaborative relationship with families typically takes time, regular meetings may be necessary to ensure that effective communication occurs. Such regular meetings may have unanticipated benefits for team members, such as providing opportunities to share in daily progress, and sharing ownership in the AT decision-making process. However, these meetings must allow for flexibility with regard to meeting sites (in response to family preferences) and times. §

Look for Part 2 next month

Conferences

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ACCESSIBLE LEARNING

by Lorianne Hoenninger

As an Apple Macintosh devotee, I hesitate to suggest that any Apple software products are less than perfect, especially as compared to the software products created by the nefarious competition (read Microsoft), but I must admit that I have looked upon the auto-correction, abbreviation expansion and grammar checking capabilities of Microsoft Word with, yes, envy. AppleWorks is a fine program, but since many special needs students are included in typical settings, they need to be able to independently use the same word processing tools as their fellow students. They need the spell checker to be phonetic to support their idiosyncratic spelling, and they need text-to-speech support, so that they can hear unfamiliar words in the correction box. Auto-correction would seamlessly eliminate many of their typing and spelling errors, thus improving self esteem and decreasing the amount of time needed for project completion. Abbreviation expansion decreases the number of keystrokes needed overall, and grammar checking improves readability.

But now, fellow Macintosh users, we need be envious no longer!! Casady and Greene have created a set of writing tools that work with Macintosh programs, adding all the capabilities to AppleWorks that one could dream of!

“Spell Catcher 8” is an integrated phonetic spell checker, customizable dictionary and thesaurus that works with all Macintosh products, even programs that traditionally do not have a spell checker. The user needs to

maintain only one word list, thus eliminating the need to teach the same words to each program that has a built-in spell checker, and eliminating the need for students to learn how to use a variety of spell checking programs. “Spell Catcher 8” is totally customizable. One can choose interactive spell checking or spell checking upon request, in eight languages. Text-to-speech capabilities, auto-correction and abbreviation expansion are built-in, as is automatic proofreading for capitalization and other common errors. It is accessible through both the mouse and keyboard shortcuts.

“Grammarians 2” adds an interactive and batch grammar checker to virtually all Macintosh applications. It also is customizable for the age and writing style of the student, and is the most accurate and comprehensible of all the grammar checkers I have had an opportunity to use. “Grammarians 2” was noted to be especially helpful in the correction of errors typically found in the writing of students with hearing impairments. Both programs sell for a mere \$49.95, with a \$10.00 discount for electronic downloads. Macintosh users, go directly to <http://www.casadyg.com> to download your demo versions today!

Windows users should explore “Spell Catcher Plus” from Casady and Greene. “Spell Catcher Plus” contains the same features as the Macintosh version, with spelling dictionaries in 9 different languages, and reference dictionaries for legal, medical, HTML, biological/geological and more. “Spell Catcher Plus” sells for \$29.95 physical/\$19.95 download version.

Younger students who are still learning grammar should explore “StoryMaker” from <http://www.gepetossoftware.com/> This Windows platform \$10.00 shareware product is a “Mad-Libs”-style grammar practice program that is completely customizable. The program asks students to fill in the blank with a verb, pronoun, adjective, etc. The hint feature helps unsure students choose a word, then creates a funny story when they are done. Teachers can create their own “fill in the blank” stories with the included authoring interface. The registered version includes 20 new ready-made stories.

“Grammar Quest” is another \$0.00 shareware program from <http://www.gepetossoftware.com/> that concentrates on fragments and run-on’s, parts of speech, subject-verb agreement, adjective vs. adverb and much more! Students click on a treasure chest, then answer the questions to win the prize. Teachers can easily print worksheets to be used as additional practice or homework.

As always, I hope you find these programs as fun and useful as I do. If you have questions, do not hesitate to e-mail me at accessiblelearning@erols.com, visit my website at or write c/o: Accessible Learning Technology Alternatives, P.O. Box 597, Shirley NY, 11967.§



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New Ideas

Source: *The Catalyst*, Winter 2000, Volume 17, #2

Language Software for Young Children

The National Speech/Language Therapy Center has produced *Marching Ahead to Progress (MAP)*, a program designed to help parents of young children with Autism Spectrum Disorder to teach their children. MAP provides video clips to assist in monitoring and shaping difficult behaviors, as well as showing how to teach concepts in a clear, concise, and consistent manner. MAP features a Learning Lab, which organizes learning by level of developmental ability. Children as young as two can benefit from MAP. The program is designed especially for families awaiting evaluations or placement in preschool programs. No

special computer expertise is needed, but technical support is available. For further information contact the National Speech/Language Therapy Center, Wyngate Medical Park, 5606 Shields Drive, Bethesda, MD 20817, (301) 493- 002 <nsltC@erols.com> Web: <www.NationalSpeech.com>

Websites worth watching

Both *Business Week* and *U.S. News and World Report* offer disability features online. John Williams publishes excellent weekly features in *Business Week*, which can be accessed at: <<http://www.usnews.com/usnews/issue/001106/nycu/disabled.htm>>

U.S. News articles can be found at:

<<http://www.businessweek.com/bwdaily/dnflash>>

Free Booklets about Blind Access

The Royal National Institute for the Blind has released two excellent new booklets. One is about the Tiresias a typeface, originally designed to improve television subtitling and now widely used on all screen-based devices. The other, "*Which Button?*" is an excellent overview of visual impairments and the control interfaces necessary to accommodate them. These and other publications are free from RNIB, 224 Great Portland Street, London WIN 6AA, UK. E-mail: <jgill@mib.org.uk> Web: <www.tiresias.org/training>

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News Release

AMERICAN PRINTING HOUSE FOR THE BLIND, INC.

Louisville, Kentucky, January 2, 2001

J. Gary Mudd promoted to the position of Vice President for Public Affairs at the American Printing House for the Blind.

Mudd is the first vice president in the organization's 142-year history who is blind or visually impaired.

Contact Roberta Williams, Public Relations Specialist, for more information.

Telephone: 1 -800-223-1839 or (502) 895-2405; e-mail: rwilliams@aph.org

The American Printing House for the Blind (APH) has promoted J. Gary Mudd to the newly created position of Vice President for Public Affairs. In addition to assuming the duties associated with his new role as Vice President, he will continue as head of the public affairs department.

Mudd joined APH in 1986 as Consumer Information Consultant. In 1992, he became director of the Public Affairs Department. As director of Public Affairs, he is responsible for managing the department's day-to-day operations, overseeing personnel, and developing and implementing goals and objectives in support of the APH mission. His particular focus is developing and maintaining contact with government officials, and educating them about how APH uses its annual federal appropriation (nearly 50% of the APH operating budget). He is also actively involved with advocating on disability issues, both locally and nationally, and presents educational programs to civic groups and educational organizations.

Mr. Mudd grew up on a farm near Frederickstown, Kentucky, and graduated from high school at the Kentucky School for the Blind in Louisville. He attended the University of Kentucky and the University of Louisville. He received a BS in sociology from the University of Louisville in 1994.

Before joining APH, he was a production engineer and assistant music director at WHAS Radio in Louisville.

The American Printing House for the Blind, founded in 1858, is the oldest organization of its kind in the United States and the world's largest not-for-profit company that creates educational, workplace and life-style products and services for people who are blind or visually impaired.

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