Augmentative Communication News

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Professionals who work in the area of augmentative and alternative communication (AAC) have grown increasingly familiar with the needs of people who have cerebral palsy, amyotrophic lateral sclerosis, autism, Down syndrome, aphasia and head injury. These diseases and conditions are commonly associated with severe communication impairments.

This issue focuses on a condition less frequently encountered—Angelman Syndrome (AS). Children and adults with AS usually lack speech; and most comprehend more than they can express. Like other ambulatory individuals with communication impairments and severe mental retardation, these individuals require our help, but have only recently begun to receive our attention.

For Consumers describes characteristics of individuals with AS. **Clinical News** summarizes what is known about the clinical course of AS across the life span. It also hypothesizes ways AAC may improve communication outcomes. The **Equipment** section suggests how and when technology might be introduced to children and adults with AS. **Governmental** covers the growing network of AS Support Groups, which *(cont. on page 2)*

For Consumers
Angelman Syndrome & AAC

The history of medicine is full of interesting stories about the discovery of illnesses. The saga of Angelman Syndrome is one such story. Dr. Harry Angelman reflects:

"It was purely by chance that nearly 30 years ago, three handicapped children were admitted at various times to my children's ward in England. They had a variety of disabilities; and although at first sight they seemed to be suffering from different conditions, I felt that there was a common cause for their illness. The diagnosis was purely a clinical one because in spite of technical investigations, which today are more refined, I was unable to establish scientific proof that the three children all had the same handicap. In view of this, I hesitated to write about them in the medical journals. However, when on holiday in Italy, I happened to see an oil painting in the Castelvecchio museum in Verona called a *Boy with a Puppet.* The boy's laughing face and the fact that my patients exhibited jerky movements gave me the idea of writing an article about the three children with a title of *Puppet Children.* It was not a name that pleased all parents but it served as a means of combining the three little patients into a single group. Later the name was changed to Angelman syndrome. *(cont. on page 2)*

"They had a variety of disabilities; and although at first sight they seemed to be suffering from different conditions, I felt that there was a common cause for their illness."

UPFRONT *(cont. from page 1)*

are strong advocates for addressing the communication needs of people with AS. Finally, the **University/Research** section raises research questions that can provide information needed by families and the professionals who work with these individuals. Thanks to all interviewed for their thoughtful insights. See **Your Resources**, page 8.

Enclosed is information about **Alliance '96,** *Outcomes Measurement: Next Steps in AAC and Assistive Technology*. Conference dates are February 16 - 19, 1996. Space is limited and on a first-come, first-served basis. If you plan to participate, please fill out the enclosed form and mail it immediately. Get your name on the participant list, so you won't be disappointed.

The **Alliance '95** Outcomes in AAC Conference Report is available for *$22 US plus shipping and handling*. This easy-to-read report contains lots of information about outcomes management in AAC and captures the ambience of the conference on beautiful Monterey Bay.

Recent months have required far more travel than usual, which accounts for the delay in mailing this issue. And, it's not over yet. I'll be gathering information for upcoming issues of ACN during October when I'm in Portugal speaking at the ECART Conference. In December, I go to the ASHA Convention in Florida. In January, I'm off to Chile for the AAC Iberoamerican Conference. I'll be at the Center for Literacy and Disability Studies Conference in North Carolina on January 25-26.

Sarah W. Blackstone, Ph.D.

For Consumers *(cont. from page 1)*

"This article was published in 1965 and, after some initial interest, lay almost forgotten until the early 1980s. In fact many doctors denied that such a condition existed. In the past ten years, American and English doctors have placed the syndrome on a firm footing with the ability to establish the diagnosis beyond doubt. . . "[1]

Reading Dr. Angelman's story leads us to note that:

1. Observations by practicing clinicians often are ignored (or devalued) by academicians and researchers, but are critical to perceiving and unraveling important questions and information. In this case, Dr. Angelman's hunch that three children shared a common cause for their disabilities was right, but not confirmed for almost two decades.
2. New technology and medical procedures now exist that can confirm the existence of syndromes caused by chromosomal and genetic abnormalities. This means the field of behavioral neurogenetics, which combines areas of genetics, neuropsychology and neuropsychiatry, is leading us toward an understanding of the biological basis of behavior. The field is of growing interest because it provides a "window to the understanding of a broader spectrum of learning and developmental disabilities."[2]
3. Identification of congenital conditions that place children at high risk for severe communication impairments (like AS) should compel AAC professionals to develop plans that result in better communication outcomes across the life span.[3,4] Successful AAC interventions are likely to enhance other outcomes as well (*e.g.*, social relationships, independence, community participation, employment and the individual's sense of well-being).

Characteristics of AS

AS is always associated with mental retardation (functionally severe), a nearly total lack of speech, a movement or balance disorder (unsteady, widely based gait, stiff, ataxic movements, fine motor problems), and unique behaviors (*e.g.*, inappro-priate bursts of laughter and hyperactivity).[2,5-8] Individuals with AS usually are microcephalic by age three years. Many have seizures and abnormal EEGs. Other characteristics are:

- hypopigmented skin; light hair and eye color
- heat intolerance; excessive sweating
- flattened back of head
- protrusion of the tongue with prominent jaw, wide mouth
- small, widely spaced teeth
- drooling and oral motor problems
- feeding problems during infancy
- strabismus (crossed eye)

Prevalence

The incidence and prevalence of AS remains unknown. Reasons are: (a) the diagnosis often isn't made until after age three, (b) many professionals are still unaware of the syndrome and (c) confirming the diagnosis requires identification of clinical findings, EEG studies, chromosome analysis using *in situ* hybridization techniques, and molecular studies.[2]

To date, more than 300 patients with AS are reported in the literature.[6] According to the AS Foundation, over 800 individuals with AS have been identified in the US and Canada. It seems likely that thousands more people remain undiagnosed or misdiagnosed as having cerebral palsy, Rhett syndrome, autism or other developmental disorders.[5]

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Genetics

Males and females are equally affected. Four classes of AS are identified.[8,9]

- Type I (60-70%) - a deletion on chromosome #15, of maternal origin
- Type II (2-5%) - two copies of chromosome #15, from their fathers (uniparental disomy)
- Type III (2-5%) - abnormal DNA methylation pattern
- Type IV (20-35%) - genetic change not yet identified

Familial cases exist in Types III and IV. Some types seem to be associated with higher cognitive and better motor functioning than others.[8,9]

Note: Prader-Willi Syndrome (PWS) also results from deletions on chromosome 15, of paternal origin. PWS is associated with mild to moderate mental retardation, obesity, short stature and hypogonadism. Prevalence is 1 in 10,000 births.[10]

Communication challenges

People with AS have greater receptive than expressive language abilities. Both speech and nonverbal communication are affected. Dysarthria and atypical facial expressions, intonation and gestures can make communication acts difficult to interpret. A recent review article noted:

> In AS, the absence of speech is not solely dependent on the level of MR. It is also related to social interaction and oral-motor development.[11]

Researchers also report variations in cognitive, language, social and oral-motor abilities in severely retarded adults with AS.[4] Some articles mention the use of AAC techniques (*e.g.*, language boards and manual signs).[11,12] However, despite the well-documented existence of severe communication impairments, we were unable to find any article that discusses the AAC management of communication problems in persons with AS across their life span.

Clinical News

AS & AAC across the life span

Two significant facts emerge from available descriptions of the clinical course of individuals with AS: (1) they rarely, if ever, develop functional speech, and (2) they seem to have a normal life expectancy. To date, we have limited information about what AAC strategies and devices are helpful, when these should be introduced, and how they should be taught. This article (and the **Equipment** section on page 6) suggests a framework to address AAC intervention issues with persons who have AS. Suggestions are anecdotal and/or hypothetical. They are not based on research or extensive clinical experience. This article simply offers a place to start. Readers are invited to react, offer suggestions, agree and disagree.

Table I summarizes ages and stages of life that roughly parallel those described in the literature. A quick glance reveals that information about adulthood is sparse. Each category in Table I (*i.e.*, General Characteristics, Description of Communication, Desired Outcomes and Strategies for Supporting Families and Caregivers) is discussed in more detail below.

Pregnancy and Birth

The perinatal history of individuals with AS is often unremarkable. Genetic counseling for those who have children with AS is available, although there is no increased chance of recurrence in Types I and II. Prenatal identification of AS for Types III and IV is not yet available. Chances of giving birth to another affected child (in the same family) may be as low as 1 percent or high as 50 percent.[8,9]

Birth to 1 year: Infancy

Although the diagnosis of AS is rarely made until later, behavioral and physical problems emerge during this period. The head circumference begins to fall below normal ranges; and infants may develop seizures. Hypotonia and delayed motor milestones are evident by 6 to 12 months. Some babies are thought to have cerebral palsy. Feeding problems include difficulties sucking and swallowing and frequent spitting up. Strabismus may be noted.[6,7,13]

Description of communication

All development is delayed. Oral and speech motor problems underlie, to some extent, delays in cooing and babbling. Oral motor problems include feeding problems, abnormal tongue thrusting and excessive drooling. Early social smiling as well as giggling and unprovoked "chortling" may occur in some babies.[6,7,13] Even if a diagnosis of AS is made during the first year (and it rarely is), doctors are unlikely to refer babies to a communication specialist. Doctors and families may find these guidelines useful:

Desired outcomes for infants. (a) Engage in soundplay; (b) Take turns and interact with people and objects; (c) Respond and initiate interaction using signals, *i.e.*, vocalizations, gestures, facial expression, body language; (d) Develop a small repertoire of signals, recognizable to caregivers.

Supporting caregivers. Professionals should: (a) answer all questions regarding speech and language development; (b) reassure families their child will be able to communicate, even if speech never develops; (c) help primary caregivers recognize the infant's signals, both vocal and gestural.

1-3 years: Toddler

Developmental delays in all areas are evident. A neurologic exam may reveal microcephaly, ataxia, seizures, *(cont. on page 4)*

TABLE I. Angelman Syndrome and AAC Strategies: A Lifespan Approach

Age & Stage	General characteristics	Description of communication	Desired outcomes for persons with AS	Supporting families and caregivers: AAC strategies
Infancy 0 - 12 months	Feeding difficulties. Developmental delays in all areas. May develop seizures.	Cooing, babbling delayed. Social smiling/laughing atypical. Cognitive delays.	Engage in soundplay. Interact with people and objects. Respond and initiate interaction. Develop a small repertoire of signals, which are recognizable to caregivers.	Offer information. Introduce to support organizations. Teach to encourage sound play, use signals and engage in turn-taking. Train to use co-active movement approach.
Toddler 1 - 3 years	Developmental delay, Microcephaly, ataxia, seizures, hyperactivity. Not yet walking. Restricted play.	Lack of speech, oral/ speech motor problems. Limited attention span. Cogntive/ receptive language delays less severe than expressive delay	Engage in turntaking and soundplay. Use signals, initiate, respond. Enjoy interaction with caregivers.	Provide information. Reassure family AAC interventions do not inhibit speech or mean professionals "give up on speech." Help caregivers recognize signals.
Preschool/ Early Childhood 3-8 years	Severe delays. Ataxia and instability, fine motor problems, Limited attention, sleeping problems, mouthing. Restricted play, seizures, hyperactivity.	Everyday, use objects, pictures, ommunication books, VOCAs, calendar boxes, remnant books to interact with adults and same-age peers.	Use signals, symbols to express various communicative functions. Enjoy interacting. Use a VOCA. Use computers to participate in learning and play activities with peers. Participate in adapted school curricula.	Teach caregivers to help children interact with toys and people and establish symbolic value of real objects and photographs/pictures if child shows interest. Model functional use of simple VOCA during activities.
Childhood 8 - 21 years	Severe delays, gradual improvement. Sexual maturation a bit delayed. Tremors. Behavior problems (attention, sleep, hyperactivity).	Use AAC aids and devices (see above) in everyday interaction with adults and peers. Use other tools (*e.g.*, computer) to participate in activities with same-age peers.	Participate in school and community activities. Engage in interactive, recreational activities. Express emotions using appropriate AAC techniques. Have friends.	Actively support the use of communication books, devices, and computers. Teach ways of expressing a range of communicative functions. Interpret challenging behavior as communicative.
Adulthood 22^{+} years	Individuals tend to "calm down." Fewer bursts of laughter. EEG pattern improves. Some now prefer wheelchairs. Health generally good.	Little information about communication available.	Work and live in the community. Have friends. Communicate feelings, thoughts, ideas. Use the phone. Continue to learn new things. Be supported in ways that enable person to make real choices re: activities, food, clothes, hobbies, friends, and so on.	Support the use of AAC devices. Advocate for interventions that continue to address functional communication skills. Expect individuals to communicate using language as well as their already well-developed idiosyncratic signals.

Clinical News *(cont. from page 3)*

an abnormal EEG and possible atrophy of the cortex on MRI or CT scans. Professionals identify a variety of behavioral concerns including hyperactivity, excessive laughter, mouthing, a short attention span, motor problems, general developmental delay and a lack of speech. Children rarely walk during this stage; fine motor skills also are delayed. Tactile hypersensitivity is noted in some. Play skills are restricted.[6-8, 15]

Description of communication

Significant oral and speech motor delays, as well as severe cognitive delays underlie the lack of speech. Immature babbling, periodic shrieks or screams and one or two apparent words may be used indiscriminately and inappropriately. Expressive language and speech delays are more severely affected than the child's understanding of language. Communication is made even more difficult because intonational patterns, facial expression and body gestures may not express clear communicative intent. Professionals and families should introduce AAC strategies (and simple technologies) to children with AS. Their prognosis for speech is quite guarded.[3,6-8,12,14-15]

Desired outcomes for toddlers. (a) Engage in soundplay; (b) Use signals (gestures and vocalizations) to communicate; (c) Make choices and requests, initiate interaction, respond, and reject, using signals recognizable to caregivers; (d) Engage in turntaking; (e) Demonstrate understanding of cause/effect; (f) Interact with some objects in a meaningful way; (g) Enjoy interaction with caregivers.

Supporting caregivers. Professionals should: (a) answer all questions honestly and provide information about neurogenic speech problems; (b) discuss how AAC techniques can help; (c) reassure the family that AAC interventions do not inhibit speech development or mean professionals are "giving up on speech;" (d) help primary caregivers recognize signals and establish a repertoire of signals, both vocal and gestural; (e) begin to introduce simple technology.

3-8 Years: Preschool/Early Elementary

Walking is a major theme during this period. However, ataxia may preclude independent ambulation until a later stage, and hyperactivity and instability place these children at risk for injury. Sleeping problems are frequently noted. As a result, families generally construct a special "safe" room for their child. Cognitive and fine motor problems interfere with play, so toy adaptations are almost always necessary. Seizures continue, and, in some children, management can be difficult.5-6,15-16

Note: By 8 years of age most children who develop seizures will have done so.

Intervention generally occurs in the school setting, with self help skills, toilet training, communication and play the focus. A team approach is recommended. Patience and flexible, functional training programs are needed.[3-6,12,14-15]

Description of communication
Some children (39%) are reported to use a few words (4 or less) starting at a mean age of 3.8 years; however, dysarthria continues to preclude functional speech. Protrusion of the jaw and the wide mouth may become more pronounced, but less tongue protrusion may occur. For many, fine motor and cognitive problems result in a limited use of intelligible signs/gestures. To access language, these children generally need to use AAC aids and devices.[3-6,12,14-17]

Desired outcomes for children. (a) Understand signals (gestures and vocalizations) and some symbols (real objects, photographs, adapted signs); (b) Use a calendar/schedule box; (c) Express a variety of communicative functions using signals and symbols (*e.g.*, make choices, initiate interaction, request, express emotions, refuse); (d) Enjoy interacting; (e) Interact with peers; (f) Participate actively in school curricula that accommodate cognitive, motor, language, and cognitive disabilities.

Supporting caregivers. Professionals should help families: (a) encourage children to explore and interact with toys and people; (b) participate in activities at home and in school; (c) recognize idiosyncratic signs and body language as a primary means of expression; (d) establish the symbolic value of object symbols. (Note: Miniature objects are not recommended as long as child puts objects in his/her mouth; (e) begin to pair objects with photographs and pictures if child shows an interest.)

Childhood: 8 - 21 years

Gradual improvement occurs and children continue to learn, but at their slower pace. Tremors may occur and be secondary to anti-epileptic drugs. During adolescence, sexual maturation may be somewhat delayed. Behavior and sleep problems are noted.[6,7,11,15-16]

Description of communication
Bursts of laughter occur in approximately 72% of patients in certain situations (after convulsions, during menstruation, in new situations). Drooling, chewing and licking of objects are still noted. As speech does not develop, the use of AAC techniques grows ever more critical. A survey of 179 families (with approximately half of the children in this age group) reports that the "majority of these children communicate intimately using sounds, hand-over-hand, and gestures. In a school environment electronic communication is favored."[6,11,15-17]

Desired outcomes for children and youth. (a) Participate in school and community activities using AAC techniques, strategies and devices; (b) Engage in interactive recreational activities for increasing lengths of time using adapted equipment; (c) Use a calendar/schedule box, conversation book and remnants; (d) Express needs, preferences and emotions using appropriate AAC techniques; (e) Have friends; (f) Develop skills increasing the likelihood of living in a community and doing meaningful work; (g) Learn about using the phone.

Supporting caregivers. Professionals should: (a) expect continued improvement and increasing independence in communication; (b) interpret challenging behavior as communicative; (c) teach socially appropriate ways of expressing a range of communicative functions; (d) actively support the use of communication books, devices and computers. (Equipment must be rugged and protected as individuals can be "very rough on it.") (e) acknowledge person's efforts and frustrations; (f) deal with issues that affect all adolescents (*i.e.*, sexuality, independence, confusion, peer relationships); (g) make every effort to provide age-appropriate materials and activities; (h) encourage child's independence.

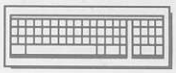
Adulthood: 22^{+} years

Individuals with AS tend to "calm down and have less bursts of laughter" as they grow older. EEG patterns also tend to improve. Major characteristics are a lack of speech, mental retardation, happy disposition, and ataxia. Some older patients refuse to walk after discovering the comfort of a wheelchair. Adult patients studied were in excellent general health except for thoracic scoliosis reported in elderly patients (predominantly females), which can result in cardiorespiratory problems. The oldest patient described in the literature is 76 years old. Many adults with AS probably remain undiagnosed.[6,8]

Description of communication
Functional communication continues to be the key issue throughout adulthood. Unfortunately, case reports that focus on adults with AS are lacking. However, the general trend is for adults with mental retardation to reside in group homes and work in their communities. To do so, they will require adequate support and independent, functional communication skills.[6,8,18,19]

Desired outcomes for adults. (a) Work and live in the community with support; (b) Be supported in ways that enable person to choose activities, food, clothes, hobbies, friends, and so on; (c) Communicate feelings, thoughts, ideas; (d) Have friends; (e) Continue to learn new things; (f) Use the phone.

Supporting caregivers. Professionals should (a) support the use of AAC devices; (b) advocate for interventions and living situations that address functional communication skills; (c) expect individuals to communicate using language, as well as their well-developed idiosyncratic signals; (d) expect continued improvement and increasing independence in communication.



Equipment

Low and high tech strategies

What assistive technology can we expect individuals with AS to use to communicate during their lives? What devices and strategies should AAC specialists recommend to families? These and other questions remain unanswered (see **University/Research** for more discussion).

The literature supports the use of communication aids, at least with children. Nevertheless, Miller's recent report on 176 families who are raising children with AS[15] revealed that while most children use signs and gestures, only forty percent (40%) use picture boards and only twenty percent (20%) use electronic communication devices. An additional thirty-eight percent (38%) reportedly use "other" non-electronic techniques. According to people I interviewed, even children who have devices may not use them functionally to communicate. Table II focuses on communication outcomes that may be achieved using AAC aids, devices and other assistive technology. Listed are examples of low and high tech strategies that, when introduced using a functional intervention approach, may improve the interaction experiences of persons with AS and their communication partners. It seems likely that AAC aids and devices (both electronic and non-electronic) can enhance the communication ability of individuals with AS, which may, in turn, enable them to participate more actively in their school, home and work settings.

It is important to keep in mind that desired outcomes for adults are the sum of desired communication outcomes for infants, toddlers, preschoolers, school-aged children and adolescents. The framework summarized in Tables I and II represent a continuum that relates what we do today to what we do tomorrow.[20] Therefore, suggestions are not to be perceived as strategies appropriate only for discrete ages and stages. Rather, each age and stage builds upon the next.

TABLE II. Helping people with AS communicate using assistive technology

Age & Stage	Description of communication	Desired outcomes	Low-tech strategies (non-electronic)	High-tech strategies (electronic)
Infancy 0 - 12 months	Cooing, babbling delayed. Social smiling/laughing atypical. Cognitive delays.	Interact with caregivers using recognizable signals. Respond and initiate.	Stable positioning is important for face to face communication. Commercially available products applicable.	Shine flashlight on caregiver's face to encourage facial contact and visual attention.
Toddler 1 - 3 years	Lack of speech, oral/ speech motor problems. Limited attention span. Cogntive/receptive language delays less severe than expressive delay.	Use simple switches to activate toys, turn on/off appliances and express simple messages. Begin to attach meaning to objects. Enjoy interaction.	Use objects as symbols to make requests, choices. Present objects on choice boards and encourage child to make choices.	Use simple switches to activate toys, turn on/off appliances and express simple messages (*e.g.*, coo, babble, or "do it again" using loop tapes, Big Red switch, Voice Pal).
Preschool/Early childhood 3-8 years	Dysarthria precludes functional speech. Difficult to interpret signs, gestures & facial expressions. Cognitive delays.	Everyday, use objects, pictures, communication books, VOCAs, calendar boxes, remnant books to interact with adults and same-age peers.	Begin to pair two-dimensional symbols (photographs, simple pictures) with preferred objects when child shows interest. Use calendar box throughout day.	Caregivers become familiar with simple VOCAs and use with child on a daily basis. Also appropriate computer software can be introduced.
Childhood 8 - 21 years	Idioscyncratic gestures. Bursts of laughter, drooling, chewing, licking. Behaviors can interfere with using AAC devices. (See above.)	Use AAC aids and devices (see above) in everyday interaction with adults and peers. Use other tools (*e.g.*, computer) to participate in activities with same-age peers.	Continue to expand functional communication by using objects and context-specific mini-boards and communication books, calendar boxes, remnant books, conversation books. Use them to teach, as well as help child/youth express language.	If the need for messages increases, consider using Macaw, Parrot, AlphaTalker, WalkerTalker, Message Mate, Digivox. These VOCAs offer from nine to hundreds of messages and digitized speech.
Adulthood 22^{+} years	Little information about communication available.	Have necessary communication skills to reside and work in communities when supported. Have friends.	Depending upon representational level, use a combination of communication boards/books, schedule boards/books.	The above devices can be considered. In addition, the phone and computer may be useful.

MANUFACTURERS OF DEVICES MENTIONED ABOVE

AbleNet, 1081 Tenth Avenue, S.E. Minneapolis, MN 55414. 800-322-0956
Adaptech, Inc., ISU Research, 2501 N. Loop Dr., Ames IA 50010. 800-723-2783
Prentke Romich Co., 1022 Heyl Road, Wooster, OH 44691. 800-262-1984
Sentient Systems, 2100 Wharton St., Ste 630, Pittsburgh, PA 15203. 800-394-1778
TASH, Inc., Unit 1, 91 Station St., Ajax, Ontario, L1S 3H2, Canada. 905-686-4129
Toys for Special Children, 385 Warburton Ave., Hastings-On-Hudson, NY 01706. 800-832-8697
Word+, Inc., 40015 Sierra Hwy, B-145, Palmdale, CA 93550. 800-869-8521

VOICE OUTPUT COMMUNICATION AIDS (VOCAs)

Speak Easy, Big Red Switch
Voice Pal with Taction Pads
WalkerTalker, AlphaTalker
Digivox
SwitchMate 4; ScanMate
Cheap Talk 4, Say It Switch Plate
Message Mates

Governmental

Support groups for persons with AS

Angelman Syndrome is receiving increased attention due to the existence of local and national AS groups, supported, at least in part, by government funds.[5,11,21]

According to Frank McCullough, newly elected President of the Angelman Syndrome Foundation, Inc. (ASF) in the United States, the first AS group was founded by families in England where Dr. Angelman carried out his initial work.[21] In North America, cases of AS were not diagnosed until the 1980s, when Dr. Charles Williams of the University of Florida–Gainesville began to recognize and diagnose individuals with AS. Today AS has "emerged as one of the more common identifiable syndromes of ataxia, mental retardation and severely diminished or absent speech."[8]

AS foundations and support groups educate and support parents and professionals in many countries throughout the world (see partial list on page 8).

Currently, a major focus of AS support groups is communication. A videotape about communication issues in AS, *Promoting functional communication in children with Angelman Syndrome*, featuring AAC's own Dr. Stephen Calculator, is available from the AS Foundation for $25 US. Two excellent publications listed below also are available from this group (free to members):

- *Angelman Syndrome.* A 25 page comprehensive, state-of-the-art report on all aspects of AS. Currently in press for Current Problems in Pediatrics.
- *Angelman Syndrome: A Parent's Guide.* This practical, informative guide is based on a survey of 179 families and written by the parent of a child with AS. The survey covers classroom settings, medications, communication strategies, respite care, vacation ideas, meal choices, toys and entertainment preferences for children with AS.

University/Research

What are the questions?

Few research studies describe the communication characteristics of persons with AS in any detail. Even fewer mention intervention strategies. Thus, many questions remain unanswered about the communication support needs of persons with AS across the life span. Most individuals now identified as having AS are still children. Many speech-language pathologists and AAC professionals are still unfamiliar with AS, and the majority of adults with AS are probably still undiagnosed. Therefore, we have a long way to go before we understand (1) the clinical course of this syndrome and (2) the most efficacious ways to provide AAC intervention. Talking with colleagues about this population generated the following list of research questions:

- How can we support families more effectively, given that communication is often their major concern?
- How homogeneous is this population? For example, is the range of cognitive, language and motor skills broader than currently reported? Does speech ever develop? To what degree? Do differences correlate with type of AS?
- If the group is more heterogeneous than currently reported, are there ways to predict who will do better with what types of AAC interventions?
- Can we accurately predict the degree of communication impairment? Can we do this based on type of AS alone? What are important contributing factors?
- What are the kernel communication issues in infancy and early childhood? In school-aged children? In adolescents? In young, middle-aged and elderly adults?
- What is the efficacy of different kinds of AAC intervention with this population, *i.e.*, are there substantial differences in the types of communication generated with and without communication devices? with and without communication books?
- What is the impact of AAC intervention in meeting the communication needs of children and adults with AS over their life span?
- What are the outcomes of AAC intervention if measured at the World Health Organization's level of impairment? Of disability? Of handicap? How should we measure communication outcomes?
- How can we develop an integrated communication and educational program for individuals who have AS?
- How can we most effectively manage challenging behaviors in persons with AS?
- What are variables that predict success in inclusionary classroom settings for children with AS? In group living situations for adults with AS? In supported work environments for adults with AS?
- When and how should we introduce symbolic communication (tangible objects, signs, photographs, pictographs) to children with AS?
- What types of assistive technology are effective? When and how should voice output communication aids (VOCAs) be introduced?
- Given that individuals with AS are reportedly "tough" on adaptive equipment, how can we decrease the likelihood that difficult behaviors limit their access to VOCAs?
- What impact does a VOCA have on the opportunities and active participation of individuals with AS?

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Angelman Syndrome Support Groups

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  PO Box 12437
  Gainesville, FL 32604 USA
  Phone: 904-332-3303
- **Angelman Syndrome Support Group**
  15 Place Crescent
  Waterlooville
  Hants, PO7 5UR
  United Kingdon
  Phone (01705) 264224 or (01705) 385566
- **Canadian Angelman Syndrome Society**
  PO Box 37
  Priddis, Alberta T0L 1W0
  Canada
  Phone: 403-931-2415
- **National Angelman Syndrome Association**
  PO Box 554
  Sutherland 2232
  New South Wales
  Australia
  Phone (02) 587-2444

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YOUR RESOURCES

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