Is demographic information important to you? Yes! People and agencies that control money, write laws, and set policy often require demographic information before they will commit resources to a program. In addition, demographic information can help professionals plan and implement relevant service delivery programs. Demographic studies may, for example:

- Count a specific population, e.g., those with severe speech and/or writing impairments within a specific geographic region, e.g., Israel;
- Count a portion of a target population within a specific area, e.g., adults with motor neuron disease seen from 1980-1990 at a hospital in London;
- Describe characteristics of a targeted population, e.g., age, sex, socioeconomic status, living arrangements, disabling conditions of children with C.P. in Victoria.
- Identify the needs of a population (e.g., telecommunication, writing, cooperation, partner education, money for equipment) in British Columbia.

All types of demographic studies exist; however, 62 percent of those responding to the ACN survey reported being unaware of any. Examples of published studies listed by respondents are noted in Table I.

**Table I: Examples of Demographic Studies (for complete reference see page 8)**


**What we know**

Demographic studies suggest:

(continued on page 2)
For Consumers (cont. from pg. 1)

1. AAC symbols, aids, and techniques are being used with individuals who have congenital, degenerative, acquired, and temporary conditions severely affecting communication.

2. The AAC "population" is small, representing less than one-half of 1 percent of the general population. However, even small percentages constitute a very large number of individuals...literally millions in the world.

   a) In Canada, for example, adults and children with congenital, acquired, and progressive disabilities with severe speaking and/or writing impairments, were estimated in the early 80s to number 200,000, representing .7% of their citizenry. 

   b) In Victoria, Australia, over 5,000 adults and children have severe communication impairments. This represents .12% of their total population.

3. Data from 3 multiple studies suggests that .15% to .6% of the total school-age population are "nonspeaking." 

4. Although descriptive information is limited, school-age children who are "nonspeaking" are also likely to be multi-handicapped (45%) and/or retarded (62%). Over 70% of adults and children with AAC needs in Victoria are intellectually impaired. 

5. Demographic information for adults is very limited. However, it is reasonable to assume that more adults than children require AAC because: a) children grow up, b) many children who require AAC do so over their lifetime, c) adults acquire disabling conditions associated with severe communication impairment (e.g., head injury, stroke, degenerative diseases), and d) most people are adults longer than they are children.

6. Adults with some disabling conditions are at very high risk for severe communication disabilities requiring AAC. For example, most (90%) with amyotrophic lateral sclerosis are unable to speak prior to their death. Other conditions have a lower prevalence, e.g., only 4 percent of persons with multiple sclerosis become nonspeaking.

You can use existing demographics!

With appropriate caution and disclaimers, you can extrapolate findings from some studies. For example, you may estimate the number of students ages 6 to 22 years that can benefit from AAC because the prevalence is surprisingly consistent across studies. Simply multiply 2% to 6% (you can use 4%) by the total school age population in your district, school, state, or region.

Unfortunately, too few studies exist to use other data. However, you could argue that more adults
than children are in need and could benefit from AAC services.

Perceptions of professionals

Populations well served. As illustrated in Figure 1, respondents to the ACN survey from all countries feel children, specifically those with cerebral palsy and good cognitive abilities, are better served than any other AAC group. Other populations said to receive good services were children with developmental disabilities and adults with motor neuron disease, as noted above. Responses also included: adults in rehabilitation hospitals and people with advocates, insurance, and money. The recent consumer survey, conducted by Bristow and Creech, asked consumer members of ISAAC to describe and rate the services they had received. Fifteen users (ages 10 to 30 years), who were physically disabled with good cognition and who used a variety of light and high tech devices, judged the AAC professionals and services they had received positively.

Populations not well served. Figure 2 also illustrates agreement among respondents world-wide. Adults, no matter what the disability type (i.e., aphasia, degenerative conditions, traumatic brain injury), are not perceived as receiving adequate services. Also listed were: children with severe/profound mental retardation, those who are very young, and those who are ambulatory [see ACN, Vol. 2, #2, 6; Vol. 3, #1, 3, which highlight these groups].

Age groups served by AAC professionals

Respondents were asked to estimate the percent of clinical time they spend with clients at various ages: 0-3; 3-6; 7-12; 12-21; 21-65; and over 65 years. No differences were noted among respondents from various countries, so data were pooled prior to analysis. Results showed that:

1. Almost 80% of AAC professionals who responded to the ACN survey serve people less than 22 years of age. Only 8% reported working with people over 65 and 12% work with those in the 21 to 65 year age range.

2. Nearly all report working with many age groups. And, most spend a limited amount of clinical time with any age group.

Note: other responsibilities of respondents (e.g., teaching, research, administration, working with non AAC clients) are not reflected here.

Conclusions

In light of the demographic information considered earlier, here are some arguments you can use to expand AAC services:

1. Children. The majority of children who can benefit from AAC services are multi-handicapped and retarded. Yet, worldwide the focus is on the needs of children who have cerebral palsy and normal (or near normal intelligence). Current AAC service delivery efforts may be successfully addressing the needs of less than 10 percent of children who could benefit. With intervention, ambulatory children and those with mental retardation can participate in and contribute to society. They should not be given a back seat!

2. Adults. Respondents worldwide agree... adults are not well served. It is likely that more adults than children are in need of AAC services. However, results of the ACN survey suggest most professionals serve persons under 22 years of age, while a comparatively small percent work with adults.

3. Consumers and families beware! Once you reach the age of 21, it will become more difficult to find professionals or places that provide AAC services, no matter where you live.

4. Demographic projections for the general population reveal individuals over 65 years of age will represent a greater portion of the general population. Many will have serious communication needs. The AAC area is not prepared to meet either the current or the future needs of this expanding group!

5. Professional skills. Many AAC professionals are required to address a wide spectrum of disability types, assistive technologies, instructional strategies, funding approaches, and agency policies. No wonder professionals feel "it is difficult to keep up" and "time is a major problem!" Many find reading ACN very helpful!
"What 3 service delivery practices work and what 3 do not work well in your country?" Respondents from 10 countries listed a total of 239 practices that "work" and 259 practices that "do not work." Because responses were similar within and between countries and because only a few responses were received from some countries, data were combined prior to analysis. The four most frequently cited "practices that work" were:

- A team approach
- Intervention that occurs in natural contexts
- An approach that supports and involves families
- A bank of equipment for rental and/or loan

The five items listed most frequently as "not working" were:

- Lack of funding
- Center-based evaluations
- Lack of team approach
- Lack of follow up
- "Pull out" therapy

By grouping responses, major categories emerged. Most categories are represented on both lists suggesting that both exemplary and not so exemplary practices exist within each service delivery area. Items within major categories are summarized below. Use this information to help you provide better services.

Professional practices

The good news: Respondents from all countries consider a team approach AAC's very best practice. Although the configuration is described differently (e.g., interdisciplinary, transdisciplinary), the concept is a group of experts from pertinent disciplines working together to deliver AAC services. The dedication of service providers is perceived to underlie the success of AAC intervention worldwide.

The not-so-good news: Respondents said single discipline involvement, lack of coordination between service providers, lack of physician awareness, and "self-proclaimed AAC experts" are examples of practices that don't work. In the U.S., respondents have ethical and quality control concerns: a) should a manufacturer and/or their representative be recommending devices directly to families? b) Should professionals designate themselves as augmentative communication specialists?

Clinical practices

The good news: Practices listed underlying the success of AAC intervention are: administrative support; intervention in natural contexts; intense, periodic time blocks with flexible scheduling, and ongoing follow-along.

The not-so-good news: "Not enough time" is a major concern. Other practices that interfere with successful AAC intervention are: "pullout" therapy (working with a client in isolated contexts); lack of follow up, lack of central information and equipment resources, and lack of administrative support.

Equipment

The good news: Loan banks and rentals work! Other practices that work are: manufacturer support of equipment (e.g., toll free numbers) and the equipment itself (e.g., users friendly with lots of options).

The not-so-good news: Quality control issues are being raised about how and by whom equipment is being prescribed and distributed. In countries where communication devices are imported, respondents want better access to equipment, and to repair and maintenance services. Respondents from all countries agree it is not a good idea to fund equipment without funding services that train individuals and their partners to use equipment in various settings. Finally, some professionals are concerned about marketing strategies that raise "unrealistic expectations" about what technology can do.

Funding

The good news: There is little good news here! Professionals from most countries continue to perceive funding of equipment (and services) as a major challenge. Specific items listed were the: time required to procure funding, inconsistency and rigidity of funding sources, limited availability for some populations, and lack of monies for upgrades and equipment maintenance.

Family/consumers

Comment: "Approaches that actively support, involve, and empower families. Others do not," say respondents.

Professional training

The good news: The increased number of knowledgeable professionals in some countries was noted. Educational mechanisms respondents feel work are: on-site training, training by manufacturers, and ongoing training by experts and regional centers. Some U.S. professionals listed the availability of university programs as an asset.

The not-so-good news: Respondents listed one-day workshops among the educational mechanisms that do not work. (Note: it appears training needs to be ongoing). The limited number of trained professionals and lack of sufficient university training programs are seen as barriers to intervention.

Assessment

The good news: Specifically cited as exemplary practices were: needs assessments, ecological inventory of settings, and task discrepancy analysis of communication opportunities. The availability of comprehensive evaluations by experts is perceived positively, but only under certain circumstances, as described below.

The not-so-good news: Long, one-time evaluations carried out at centers without the involvement of professionals from the community and the participation of the consumer and family in the decision-making process are perceived negatively. Other "practices" respondents do not like are evaluations that result in written recommendations only; and multidisciplinary assessments involving several agencies that are not well-coordinated.

"Looking at assessment as a one-shot deal in AAC is na"ive, at best."


The good news: The world-wide disability rights movement, legislative initiatives in some countries, and organizations (i.e., ISAAC and ASHA) are perceived as making positive contributions to AAC service delivery.

The not-so-good news: The lack of public awareness and consumer advocacy is seen as a barrier. Also mentioned were the low expectations of professionals, families and the community. If we do not assume a proactive and a vigilant stance, laws and policies will be made that do not reflect the needs of those with severe communication impairments!

School issues

The not-so-good news: Providing services in the schools without access to persons with expertise, using itinerant services as major sources of support, hit and run consultations, self-contained (i.e., segregated) programs, a lack of consistent AAC training in classrooms, and staff burnout were cited.

Editorial comment: Research activities are seen as positive aspects of AAC service delivery but were mentioned by only a few. I believe it is our growing research base that underlies our "best practices."

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University & Research

Literacy Center for Persons with SSPI: University of North Carolina - Chapel Hill

The Department of Medical Allied Health Professions at the University of North Carolina-Chapel Hill has received a two year grant from the Kate B. Reynolds Health Care Trust to establish the North Carolina Literacy Center: Serving the needs of persons with severe speech and physical impairments (SSPI). Directed by Dr. David Yoder, with David Koppenhaver serving as Associate Director, the mission of the center is to assist individuals of all ages with SSPI to fulfill their literacy learning potential. It is the contention of Center staff that literacy strategies addressing both prevention and intervention can enable individuals with SSPI to read and write at levels commensurate with their cognitive abilities. Goals of the Center are to:

- develop ecologically sound programs of prevention and intervention for individuals with SSPI.
- provide specialized education for parents and professionals who work with this population.
- initiate and sustain inter-agency communication so literacy issues in homes, communities, instructional settings, and vocational environments are addressed.

Research Projects: A number of research activities will be carried out:

1. Interviewing parents of preschoolers and observing as they interact with children during reading of bedtime stories. Staff will determine if and how impairments of speech and physical movement alter or impede this type of social interaction. (D. Koppenhaver, P.J. Cushing, P. Coleman, D. Yoder)

2. Developing and testing intervention strategies that foster more intensive and extensive parent-child interactions to enhance language and literacy learning. Staff will determine the efficacy of a preventive storybook reading program by measuring change in the number and range of questions and comments from children and parents, communication attempts involving use of an AAC device, story understanding and vocabulary of the children, and requesting behaviors by children for more or longer storybook reading sessions. (P. Coleman, D. Yoder)

3. Developing specialized reading materials and supportive learning activities in school-age children with SSPI. An instructional approach that integrates the use of adapted reading materials and supportive activities will be evaluated to determine if children with SSPI increase their knowledge of the functions of print, spelling and word recognition, vocabulary and reading comprehension, written composition, and enjoyment of reading and writing. (P. King-DeBaun)

4. Developing computer and video technology that serves to enable teachers to personalize literacy learning and instruction. The efficacy of intervention using computers and digitizers will be measured by gains made by individuals in spelling and word recognition, vocabulary and reading comprehension, written composition quality, complexity and length, as well as by increases in computer use and independent reading. (J. Steelman)

Educational projects: Staff will conduct workshops and host an annual literacy symposium for parents, allied health professionals, and educators beginning in March 1991. A graduate level seminar for speech language pathologists and literacy specialists who work with SSPI individuals is planned in the summer of 1992.

Under Dr. Yoder's leadership the Department of Medical Allied Health Professions utilizes a transdisciplinary model for educating professionals in health related fields. Masters degree programs in speech-language pathology, occupational therapy, and physical therapy are among those offered. Practicum experiences are available to students with a major interest in AAC. In addition, doctoral students can pursue areas of interest through the Special Education and Literacy Studies Program in the Department of Special Education. A focus on very young children with AAC needs is also possible in cooperation with Dr. Don Bailey. Stipends are available.

For more information, contact Dr. Yoder, Chair, CD# 7120, Medical School Wing E, The University of North Carolina at Chapel Hill, Chapel Hill, NC 27599-7120. Phone: (919) 966-2343
Public laws and policies have a major impact on AAC service delivery around the world. So do the attitudes of citizens about people with disabilities. Although AAC service delivery programs should be referenced to the needs of consumers, they more typically conform to existing structures.

People requiring AAC (and professionals who serve them) depend, to some extent and often concurrently, on multiple government agencies, e.g., Health, Education, and Social Services. Each agency has a different way of doing things. In places where the lead agency is Health Services, medical models of delivery (often with an acute-care perspective) prevail. When Dept. of Education, Local Education Authorities or Social Service Departments undertake a leadership role, many people (e.g., adults) fail to qualify for services.

AAC is often treated like a "hot potato," i.e., no one wants it, because services and equipment cost money. The likelihood is, however, that no single agency can address criteria for AAC service delivery as delineated in Table II.

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### Table II. Service Delivery Criteria

- a team of experts, who keep abreast of instructional and technical developments, and are available within reasonable travelling distance, longitudinally.
- time to do what needs to be done.
- focus that empowers consumers.
- leadership that empowers team members using consensus management strategies, brainstorming, etc.
- built in accountability for all involved with regard to aspects of implementation.
- integration of non-speaking persons in their local community for education, recreation, and vocation. (See ACN issue on this topic, September, 1989.)
- comprehensive life-long management & support.
- mechanisms to support communication partners.
- access to equipment.
- ongoing mechanisms for judging the process and outcome of intervention. (See ACN, May, 1989.)
- flexibility so as the consumer, living environment, and technologies change, so will AAC intervention.

### Government Effects on Structure, Process, & Outcome of Services

Government agencies provide structure to AAC service delivery. For example, they may designate (or recognize) certain places as centers or people as experts and/or compile lists of approved equipment. Professionals then, carry out the process of assessment, prescription, training, and in some cases dispensing of equipment. For example:

- Sweden has 35 mobility/communication centers as well as regional resource centers. They provide services and support to consumers and professionals. Professionals who work at designated centers prescribe communication aids from approved lists.
- The United Kingdom's original 6 Communication Aid Centres have nearly doubled. Located in large population areas, they reflect local needs and funding realities. Although they meet annually, the process of delivering services varies. "Link therapists" receive training from center staff and work directly with consumers in their communities, are a component of some centers. An important study is being carried out by the Dept. of Health in the U.K. They are looking at the quality of services provided by the centers and the cost effectiveness of equipment and services.
- Ontario, Canada has a network of 14 centers designated by the Department of Health to carry out AAC related functions, including the delivery of services and prescriptions for approved equipment. As in other areas, education of community personnel and families is a major component of their system.

In Australia, the U.S., and Canada, practices vary. Each state or province "does it their own way" (or doesn't do it!). Providing services or equipment through a local agency, for example, often requires physician involvement. Within educational agencies, on the other hand, Department of Education (from the national to local level) provide services and buy equipment. Many examples can be found in Australia. For example, in Pennsylvania, the Assistive Device Center (funded by the State Department) loans equipment to students (short or long term) after the appropriate assessments from local augmentative communication specialists. However, in areas, personnel who may (or may not) have experience in AAC, are expected to recommend communication aids that are then purchased by administrators, who often have no information about the equipment or the student.

The service delivery problem to solve in AAC is not what equipment to recommend, but how to promote the growth of expertise and support needed to implement plans in the community. Structures and processes that address these elements of delivery programs are more likely to result in successful outcomes.

Models of service delivery describe how services are provided. Authors may use different terms; however, the concepts depicted are similar.
Administrators may not support team approaches and may expect professionals to deliver services in traditional ways, which are not effective in AAC intervention. Disadvantages are community resource personnel feel isolated, "burn out," and become frustrated with the lack of local support. Also, equipment may not be available.

Collaborative: The wave of the future. Advantages are mostly conceptual at this time because few models are in place. Practitioners strive to empower consumers and families by drawing on expertise and support from multiple agencies, institutions, etc. Realities are administrators MUST be supportive. This approach requires management by consensus and formalized procedures that drive the intervention process. Success is determined by measuring functional outcomes and consumer satisfaction. Disadvantages are related to problems encountered encouraging interagency agreements and professional collaborations.

Service delivery options that reflect best practices

Alternative models promise workable options for both professionals and consumers. Consider these varied examples:

1. Speech-language pathologists, educators, occupational and physical therapists, and rehabilitation engineers in private practice are delivering AAC services across environments. This professional option (originally described in AAC by Dr. Marilyn Buzolech) enables "experts" to provide community-based intervention and education. Accountability and credentialing issues are being raised. How is the public (and funding agencies) to judge who is (and is not) qualified to provide AAC services and under what circumstances?

2. In Canada, the Hugh MacMillan Center's Augmentative Communication Service (ACS) is implementing a new collaborative model linking their central resource to community-based programs. Here's a sketch of how it works. All clients and facilitators are contacted yearly to outline upcoming service needs. Each client is assigned to a level of service for that year:

   - Full service: those requiring substantial support;
   - Select service: those with fewer, well-defined needs;
   - Indirect service: those with minimal needs
   - No service

For those requiring services, the client, ACS staff, facilitator, and local team meet to set priorities and develop a service plan and timeline for the delivery of services. Community agencies supporting these individuals determine levels of services available locally for the client. A plan is developed, written down, and signed by those involved. This approach provides Centre staff with a relatively fixed caseload. Preliminary results? Staff are expressing greater job satisfaction. Consumers and facilitators are progressing faster because adequate support is provided.

3. I am currently working with the Berkeley school district in California to develop and evaluate a collaborative model of delivery. Goals are to insure students who have AAC needs achieve within their educational and vocational curriculum, empower families, develop professional expertise within the district, and facilitate linkages among community agencies and professionals who are or will be involved with each child. Each child's team meets regularly (e.g., monthly) to generate an Action Plan (see Table IV. for an example). This process builds in accountability and literally drives the team through each phase of intervention (screening and assessment, communication system development and implementation, expansion and independence, and integration and growth.) After 1 year, functional student outcome and consumer satisfaction measures suggest we are on the right track!

Final Comments: Advocacy, accountability, and interagency cooperation are the major challenges professionals and consumers face in countries around the world. AAC leaders (see list of resources and references) are working hard to encourage government agencies, professionals, and institutions to cooperate and collaborate. You can help! Because all governments have limited resources and a myriad of special interests trying to capture "their fair share," advocacy and education are required if AAC service delivery is to improve. Working together, costs can be "effective," duplication of efforts will diminish, and a continuity of services may be provided to a greater number of citizens in need of AAC.

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### Table IV. SAMPLE ACTION PLAN FORMAT

| Robin Billes - 7/90 |

| List of communication needs | Team members |

| GOAL 1: Increase active participation in class |

| Plan | Who | When | How Measured | Status |

| Obj a | SLP 9/10/90 Take baseline --- |

| Obj b | OT/Aide 9/5/90 Checklist Set up & teacher workstation |

---

"Finding monies so consumers can purchase equipment" was the concern mentioned most often by those responding to the ACN survey. An old, familiar problem. Is it getting any better?

Responses to the question "What are the 3 most common funding sources of AAC related equipment in your country" are discussed below:

- Funding for AAC equipment comes from a variety of sources.
- Children: When responses from each country were rank ordered, the top 3 funding sources were:
  - U.S. - Private insurance, clubs, public schools
  - Canada - Provincial government, clubs, public schools
  - U.K. - State/local governments, clubs, public schools
  - Australia - National government, family savings, state government

Public schools and the "state" are perceived to be assuming a major responsibility for funding. When compared to past information, a positive trend toward more reliable funding sources may be emerging. 14

- Adults: Rank ordering responses from each country for adults, the top 3 sources noted were:
  - U.S. - Private insurance, family savings, public insurance
  - Canada - Clubs, private insurance, family savings
  - U.K. - Clubs, state government
  - Australia - Clubs, savings, national government

Clubs, family savings and insurance continue to be major funding sources for adults. Unfortunately these resources are less reliable that institutional or governmentally supported programs. Respondents perceive that adult services are not well supported by formal structures.

- Insurance, both private and public, seems to be becoming more of a resource to consumers. If so, this represents an improvement. 15

AAC professionals, consumers, and manufacturers have been actively advocating to improve the funding picture. 16 Looks like the work may be beginning to pay off!
Augmentative Communication News

Selected Reading List


Your References and Resources


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Please forward