Augmentative Communication News

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INSIDE THIS ISSUE . . .

Loud music; dating; hanging out; makeup; challenging authority; asking questions about religion, love, life, sex, the universe; seeking answers; talking on the phone; friendships; experimenting; getting in trouble; and making plans for the future.

Guess what this issue is about! Like other ages and stages of human behavior, adolescence crosses cultural and linguistic boundaries and is unavoidable. Unique, confusing, exciting, and intense, not many adults would choose to return to it! This issue highlights a topic the field of AAC has yet to explore, the experience of being an adolescent and an AAC user. My purpose is to raise issues, ask questions, and highlight its importance. *What is adolescence like? What's important about it? What's to be done about it?*

For Consumers begins with reflections from adult AAC users on their adolescence. Michael Williams, a friend and colleague who uses AAC, who is married with two children, and holds a master's degree in library science, also worked on this section. We had help from others listed as Resources on page 10. **Clinical News** discusses the psychology of adolescence and offers suggestions about how to be of assistance. The **Equipment** section lists software and materials to consider.

In **University/Research** and **Governmental,** I describe aspects of my recent trip to Portugal and some ongoing activities in Europe. From time to time during the trip, I found myself both language and speech impaired. Although I knew some words and phrases in Portuguese, my attempts to speak were quite "unintelligible." *(cont. on page 2)*

For Consumers

Adolescence: Reflections of AAC users

Adolescence, like childhood, is best experienced against a backdrop of support, love, and understanding. It is part of the development process. With or without a disability, adolescence is a time of rapid growth and physiological changes. The landmarks of development, the sensations, physiology, emotions and needs may be roughly the same; however, the stresses and challenges in dealing with adolescence certainly are greater for individuals with disabilities, particularly those who struggle to communicate.[1] Walking and being physically normal are not the issues involved in coping successfully as an adolescent or an adult. In the long run, what really matters the most is positive self-esteem and a positive perception of who you are and where you belong in the world.[2] Communication is essential to this process.

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Michael Williams and I asked three men and three women who use AAC to reflect on their experiences as adolescents. Our colleagues have cerebral palsy, are between 29 and 51 years old (mean=40 years), and are "high functioning." They use a variety of communication devices and other assistive technologies. We realize they do not represent all, or even a majority of AAC users; however, they have experienced first hand what we need to know. Our questions and their responses follow:

(cont. on page 2)

(UPFRONT *continued from page 2)*

People stared, looked puzzled and shrugged. *"Obrigado"* which means *"thank you,"* was my only success. My reactions? First, it was great to have even one intelligible word. Mostly, I felt incompetent, embarrassed, and frustrated. Then I realized, I know what to do! Pantomime was useful. But the word boards I prepared in advance were most effective. I selected vocabulary, looked it up in the dictionary, wrote it down and then went out and pointed to the words/phrases I needed. Shopkeepers, waiters, policemen, taxicab drivers (and I) had a much easier time. Hey, I could have told me that! One additional observation . . . my attempts to repeat unintelligible words or phrases often made things worse!

Tributes. The first is a very happy one. Cheers to the *International Society for Augmentative and Alternative Communication (ISAAC)* on its 10th anniversary. More than any other organization, ISAAC's chapters and members are making a difference in the lives of AAC users. The 10th anniversary is testimony to the efforts and achievements of many, many people who work on behalf of ISAAC's mission. The second tribute is to Marsha Livent, a woman who worked behind the scenes for years to get AAC users what they need. ACN would like to recognize her, and others like her whose efforts often go unacknowledged. Written by Carol Cohen, this tribute is on page . Finally, special thanks to Dr. Terry Gandell. She worked at ACN's international headquarters in Monterey on this issue as part of a faculty development program with Bishop's University in Montreal, Canada.

Beginning with the next issue, ACN will return to its 8-page format. That's it for now. Remember the Hotline number is (408) 649-3050.

Sarah W. Blackstone, Ph.D.

For Consumers *(cont. from page 1)*

Question: *What ages do you consider the period of adolescence? When did you go through your adolescence?* All concurred that "Adolescence" begins between 11 and 13 years of age and ends at 20 years. Five of the six AAC users reported having an adolescence that was "delayed" or "extended" (from ages 28-34 years, 13-25 years, 13-28 years, or "continuing"). As one respondent said "adolescence continues until the person establishes an independent life."

Question: *Identify and rank the major issues confronted by AAC users during adolescence.* Responses are presented in Table I. To summarize, peer acceptance and the future were the most frequently mentioned issues. Self-esteem and sexuality were noted often. Most indicated that sexuality issues were often avoided "like the plague." Other issues mentioned were getting through high school and facing the future. Access to communication and to technology, as well as support for and ongoing training in technology were considered primary issues. Finally, being independent and dealing with family relationships were listed.

Question: *Were there some things people did that were helpful?* Respondents said their parents did the following positive things:

- Helped me to grow in school and in every way.
- Told me how smart I was.
- Listened to my ideas.
- Understood I should be able to talk with anyone and everyone.
- Told me not to go by the rules.
- Introduced me to an employed engineer with severe cerebral palsy.
- Got me to a therapist so I could confront my feelings, particularly about my disability.

One respondent said professionals involved him in decision-making. Several, however, did not recall anything positive professionals had done during their adolescence.

Question: *What are professionals and families doing today that is helpful?* Respondents seemed to think things are getting better. They listed the following positive practices:

- Training everyone who knows the AAC user how to interact with him/her.

Table I. Issues faced by adolescent users of AAC as perceived by adult AAC users

Concerns	Specific Issues Mentioned
Self Esteem	Being different. Having self respect. Coping with negative attitudes. Growing emotionally. Having interpersonal relationships. Figuring out your identity and your role.
Communication	Being able to have meaningful, fast communication. Being well positioned for function. Having nondisabled people stop and listen to you. Having knowledgeable teachers Having technicians available to keep systems running.
Peer Acceptance	Being accepted by peers. Feeling left out. Dealing with peer pressure. Having peers look beyond the disability and know you are really like them in every way.
Sexuality	Dealing with body image. Dating. Having privacy. Not avoiding the topic. It's not a plague!
Independence	Wanting to be on your own. Dealing with overprotective parents. Finding funding for devices and services. Getting along with the family.
The Future	Graduating from high school. Finding companies willing to hire people at age 16. Being encouraged to dream and have goals and the support to fulfill them, no matter how long it takes.
Time Management	Budgeting time for fun and work.

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- Teaching the AAC user how to train strangers to interact appropriately.
- Being advocates for AAC users in schools, communities, recreational activities and public affairs.
- Providing communication devices from an early age that allow expression of feelings and thoughts.
- Sitting down and listening to AAC users.
- Teaching AAC users and families about funding sources.
- Teaching AAC users how to utilize technology to the fullest.

One person said,"professionals who have confronted and resolved their own feelings about disability are more helpful than those who haven't."

- Integrated in all parts of life to enhance social integration, give someone a public voice, aid in educational goals, encourage creativity, and allow for independent mobility and recreational activities.
- Able to provide access to unrestricted vocabulary.
- Truly portable and as easy to use as possible.
- Fun for both parties.
- Able to reflect the teenager's personality.

Word processors with word prediction, ACCESS DOS, communication devices, and anything helping one eat, move, talk, play and work were listed as critical technologies.

TABLE II. Important things for professionals/families to do.

Encourage independence	Let teens take risks and make mistakes. Have expectations that are similar to "normal teens". Allow teens to experience "normal" things other teens do. Allow teens to participate in the decision making process.
Help teenager to succeed academically	Encourage teens to plan for the future. Develop a skill/talent for teens to use as an adult.
Support the development of a positive self image	Teach self-respect. Introduce teens to role models with disabilities. Preprogram swear words and current teen expressions in devices.
Obtain equipment	Get funding for all necessary equipment. Help teens take maximum advantage of existing technology. Provide training and make sure someone knows how to fix equipment.
Encourage social relationships	Encourage person to develop healthy peer and community relationships (e.g., church, civic club). Encourage teens (and parents) to join support groups.

Question: *Imagine you are the parent of someone who uses AAC. What important things would you expect professionals and families to do?* Table II summarizes their responses under five major headings: independence, academic success, positive self image, access to equipment and involvement with people.

Question: *What role should AAC devices play in adolescence? What technologies are critical?* All concur technology should play a very important role! One respondent said, "Just imagine if you were nonverbal. What would you want a device to do in your everyday life?" Others responses were that devices should be:

- Used when they are functional and put aside when they are not.

Michael's reflections follow:

One of the least surprising, but most important findings of this survey is the fact that most of us have had a delayed adolescence. For most teens, adolescence becomes an exercise in the crafty art of escaping their parents watchful gaze. This becomes doubly difficult when your mobility and speech are impaired.

I remember my chronological adolescence stretching out through an endless series of Sunday nights, as my parents and I would gather around the TV set and watch the Ed Sullivan show. I would sit there and watch the guys with their spinning plates and think, "Life must hold something better than this." Fortunately, I discovered my local chapter of the Young Democrats and the American Civil Liberties Union. Various members took me to meetings. This got me out of the house, kept me up on national and world events, and got me thinking for myself.

As I look back on this now, I realize that this period gave me some of the social and intellectual skills that I would use later, while going through my true "adolescence."

I also spoke with two physically disabled adults with unimpaired speech. Both are quadriplegic; Audrey as a result of polio and Steve as a result of a spinal cord injury. They concur that the major issues faced by adolescents are social, not medical. For example, Audrey recalled figuring out as a teenager that "the only reason people spoke to me was they felt sorry for me." Both stressed the importance of having friends with and without disabilities and of finding a balance between integration experiences and contact with the disabled community. Both agreed adolescents have a critical need for privacy and confidentiality. They warned, however, that few adolescents have the courage to ask questions about sex, their disability, or the future.

In response to my question about how professionals and families can help, they gave the following advice:

- Help establish opportunities so that friendships and links among people can develop.
- Help extend the world experiences of adolescents. Many people with disabilities live in a shrunken world.
- Don't treat adolescents like babies.
- Remember how sensitive adolescents can be. Be careful not to say things that hurt someone's feelings.
- Be creative. It's easy to say "allow privacy, independence and typical teenager experiences." However, it is hard to emancipate someone who is physically dependent on his or her parents.

Clinical News

The real stuff is on the inside

Why did you not accept me as I was and work with me towards what I wanted to become?[3]

This article raises two questions. First, are we missing the boat with adolescents? Second, what is the boat? I asked professionals the same question Michael and I asked AAC users, "What are the primary issues confronting adolescents who use AAC." Table III summarizes their responses.

Table III. Major issues faced by adolescent users of AAC as perceived by AAC professionals

Concerns	Specific issues mentioned
Life Skills	Being literate. Doing homework. Taking notes. Grooming. Using money. Using the phone. Having hobbies (leisure).
Communication	Accessing large vocabularies. Saying novel things. Using humor. Communicating in different environments.
Technology	Using as a tool, not an end in itself. Looking "cool". Being involved in decisions
Independence	Preparing for unfamiliar situations. Relating with families.
Prevocational	Getting work experience.
Peer Acceptance	Wanting to be like peers.

Comparing Table I (page 2) to Table III above, reveals qualitative differences. Less than 50 percent of the areas overlapped: *communication, independence and peer acceptance.* Both AAC users and professionals saw these as major issues confronting adolescents. The other areas listed by AAC users were *self esteem, sexuality, the future and time management,* while AAC professionals listed *life skills, prevocational training and technology.*

Why the differences? Issues listed by AAC professionals may reflect their interests and areas of expertise. Addressing skill development is something AAC professionals know how to do. Fostering self-esteem, dealing with sexuality, and planning for an individual's future employment and independence are not!

"Experts" in adolescence agree with AAC users about the primary developmental tasks of adolescence: self awareness, body image, friendships, sexual identity, future thinking and associated worries like employment and financial independence.[1,2,4,5] Goldberg[6] suggests it is not the severity of the disability that will determine if adolescents with disabilities make successful adjustments. Many very severely disabled people and families adjust well, while many mildly disabled persons do not. The two necessary ingredients for success are: resolving normative adolescent tasks and having a positive idea of oneself as a physical, emotional, intellectual and social person. He challenges professionals and families to:

- Spend as much time worrying about maximizing the growth of a healthy self-concept as you do in maximizing a person's physical potential or communication skills.
- Broaden your awareness beyond the educational and rehabilitation systems.
- Appreciate each person for what he/she IS rather than what he/she is NOT.
- Consider spending less time trying to remedy impairments that are always going to be part of a person's life and more time on providing opportunities for normal experiences and successes in other areas of development.

During interviews with AAC professionals (see Resources on page 10), it was apparent they were aware of a broad range of challenges and concerns confronting adolescents. All seemed to agree it is important for AAC professionals (who typically are trained in health-care, technology, and education) to consider more carefully our roles during adolescence. As previously mentioned, suggestions from AAC users are summarized in Table II on page 3. AAC professionals offered these additional thoughts:

1. **Self-Concept**: Falling short of cultural ideals can be devastating for any adolescent. Research shows the more obvious the physical differences, the more difficult it can be.[6] Changes in societal attitudes and laws, and the disability rights movement are helping. Haney[7] reports that after 8 years of intervention through the Pennsylvania Assistive Technology Center, there has been a positive change in adolescents who have grown up with assistive technology and integration experiences. She says they are self-advocates and their primary concerns are getting a job and getting married. Peers see them as classmates and friends, and only incidentally as disabled. These students also are advocates for early intervention. They say getting started at age 16 is "too late." People define who they are and what they will become as a result of their social contacts with parents, teachers, therapists, and peers, beginning in early childhood. Other suggestions were to:
   - **Be aware of what "intervention" conveys.** How do adolescents with disabilities interpret going to therapy or being in a special class. Hopefully, it is not "You are not good enough the way you are. We will fix you."
   - **Talk about disability.** It is not a stigma, shame, deficit or something that needs to be gotten rid of. Fears, beliefs and questions about an individual's disability and its outcome should be discussed.
   - **Provide assistive technology.** AAC professionals used to report that many adolescents were reluctant to use technology because it made them look (and sound) even more different. Today adolescents are more likely to perceive technology as "cool." Able-bodied peers now have technology also. It continues to be important for AAC technologies to look and be age-appropriate. An example is described by DeTommaso:[8]
     "I developed an overlay for a teen-age boy. You know how long that takes. . .it was color coded, full of symbols representing all the vocabulary he wanted and so on. When I presented it to him, he took one look at it and said, 'You don't expect me to touch pink, do you?'" GUESS NOT!
     Moral of the story? "Never develop anything for an adolescent without their input."
   - **Increase self-esteem by making age-appropriate demands.** Don't treat adolescents like younger children by overprotecting them or assuming they have limited cognitive skills. For example, hugging and patting the head of a 19 year old is highly inappropriate on many levels.[9]
   - **Introduce to role models.** Make certain adolescents who use AAC meet and interact with disabled peers and adults who are coping successfully.
2. **Friendships.** We are all on our own when it come to developing true friendships; however, professionals and families can provide opportunities for them to emerge. It is important to know that social skills are things that all people, with or without disabilities, learn only with practice.

DeTommaso[8] did a vocabulary inventory and reported teenagers talk about: Friends, the opposite sex, hobbies, sports, what they are going to do or go, things they have done, sex, and Aids. She feels most teens want to say novel things and need access to large vocabularies. Literacy skills are critical not only for academic and vocational reasons, but for social and personal growth.[10]

Several people described the value of group experiences for nonspeaking adolescents who use AAC. The group process can facilitate the interactive use of AAC systems, provide peer support in developing self-advocacy among AAC users, and assist in addressing social and emotional needs. Thurston and Deegan[9] reported the results of two groups over a 2 1/2 year period: a Communication group with 6 nonspeaking physically disabled adolescents and their speaking peers and an after school Psycho-Social group. They observed the AAC teens were less mature in their social development than peers. It was suggested this was due to major deficits in their developmental experiences and lower expectations on the part of parents and professionals. These researchers suggest the building blocks toward interactive communication with peers and the development of social skills must begin much earlier. In addition, they suggest professionals and parents should expect more normal behaviors from nonspeaking adolescents.

Other strategies for socialization are to use modeling, role playing and self-instruction to assist in dealing with real life situations. More than anything, it is important to make sure teens have opportunities to get together, hang out, and talk. One mechanism is the use of electronic mail and teen Bulletin Boards as described on page 9.

3. **Sexual identity**: The literature suggests many parents and professionals consider children and adolescents with disabilities asexual with no chance to marry, reproduce and lead a normal sexual life.[11] These attitudes not only show a lack of contact with reality, but a lack of information about what is possible. Even worse, they can result in the disabled adolescent feeling their body is ugly and sexually unattractive. For AAC users, the problems are exacerbated by their difficulty asking questions about a range of sexual issues. Most lack information and few have access to extensive and explicit vocabularies. Even fewer have opportunities to show an interest in sex during normal activities such as school dances, in conversations with the opposite sex, and so on. Readers are referred to Communicating Together,[12] for an excellent discussion of sexuality issues. Suggestions are:

- **Parental influence.** Disabled children need to hear from their parents that they are indeed sexual people, with sexual thoughts and feelings and can expect to socialize, date, marry and have children, if they wish.
- **Preparing teens so they can decrease any possibility of sexual abuse.**
- **Introducing to role models** (e.g., married AAC users).
- **Advocating for normal social experiences and privacy.**
- **Appropriate vocabularies.** Teenagers with disabilities should have access to age-appropriate vocabularies with public and private messages concerning sex and sexuality.
- **Appropriate representation of vocabulary.** McNaughton[13] reminds us that symbols play a role in self esteem, self determination and self actualization. Thus, in selecting symbols to express vocabulary, consider whether the symbols: portray accurate and relevant information; respond to the user's feelings regarding privacy; protect the dignity of the user; consider the reactions of others.
- **Counseling (group or individual).** Counseling can provide a setting for discussions of sexuality among AAC users. However, several (including AAC users) mentioned that during adolescence, many will "shut-down" any discussion of sexuality issues. Thus, professionals who do counselling must be familiar with ways to assist individuals with severe motor, sensory, language, and cognitive impairments to learn the "how tos" of sexual behavior and to develop a sexual identity. Programs need to focus beyond the anatomy, physiology and function of sexual parts and permit an open expression of feelings.

Why did you waste my time with therapy when you could have been training me for a job, to live independently, to balance my budget?[3]

4. **Independence.** Achieving a balance among independence, dependence, and interdependence is very difficult. For one thing, there are no universal criteria. Cultures differ on their perceptions of this balance. Interdependency and dependency are not substitutes for independence, but important values in and of themselves. All over the world, however, people with disabilities have limited experiences with independence. Separation from one's family can be very difficult and often is prolonged until well into adulthood for people with disabilities, making it even more problematic.[14] Remember also that what may appear to be a dependent relationship is often one of interdependence. When a pattern of learned helplessness has been established, however, it will hinder an adolescent with disabilities from taking the steps required to prepare for independent living in the community. Strategies may include: providing parent discussion groups; creating opportunities to assume increasing responsibility for one's own self-help behaviors; encouraging teens to be involved with other people; and teaching older teens how to hire and manage attendants and how to deal with barriers they are likely to confront.

5. **Educational and vocational development**: Results of research suggest that problems of separation, independence, body image, sexual identify, aggression and depression must be resolved before vocational choices can be made. Amid such turmoil, which is so characteristic of adolescence, even able-bodied youths don't make realistic choices without help. Professionals need to recognize these problems must be settled by late adolescence and often are not. Concerns of adolescents extend WAY beyond the development of educational and vocational skills. Coordination among agencies and the community is essential.
Many mentioned the need for work experience. Most children have "jobs" well in advance of the time they can be employed, (e.g., baby sitting, paper routes, mowing lawns, and other jobs in the community). Without these experiences, AAC users fall behind. With them, they can learn more about themselves and their abilities, work values, and job options.

Final comments: It's clear, isn't it, that going through adolescence is far more difficult for people with disabilities, particularly AAC users. It requires enormous, skill, perseverance, and support. Today, most adult AAC users are not employed, are not married, or involved in long-term adult relationships, and are not living independently. You and I, and the field of AAC can NOT ignore any longer, the highly possible conclusion that we need to do a better job during adolescence and for adolescents!

University & Research

Activities in Portugal

What a wonderful trip! I just returned from Portugal where I was invited to speak on *Research in AAC* at the First IberoAmerican Congress of Alternative and Augmentative Communication in Lisbon, Portugal. Note: IberoAmerica is a geographical area comprised of Portugal, Spain, Brazil (where Portuguese is spoken) and all the Spanish speaking countries in Central and South America. Arriving a few days early, I spent the first day visiting the Centro de Reabilitacao de Paralisia Cerebral Calouste Gulbenkian. The Centre provides services to approximately 1200 children each year. Founded in 1960 by the Portuguese Cerebral Palsy Society, the Centre offers assessment and treatment, has a preschool, kindergarten and elementary school, and a vocational training program for children and youth. At the Centre I met children with severe cerebral palsy who are using a range of assistive devices to communicate and participate. The preschool classroom was thoughtfully engineered. Symbols and technology were accessible everywhere. I observed each child communicating with staff, each other, and strangers using gestures, speech, facial expressions, low tech and high tech devices and computers. The AAC team includes the teacher, her instructional assistants, rehabilitation engineer, psychologist, occupational, physio, and speech therapists and a physician. We discussed their 3 year research project (*An AAC Curriculum for Preschool Children),* which is funded by JNICT from the Ministry of Industry. Based on this ongoing research Margarida Nunes da Ponte, Luis Azeveda, Carlota Ferreira and their colleagues will prepare an AAC preschool curriculum in Portuguese that can be replicated across programs. The curriculum will be available in late 1994.

Between a visit to the Centre and the beginning of the conference, my mother (who is 80 years old and not easy to keep up with) and I, did some sightseeing in Lisbon. Margarida and her husband Manuel took us to the charming city of Cintra, where the royal family used to spend summers.

The Conference opened on June 29th, with speeches from dignitaries of Portugal, Spain and the European Community. Co-sponsored by CAPS (Centre for Analysis and Signal Processing of the Technical University of Lisbon), the Psychology Department at the University of Barcelona, and the International Society for Augmentative and Alternative Communication (ISAAC), the conference created an exciting forum for Portuguese- and Spanish-speaking professionals in Europe and Latin America to share their knowledge, experiences, and research. It was good to establish contact with so many talented colleagues. Papers are listed in Table IV:

After the scientific program, my mother and I travelled north by car. Our goal was to expand our "research" to include Portuguese food, scenery, history, culture, and wine. *Results?* I recommend everything! Portugal is a truly beautiful country. We drove through villages with medieval churches and homes fronted with attractively designed ceramic tiles. We ate delicious food and found warm, kind people everywhere. The long days were full of activities and history. We never felt rushed because the sun stays high until after 10:00 p.m. Among the many highlights was a two night stay at the Palacio de Mateus. the lulas (calamari), the beaches, the vinho verde (green wine), riding a burro (Yes, I did!), the Port wine, Margarida's cooking and most of all, time spent with Luis, Margarida and their delightful families!

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TABLE IV. RESEARCH TOPICS COVERED AT THE FIRST IBERO-AMERICAN CONGRESS OF AAC

TOPIC	PRESENTER(S)	COUNTRY
Language symbols and their cultural basis	Micaela Lopes	Portugal
Expectations of parents for AAC interventions	Carlota Ribeiro Ferreira	Portugal
Interaction and acquisition of language in children with cerebral palsy	Emili Soro	Spain
Communication strategies for persons with motor impairments	Carmen Basil	Spain
LOGO language: An alternative for communication/interaction of deaf children with computers	Lucilia Santarosa	Brazil
LOGO language, motor skills, and communication	Equipa do Polo Minerva	Portugal
A Brasilian experience	Fernando Capovilla	Brazil
Technologies for occupational training of youths with severe motor disabilities	Jordi Escoin	Spain
Using an ultrasonic sensor to assist in the communication process of people with visual impairments	Ramon Ceres Nahir Salazar	Spain Columbia
The role of an interdisciplinary team in AAC	M. da Graca Andrada	Portugal
Psychological profile of severe hearing impaired youths in an integrated school context	Norberto Projecta	Portugal
Strategies for communication with individuals who are autistic	Higini Miralles	Spain
Total communication: A program for children with severe mental retardation	Javier Tamarit	Spain
Cooperative projects in Europe and Latin America	Luis Azevedo, J. Antonio Cordero	Portual, Spain
Methodologies for producing multimedia software for individuals with disabilities	Jaime Sanchez	Chile
Keyboard emulator for windows	Francisco Gomez	Spain
The use of multimedia as metaphor in AAC	Gustavo Rossi, Mauricio Lumbreras, Jose Zato	Argentina, Spain

Governmental

TIDE and the HEART project

TIDE is the European Communities Research and Development Initiative in the field of Rehabilitation Technology. TIDE is seen as critical to the competitiveness of the European rehabilitation technology (RT) industry. The existence of TIDE reflects recognition by the European Community (EC) that assistive technology is a growing market and that member states (i.e., the countries who belong) currently have only small and fragmented markets:

- **Companies now focus on single impairments.** Available RT tends to address single impairments, whereas, integrated solutions are needed because many groups (e.g., elderly people) have more than one impairment.
- **Technical issues are not solved.** Manufacturers and suppliers come from different sectors. This makes device connectivity and integrated solutions very difficult.
- **National regulations differ.** Different member states are now required to conform to different technology standards and service delivery regulations.
- **Cultural differences abound.** The EC comprises countries (i.e., member states) with many languages and cultures. Attitudes towards technology and user preferences differ substantially.

In Europe and the United Kingdom, businesses that manufacture and distribute RT are currently small to medium sized and often lack the resources that would allow them to take advantage of new technology or to expand their markets geographically. Also, large high tech companies may perceive national markets in Europe as too small and fragmented to justify their investment. In the public sector, reimbursement authorities struggle to reconcile the demands of users with their limited budgets. As for users, they often have limited choices and pay high prices for AAC technology and services.

The primary goal of TIDE is to "stimulate the creation of a single market in rehabilitation technology in Europe."[x] By enlarging the market, products that incorporate up-to-date technology can be delivered to disabled and elderly people at reasonable prices. TIDE also exists to help counter the threat posed to European industry by United States legislation in favor of people with disabilities, specifically the Americans with Disabilities Act (ADA), which forces industry to take the needs of disabled persons into account and stimulates a strong RT industry in the US.[15] Finally, TIDE is meant to accelerate the emergence of a customer centered, market oriented, RT industry and to facilitate independent living and participation in economic and social activities by elderly and disabled people through technological intervention.

Already TIDE has more than 20 projects underway in the following areas: general models and tools; manipulation and control; safety and daily support; access to information; personal communications. Communication area projects are concerned with:

- Access to and interaction with multimedia environments
- Technology to facilitate personal communications, and
- Services and applications.

Currently, the single largest study funded by TIDE is HEART (Horizontal European Activities for Rehabilitation Technology). Managed by the Swedish Handicap Institute, the HEART Consortium has partners from 21 institutions, organizations and companies in 12 countries. The Consumer Board insures a consumer perspective is maintained. The HEART study concentrates on six key areas:

1. Standards, testing and certification/specification of rehabilitation technology. *Coordinated by The Danish Centre for Technical Aids for Rehabilitation and Education.* Objectives are to influence standardization of RT, testing of aids and products, and coordination of RT. Consumer influence is considered critical.

2. Coherence between and among RT industrial sectors. *Coordinated by Forschungsinstitut Technologie-Behindertenhilfe, Germany.* Objectives are to encourage European companies to cooperate in research, product development, harmonization and marketing.

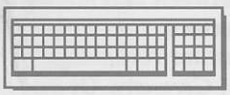
3. Rehabilitation technology service delivery. *Coordinated by the Institute for Rehabilitation Research, The Netherlands.* Objectives are to identify exemplary components of service delivery systems in 16 countries, evaluate the involvement and influence of the consumer, and recommend improvements that will both enhance the quality of services and stimulate an international market.

4. Legal and macro-economic factors impacting RT availability. *Coordinated by The Functional and Vocational Rehabilitation Centre of Nanteau-sur-Lunain, France.* Objectives are to study legislation and then evaluate possible interactions between how legal and macro-economic factors affect the availability of rehabilitation technology used in daily life, education and employment.

5. Rehabilitation Technology Training. *Coordinated by The Centre for Analysis and Processing Signal, Portugal.* Objectives are to examine a range of existing RT educational programs in Europe and North America, and identify the critical components. Ultimately this group will propose RT curricula for the EC.

6. Emerging areas of RT research and development. *Coordinated by the National Research Council, Italy.* Objectives are to identify the barriers that currently prevent elderly and disabled people from having access to new technologies. Mechanisms for ongoing technology transfer will be defined.

For more information, contact Gunnar Fagerberg or Tomas Lagerwall, The Swedish Handicap Institute, Box 510, S-162 15 Vallingby, Sweden. FAX +46 8 739 21 52.



Equipment

A place to begin

Communication aids, adapted computers, software, mainstream technology and assistive devices should be part of the life of all adolescents with severe speech impairments. The purpose of this section is to share information about software and materials designed with the needs of adolescence with disabilities in mind. Far from inclusive, the information gives you a place to start. If you have other ideas, please let me know. Special thanks to Dave Schmidt, Terry Gandell, and others for their input.

Software: Tables V and VI list software that addresses leisure activities, socialization and literacy issues respectively. Readers are encouraged to obtain additional resources. Three comprehensive guides to computer technology are listed on page 10.

Note: many programs can be operated with single switches and keyboard emulators (e.g., Ke:nx, the Adaptive firmware card, etc.)

Materials: RAPS (Reading Activities Project. These materials are designed to support emergent literacy development in children with significant developmental delays over the age of 8 years. Edited by Carolyn Musselwhite and developed by the Southwest Human Development, Inc., RAPS has ten stories, activities, communication overlays appropriate for early adolescents. Story themes emphasizing choices, consequences and problem solving. The R.A.P.S. Songbook and audiotape (available in the Fall) has songs for each story and ideas on how to incorporate music using a variety of light and high tech communication devices.

To order, send $25 US for RAPS and $15 US for RAPS Songbook to Southwest Human Development, 202 East Earll Street, Suite 140, Phoenix, AZ 85012.

Access to the Arts through Assistive Technology. This publication has ideas about how to facilitate artistic expression. The complete package includes AFC setups for the Unicorn Board and/or overlays for a TouchTalker/LightTalker.

For information, write Young Artist Workshops, St. Norbert College, De Pere, WI 54115- 2099.

Electronic Bulletin Boards for Teens. Modern technology can facilitate social interaction, support and education in an environment that levels the playing field and is available at the individuals own convenience and pace. Many communities have bulletin boards with electronic mail available at no cost. Some offer special on-line access to put children and youth with disabilities in touch with their peers (both able-bodied and others with disabilities). One example is **Ability OnLine,**[16] which offers electronic mail, a section for teenagers, a separate conference for parents, discussion topics such as sports, job searching, high technology, and specific disabilities, and games.

To connect, you need a computer and a modem. Try it!

- Set communication software to 8 data bits, NO parity, and 1 stop bit, and you modem to its fastest speech.
- Dial (416) 650-5411. There is no registration fee or membership cost,but long-distance charges do apply.
- Register (answer a few question).
- After you register a list of conferences and forum such as Teen Chat are displayed.
- Follow directions and go for it!

For more information connect with the system or contact Ability OnLine Support Network at 919 Alness St., North York, Ontario M3J 2J1, Canada or phone (416) 650-6207.

TABLE V. FUN AND GAMES (Socialization, Visual/motor, Cognitive skills)

NAME OF SOFTWARE	SOURCE	INTERFACE	COMPUTER	DESCRIPTION
Games 2 Play $125 US	**Don Johnston Developmental Equipment (DJDE)** 1000 N. Rand Rd, Bldg 115, P.O. Box 639 Wauconda, IL 60084-0639	Single switch	Macintosh	Games for 2 players Variety of activities
Interaction Games I $65 US	**DJDE** see above	Single switch	Apple IIe, IIc, IIgs	Games for 2 players Variety of activities
Interaction Games II $65 US	**DJDE** see above	Single switch	Apple IIe, IIc, IIgs	Games for 2 players Variety of activities
Single switch recreation games $10 US	Available from **Dorothy Laufer** Y.E.S., 5604 Palmer Ave. Montreal, Quebec H4W 2P1	Keyboard; single switch with interface	Apple IIe, IIc, IIgs or Macintosh with emulator card	Up to 2 players can compete Bowling, Checkers, TicTacToe, Connection, Othello, Boxing Public Domain software
Teenage Switch/ Touch Window Progressions $75 - $90US	**R. J. Cooper & Assoc.** 24843 Del Prado, Ste. 283 Dana Point, CA 92529	Single switch or Touch Window	Apple IIe, gs MS-DOS	Activities designed for low functioning adolescents. Includes training in life skills Shareware
Switch Games $5 -$6 US	**Center for Adapted Technology** 5755 W. Aladeda Avenue Lakewood, CO 80226	Single switch	Apple IIe, IIc, IIgs MS-DOS	Games for 2 or 1 player Pinball and others Public Domain software
Popular, mainstream computer games	Computer magazines (e.g., MacUser and PC Computing) list the ten most popular games.	keyboard, mouse, joystick	Macintosh MS-DOS	For programs that use the mouse or joy stick, you can adapt for switch input.

TABLE VI. LITERACY

NAME OF SOFTWARE	SOURCE	INTERFACE	COMPUTER	DESCRIPTION
TALKING WORD PROCESSORS		Note: These are examples. Many other programs are available.		
AccessBliss $250 (Canadian)	**Blissymbolics Comm. Inter.** 250 Ferrand Dr., Ste. 200 Don Mills, ON M3C 3P2, Canada		Macintosh w/ Hypercard	Allows user to find and retrieve Blissymbols for use in word processing, painting and drawing programs.
Keytalk $99 US	**PEAL Software** P.O. Box 8188 Calabasas, CA 91372	Keyboard	Apple IIe, gs MS-DOS	Beginning word processor. No editing.
IntelliTalk $39.95	**IntelliTools, Inc.** 5521 Central Ave, Suite #205 Richmond, CA 94804	Keyboard and alternatives	Macintosh, Apple IIe, gs MS-DOS(soon)	Can use with Intellikeys and Overlay maker to create talking communication boards.
Language Experience Recorder $99.95 US	**Teacher Support Software** 1035 N.W. 57th Street Gainesville, FL 32605-4486	Keyboard and mouse	MS-DOS Macintosh	Can vary text size. Gives readability estimates.
WriteAway $199 US	**Institute on Applied Technology** The Children's Hospital 300 Longwood Avenue Boston, MA 02115	Keyboard and alternatives	MS-DOS	Built in prediction and abbreviation expansion. Can vary text size.
Write:OutLoud $125 US	**Don Johnston Developmental Equipment (D JDE)** (see previous page)	Keyboard and alternatives with Ke:nx	Macintosh	Can vary text size and background colors. Has on-screen ribbon for functions. Spell checker. Uses with Co-writer (see below).
RATE ENHANCEMENT		Note: These are examples. Many other programs are available.		
Co:Writer $290 US	**D JDE** (see above)	Keyboard; Ke:nx allows all others	Macintosh	Word prediction and abbreviation expansion. Works with standard word processors.
EZ- Keys (family) $1395	**Words+, Inc.** P.O. Box 1229 Lancaster, CA 93584	Keyboard and alternatives	MS-DOS	Word prediction and abbreviation expansion. Works with standard word processers. Note: $150 US discount if prepay check/money order.
PAL $99.95 US	**Lander Software** 94 Victoria Cres Road Glascow G12 9Jn, UK	Keyboard	MS-DOS	Word prediction. Works with WordPerfect,WordStar and PALSTAR (included with order)
KeyREP $275 US	**Prentke Romich Co.** 1022 Heyl Road Wooster, OH 44691	Keyboard	MS-DOS Windows 3.1	Word prediction and abbreviation expansion. Works with any application running under windows except DOS windows.
FUNCTIONAL LITERACY		Note: These are examples. Many other programs are available.		
Community Signs $239.95 US Survival Words $149.95 US	**Conover Company** P.O. Box 155 Omro, WI 54963	Keyboard	Apple IIe, gs MS-DOS	Signs for places, information and safety Available in Spanish. 30 words essential for community living. Available in Spanish.
Multisensory software $79 US per unit	**Imaginart International, Inc.** 307 Arizona Street Bisbee, AZ 85603	Mouse, sound board or Echo, Touch Window	MS-DOS Apple IIe, c, gs	Picture cues help students learn vocabulary. Sentence building & writing at 5 levels. Easy record keeping. Available in Spanish.
Reading Realities At Risk Series $169.96 US each	**Teacher Support Software** (see above)	Keyboard	Apple IIs MS-DOS	Covering real life issues facing teens, career preparation, jury series.Each theme has 15 stories and writing activities. Usesa whole language approach.
SARAW	**Regenesis** Development Corp. 1046 Deep Cove Road N. Vancouver, BC V7G 1S3, Canada	Keyboard	MS-DOS	Talking word processor with literacy activities, word prediction. Designed for older students who read and write at grade 2 to 6 level. Reading program with activities.
Story-Ware $95 US	**DJDE** (see above)	Keyboard or alternative with Ke:nx	Macintosh with Hypercard	Allows individual to create stories and to add graphics, sound and speech.

Please note: The **Carolina Literacy Center** is a valuable resource for information about literacy and persons with severe communication impairments. For information, write to: Dept. of Medical Allied Health Professions, Campus Box #8135, 730 Airport Rd., #200, The University of North Carolina at Chapel Hill, Chapel Hill, NC 27599-8135. (919) 966-7486.

AAC Bibliography

Comprehensive bibliography on augmentative and alternative communication: A key to the AAC literature for clinicians and researchers. Published in 1993. By Franklin Silverman this is a very valuable compilation!
Available from CODI Publications, P.O. Box 261, Greendale, WI 53129.

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[14] Harrington, K. & Harrington, R. (1991). Leaving home. Communicating Together. 9:3, 8-9.

[15] TIDE: Technology Initiative for Disabled and Elderly People. 1993-1994 Workplan. (March, 1993). Commission of the European Communities: Rue de la Loi 200, B-1049 Brussels, Belgium.

[16] Arlette Lefebvre. (July, 1993). Personal communication.

Your Resources

Gail Charad, Mackay Center, 3500 Boulevard Decarie, Montreal, Quebec, H4A 3J5 (514) 486-1415.

Shelly Deegan, Technology Access Clinic, Chedoke-McMaster Hospitals, Box 2000, Station A, 1200 Main Street West, Hamilton, Ontario L8N 3Z5. (416) 521-2100 ext 7833.

Diane DeTommasso, Assistive Technology Education Network of Florida, 434 N. Tampa Avenue, Orlando, FL 32805 (407) 849-3504.

Terry Gandell, 6275 Northcrest #1017, Montreal, Quebec, Canada H3S 2N3. (514) 731-2555.

Coleen Haney, Pennsylvania Assistive Technology Center, Gateway Corporate Center, 6340 Flank Drive # 600, Harrisburg, PA 17112 (717) 541-4960.

Ron Harris, Behavior Therapy Unit, Douglas Hospital, 6617 LaSalle Boulevard, Verdern, Montreal, Canada H4H 1R3.

Peg Johnson, Express Yourself of Minneapolis, 6432 5th Avenue South, Richfield, MN 55423. (612) 861-4029.

Mick Joyce, 4 North Allen Street, Madison, WI 53705. majoyce@wiscdu

Audrey King, Client Advocate, Hugh MacMillan Medical Centre, 350 Rumsey Road, Toronto, Ontario, Canada M4G 1R8. (416) 425-6220.

Carol Krezman, P.O. Box 10098, Berkeley, CA 94709. (510) 649-0653.

Janie LaBran, 714 Bayview, Pacific Grove, CA. 93950. (408) 373-5721.

Arlette Lefebvre, Dept. of Psychiatry. Hugh MacMillan Medical Centre, 350 Rumsey Road, Toronto, Ontario, Canada M4G 1R8. (416) 425-6220.

Steve McPherson. USERNET. 2100 Weston Road, #807, Toronto, Ontario, Canada. M9N 3W6. 416) 241-8882.

Nola Milen, 110-3185 Forest Glade Drive, Windsor, Ontario, N8R 1W7, Canada. (519) 735-4443 Phone and FAX.

Frank Moore, P.O. Box 11445, Berkeley, CA 94701-2445.

David Schmidt, Director Training and Development, IntelliTools, Inc., 5521 Central Ave, Suite #205, Richmond, CA 94804. (510) 528-0670.

Bob Segalman, Department of Justice, 4949 Broadway, Room 202E, Sacramento, CA 95820. (916) 227-3547 Phone 227-3880 FAX.

Technology Resources

You'll have access to lists of computer software (and more), including products appropriate for adolescents.

- The 1993 Closing the Gap Resource Directory, $14.95 US. P.O. Box 68, Henderson, MN 56044.
- IBM Resource. People helping people through technology. IBM Special Needs, P.O. Box 1328, Boca Raton, FL 34429. (no charge)
- Apple Resource Guides. Worldwide Disability Solutions Group, Attn: MDR 20525 Mariani Avenue, MS2-SE, Cupertino, CA 95014.

Note: AccessUnlimited helps put things together with free telephone consultation. 3535 Briarpark Dr. #102, Houston, TX 77042. (713) 781-7441.

Susan Thurston, Technology Access Clinic, Chedoke-McMaster Hospitals, Box 2000, Station 'A', 1200 Main Street W. Hamilton, Ontario, Canada L8N 3Z5. (416) 521-2100 ext 7833.

Geb Verburg, Coordinator Research in Cognitive Development, Rehabilitation Engineering, Hugh MacMillan Medical Centre, 350 Rumsey Road, Toronto, Ontario, Canada M4G 1R8. (416) 425-6220.

Michael B. Williams, P.O. Box 10098, Berkeley, CA 94709. (510) 649-0653. mbwill@well.sf.ca.us

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