Augmentative Communication News

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INSIDE THIS ISSUE . . .

UPFRONT

People with cerebral palsy (CP) face major challenges and barriers every day of their lives. The field of augmentative and alternative communication (AAC) is focused on meeting their communication needs. It is widely recognized that one of the most significant developments for individuals who have CP has been AAC symbols and devices. Computers and voice synthesizers are enabling people with little or no speech to communicate.[1]

In preparing this issue, I interviewed individuals with different perspectives. They are listed on page 8. Thanks to each for sharing their time, expertise, and insights. **For Consumers** reviews facts and figures about CP and major issues confronting individuals with CP today. Also discussed is what the term CP means. **Clinical News** considers what the field of AAC has done for people with CP and what it should do in the future. The **Equipment** section considers a wish list of device features. **Governmental** shares information on the International Cerebral Palsy Society. Finally, **University/Research** focuses on drooling—a problem for many individuals with CP who use AAC.

If you registered with us for 1993 ASHA CEUs, you should receive a quiz with this issue. If you didn't get one (and signed up for CEUs), please call us immediately. If you still want to register for ASHA 1993 CEUs, it is not too late. In addition to the subscription rate,

(cont. on pg. 2)

For Consumers

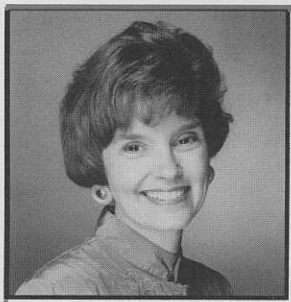
We must play the cards we are dealt

While it is clearly true that we must play the cards we are dealt, people with cerebral palsy (CP) often have not even been allowed in the game. Many continue to confront barriers that preclude their access to other people and to educational, social and health care systems.

CP is a life-long condition, affecting at least 15 million people throughout the world.[4] CP is an "umbrella" term used to describe a group of non-progressive disorders of movement and posture caused by a defect of, or injury to, the developing brain[5] before the age of five years when the brain is nearly matured.[6] In most cases (90%) the damage is caused by factors that take place early in pregnancy (rather than late), at the time of labor and delivery, or during the first 28 days of life. Comparably few children (10% or less) develop CP after the first month of life.[7]

The prevalence of CP in industrialized nations ranges somewhere between 1 and 3 per 1000 live births.[6] While most children who have CP (65%) were full-term infants with no apparent complications, many (35%) were low birth weight—under 3.3 lbs or 1500 gms.[8] Epidemiologic studies from many nations[9] (e.g., Sweden,[10] Western Australia,[11] Japan,[12] Finland[13] and the United Kingdom[14]) show the prevalence of CP is increasing, despite the fact that a major cause, hyperbilirubinemia, is now treatable.[1] This is due to the very small premature babies—those under 2 pounds at birth—who survive because of technologically advanced neonatal care. These babies, particularly those born to mothers who are drug addicted or infected with the HIV virus, are 20 times more likely to have CP as normal birth weight infants.[6,9,15] Health care, educational, and social welfare

(cont. on pg. 2)



UPFRONT (continued from page 2)
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<u>'TIS THE SEASON TO BE JOLLY</u>. Another holiday season approaches. Despite your busy life, you'll make time to celebrate with family and friends. I have two stories for you. Both are contemporary parables. The first captures the warmth that hope and healing can generate; the second, a certain wisdom. I think both convey a holiday spirit, and I hope they make you smile.

STORY #1: *A LIGHT IN THE TUNNEL*[2]

A doctor once described working with a young man who had his leg removed at the hip to save his life. He had bone cancer. This man was very angry and full of grief and rage and pain. Using painting, imagery, and deep psychotherapy, they worked for more than two years before the man began "coming out of himself." He then started to visit other people who also had suffered severe physical losses. Once he visited a young woman who was almost his own age. It was a hot day and he came into her hospital room wearing running shorts. Thus, his artificial leg showed. The woman was so depressed about the loss of both her breasts that she wouldn't even look at him. Desperate to get her attention, he unstrapped his leg and began dancing around the room on one leg, snapping his fingers to the music the nurses had left playing to cheer her up. The woman looked at him in amazement and suddenly burst out laughing, saying "Man if you can dance, I can sing"

A year following this incident the man and his doctor sat down to review their work together. During the session, the doctor opened her file and discovered several drawings the man had made early on. She handed them to him. The man looked at them and said, "Oh, look at this one. It isn't finished." He was showing her one of his earliest drawings, a vase he had drawn to represent the image of his body. Through the vase ran a deep, black crack. The doctor recalled how very painful it had been to watch the man as he drew it. He had taken a black crayon and drawn the crack over and over again, saying the vase would never function as a vase again. It would never hold water.

"So" said the doctor, extending the box of crayons, "Why don't you finish it?" The man picked up a yellow crayon. Putting his finger on the crack, he said, "You see, here—where it is broken? This is where the light can come through." And with that, he drew light streaming through the crack. "We have an opportunity to grow strong at the broken places," he said.

STORY #2: *BEING WHERE YOU WANT TO GO* [3]

The rich industrialist from the North was horrified to find the Southern fisherman lying lazily beside his boat, gazing at the sea gulls. "Why aren't you out fishing?" said the industrialist. "Because I have caught enough fish for the day," said the fisherman. "Why don't you catch some more?" said the industrialist. "What would I do with more?" replied the fisherman. "You could earn more money and have a motor fixed to your boat to go into deeper waters and catch more fish. Then you would make enough money to buy nylon nets. These would bring you more fish and more money. Soon you would have enough money to buy two boats...maybe even a fleet of boats. Then you would be a rich man like me." "What would I do then?" asked the fisherman." Then you could really enjoy life." said the industrialist. "What do you think I am doing right now?" said the fisherman.

Have a joyful holiday! Gone fishing *(from the beach)*,

Sarah Blackstone, Ph.D., Author

For Consumers *(cont. from page 1)*

systems need to plan to accommodate more, rather than less children with severely damaged brains, at least for the foreseeable future.[1,9,15]

The Basics

Successful AAC intervention for people with CP requires the participation of specialists who know about an individual's motor patterns and about assistive technology. Basic to all intervention is positioning, seating, mobility, and computer access, as well as communication.[16,17,18]

Several resource books are available to assist families and professionals in learning more about these basic issues. They are listed on page 6.

<u>Motor problems</u>: The exact motor characteristics of each individual are determined by the location and extent of the damage in the brain and must be taken into account during AAC intervention. A popular classification scheme is:[6]

- ☐ **Spastic** (hypertonic) - Subclassified into hemiplegia, diplegia, and quadriplegia. Characterized by tightness of the body musculature. Estimates range from 63%–94% of cases identified.
- ☐ **Ataxia** - Subclassified into congenital ataxia and ataxic diplegia. Characterized by difficulty with rapid and fine movements. Estimates range from 10-15%.
- ☐ **Dyskinetic** - Subclassified into athetoid and dystonic types. Characterized by involuntary and irregular movements. Estimates vary from 6% to 37% of all cases. Athetosis now is rare because hyperbilirubinemia is treatable.
- ☐ **Mixed** - A combination of spastic and athetoid types is most common. Approximately 12% of cases.

<u>Associated problems:</u> When the brain is damaged early in life, the motor system is often not the only system affected. Studies show as many as 82% of children with CP had at least one associated handicap and 42% had three or more.[19] Mental retardation occurs in approximately 60%. Other difficulties include visual perceptual deficits, language difficulties, epilepsy, speech disorders, hearing impairment, and organic behavior disorders.[1,6,20]

The term Cerebral Palsy

Of course! The term means different things to different people. Table I lists the responses individuals gave to the question *"What do you associate with the term cerebral palsy*?" Unedited, these statements capture a range of responses—from the poignantly painful and personalized words of adults and children with CP, to the concern (and lack of information) in the general public. I'm glad I asked. It sure makes it clear we have work to do!

The Top Ten Major issues

As perceived by those interviewed, the major issues faced by individuals with CP are:

1. **Access.** The need for access to people, places, assistive technology, communication, transportation, and so on underlies all major issues. Access issues begin in infancy and extend throughout each person's lifetime. Without access, a person's productivity, income, participation, control, choice, self esteem, independence, ability to learn, communicate and get around are jeopardized.
2. **Inclusion.** People with CP have been, and still are, excluded. The balance of intervention should be skewed toward life in the mainstream, alongside family and peers, both nondisabled and disabled. Peoples' needs can be met where they live, play, work, and learn, rather than in a therapy room or clinic. "People

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TABLE 1. "What does the term cerebral palsy mean to you?" N=30

<table>
<tr><td colspan="2">RESPONSES FROM ADULTS WITH CP: CP sucks! Me (I live it, teach it, work with it). Being smothered, out of control, reviled by others. Feeling miserable because you can never relax your body. A curse, a pain in the ass. Not going out most Saturday nights. Rarely going out socially. Being frightened to ask to be included because you don't want to impose. Painful, embarrassment, frustrated. A blessing because I probably wouldn't be doing what I do otherwise. It's been an education for my children.
RESPONSES FROM CHILDREN WITH CP (ages 7-14): I don't know. No response. Retarded. Like I don't belong in this world. CP means you can't move in a certain way.</td></tr>
<tr><td>RESPONSES FROM PROFESSIONALS: A condition. Movement disorder. A term that doesn't give me a picture of a person. Wide range of disabilities. Increasing population; Dysarthria. Drooling. Majority of AAC users. Adults who are experientially retarded. Illiteracy. Unemployed. Not helped by vocational rehabilitation. Group of people who are persistent, who hang in there. Patient, determined people. Healthy despite their disability. Other people think they are retarded. Poor fitting wheelchairs, poor fitting clothes.</td><td>RESPONSES FROM PARENTS: A gift to me and my large family, but not to her. It's a label we don't use because it doesn't relate to who he is. When I first heard the diagnosis, I only saw people writhing; now, I feel a strong affinity to people with CP . . . as though we share a special secret. Wheelchair. Dependence on others. The United Cerebral Palsy Foundation; People feeling sorry for individuals and their families. A physical condition. Athetoid. Drooling. Limited self-help skills. May or may have communication and/or learning problems. Social inadequacies. Loneliness. A small circle of friends. Employment and education difficulties. Learned helplessness. Skills not developed to full potential. Muscles don't work right. Brain damage. Various abilities and disabilities.</td></tr>
<tr><td colspan="2">RESPONSES FROM THE GENERAL PUBLIC: Bad muscles. Muscular disorder. Handicapped. A crippled child with crutches. Special—can't do some things, but can do others; Sadness.I'm concerned about children with CP. A muscular disorder. People in wheelchairs who can't get around.</td></tr>
</table>

with disabilities don't want a program, they want a life."[21]

3. **Early intervention.** Inclusive child care and preschool programs provide experiences using assistive technology, create opportunities, and build positive peer, parental and professional expectations early in life.

4. **Education and literacy.** Our governments fund educational programs to create the next generation of workers and a citizenry prepared to contribute to society. In most industrialized nations, children are given one to two decades to become educated. Society's investment in education and literacy obviously pays off! Nobody, least of all children with CP, can afford to waste this opportunity. Unfortunately, "special" education often has led people with CP away from society to its fringes —sheltered workshops—rather than teach them skills that enable them to contribute and participate.

Literacy, more than any other skill, is critical to people who can not speak. Without literacy, use of language is restricted; and a range of living options remain out of reach.

5. **Self determination.** Because motor impairment leads to passivity and "learned helplessness," self determination for people with CP continues to be a major issue. As expectations shift and advocacy increases, people with CP are taking control of their own lives. Professionals and families can expect some surprises. For example, at a recent conference *My Day My Choice* in Australia, adult consumers said:

- We don't want therapy. We want mobility on public transportation, taxis that arrive on time, wheelchairs and communication devices that don't break down, employment, access to health care, conductive education principles for children, and "real" choices.[22]

6. **Supported living.** Many adults with CP do not want to live in institutions, group homes or with their parents. Just like other adults, they want to live in an apartment or house that is near their workplace and friends. Related to a person's living arrangements are psychosocial, personal care, sexual, and marital issues.[23]

7. **Employment and standard of living.** Today many adults with CP who use AAC devices are unemployed. This is unacceptable.[24] Note: I could go on. In fact I did in the September issue of ACN!

8. **Epidemiology and prevention.** Research is needed that shows how to reduce the number of children with CP and the severity of the brain damage that occurs.[1,6,15] Also needed is information about how to prevent the onset of secondary conditions (e.g., What exacerbates problems in adulthood?)

9. **Health care.** Health care for adults with CP is a major concern. Currently no adult subspecialty exists in medicine for adults with developmental disabilities. Medical insurance may not be available. Few general practitioners, gynecologists, internists, or nutritionists have information about people with CP. In addition, adults with CP may be reluctant to seek care.

- We haven't been encouraged to take excellent care of ourselves.[25]
- Memories of my preschool years are dominated by those visits to my various medical specialists and therapists, who all handled me and dissected me according to their area of interest . . . all this emphasis on our physical parts can be dehumanizing and can lead to a lifetime of painful memories. Many adults in their 40s, 50s, and 60s, are still grappling with these memories and allowing them to stand in the way of obtaining needed health care.[26]

10. **Aging.** While roughly 40% of persons with CP are under 20 years of age, there is a substantial number who are in their 50s, 60s, and even older.[27] In fact, the life expectancy of persons with CP appears to be comparable to that of the general population, except for a relatively small number with more severe and numerous handicaps. Although CP is technically defined as a static condition, the capabilities of each individual with CP changes over time, initially as the brain grows and develops and later on, as the body ages. Accommodations to these changes must be made across a person's lifespan. To date, very little is known about the aging process in adults with CP.[28] Most available information is anecdotal.

- I was past 50 when I learned that the aging process makes CP a progressive disability.[29]
- I learned that I'm not alone dealing with the constant pain in my neck and shoulders from muscles that don't know what it means to relax, or the chronic heartburn and indigestion that results, I suspect, from muscle spasms along the gastrointestinal tract. Nor am I alone, I learned, with my weak bladder—or, my fears about the future.[26]
- We seem to be the first generation to ask the medical profession tough questions about the adult experience and what we can expect as we grow older. "Is a weight-lifting program going to strengthen my muscles or exacerbate the pain and stiffness?" "Were the hundreds of hours of therapy that I had growing up really helpful or was it 'over use' and the basis for problems later in life?[26]
- Living with CP is tougher at age 55 than at 15, but the tools that helped when I was a kid—professional assistance, and support from family and friends—still work. Assistive equipment is playing a much larger role in my life. . . AAC devices are becoming increasingly attractive.[29]

Clinical News

AAC for people with CP

Many people with CP have communication problems. Speech and language disorders are most common. One study reported 41% of the school-age population with CP had speech problems with 22% lacking speech.[19] In other studies motor speech disorders are described in as many as 68% of the entire group. Dysarthria, the most common speech problem, has been noted in 88.7% of those with athetosis and 51.9% of those with spastic CP.[30-32] While delayed language skills may be a function of mental retardation, isolated speech and language disorders are also observed.[6] Hearing impairment is reported in 9-10% of children. Visual problems, which can interfere with the development of literacy skills and the use of graphic symbols and communication devices, are very common. Refractive errors and strabismus are reported in 50% of children. Nystagmus (16%), field defects (11%), and optic atrophy (10%) are also described. Finally, people with CP are far more likely than the general population to have seizures (30%) and emotional and behavioral disorders (both neurologically and emotionally based).[1,6,20]

What has AAC done for people with CP?

For a person with severe motor impairment who does not speak, communication, no matter how it is accomplished, is the key that unlocks the door . . . letting the individual *Out* and the rest of the world *In*. It is language that truly connects one human to the other.

> Words are the legs of the mind. They bear it about, carry it from point to point, bed it down at night, and keep it off the ground and out of the marsh and mists. (Richard Eder, Theatre: Wings by Kopit at Yale)

First, I asked the individuals interviewed, *"What has the field of AAC done for people with CP who have severe speaking and/or writing problems?"* Their responses follow:

- Saved people with CP from spending 20 years in speech therapy.
- Saved some people from going down a path leading nowhere.
- Provided technologies allowing expression and a voice.
- Taken perceived *"nonentities"* into the world of the communicating public.
- Established a zero-exclusion criteria.
- Had faith in individuals and their potential.
- Proved that not being able to talk does not mean you have nothing to say.
- Given the world its first wave of truly interactive AAC users.
- Increased awareness of the needs of persons with severe communication problems.
- Encouraged research, developed tools, raised money, and increased the number of professionals in the field.
- Helped to change public policy for education.
- Identified critical areas that need attention (e.g., literacy, employment, the team process, funding).
- Created a backdrop against which self-advocacy can emerge by giving people a real voice that can be heard.
- Created the beginnings of an attitudinal shift in the general public and among physicians by exposing them to the person behind the motor impairment.
- Created a substantial number of jobs throughout the world for those interested in the field of AAC.
- Provided people with the means to make choices, to influence their own lives and interact with their environment.
- Provided literate users with a range of intelligible communication systems that have enabled them to command respect.
- Assisted nonliterate users to access a wider range of communication tools.
- Sought rehabilitation engineers and manufacturers as partners in the field.
- Strengthened the position of OTs and PTs in educational settings.

What should the AAC field do next?

Then, I asked, *"What priorities should professionals in AAC focus on now, and in the future, to assist people with CP?"* Their responses follow:

1. Shift focus away from clinical to real life issues.

a. Take a life-span approach to intervention.

b. Emphasize assessment less and training more.

c. Research shows children learn best from each other—not a therapist. Help children understand each other, discuss ideas and interests, be friends.

d. Train communication assistants/interpreters.

e. Use mentors to support someone through the process of obtaining, learning, and using a device or technique.

2. Educate the public.

a. Put a greater emphasis on advocacy efforts that change attitudes.

b. Make it okay to use communication devices everywhere.

3. Get efficacy data.

a. Demonstrate that the time and money spent on intervention activities and communication devices are perceived by individuals with CP as having value.

b. Show that intervention techniques and technologies do (or don't do) what they purport to do as cost effectively as possible. Publish these data.

Special times: Non-directive communication therapy

Helen Cockerill, a communication therapist at the Cheyne Centre for children with CP has developed a non-directed play approach to communication therapy. Sessions lasting 30-50 minute take place in a playroom equipped with a variety of play materials. Each session has a clear starting and finishing routine with a 5 minute warning. Children do whatever they want, with the support and undivided attention of a therapist. The therapist does not direct the play or conversation in any way, nor make suggestions or ask any questions. The therapist does not use judgmental language so the child is not praised or criticized. Limits are imposed only if the child is about to do something dangerous or damage equipment. The playroom is labelled with symbols. The therapist comments on the child's activities and provides a model of expression directly related to the child's output (e.g., speaking, eye pointing, gesturing, signing, using symbol systems and communication devices) to develop that child's awareness of his or her communication.[33]

Video and booklet entitled Communication through Play are available. Contact Cheyne Centre for Children with CP, 61 Cheyne Walk, Chelsea, London SW3 5LT (081 846 6488)

4. **Determine useful vocabulary.**
a. Determine what vocabulary is most useful and under what circumstances.

b. Determine what vocabulary is most useful in speech output devices and what is most useful on communication displays and books.

c. Investigate what vocabulary adults need to interact effectively with medical personnel.

5. **Improve intrapersonal communication.** As one person said, "If you can't express yourself to yourself, you can't know who you are."
a. Consider the role AAC techniques and technologies can play in the development of *self* for people who can not speak or write easily.

b. Help young children talk to themselves, make up jingles or interact with an imaginary playmate.

c. Encourage older children and adults to talk to themselves, write poetry, keep a journal or record their dreams.

6. **Focus on interpersonal spheres.**
a. Address the lack of personal friends and the social difficulties encountered by people with CP.

b. Focus on building relationships.

c. Encourage children with CP to take risks. NOTE: This is a message from adults with CP to parents of children with CP.

7. **Make systems more consumer responsive.**
a. Maintain a dialogue with all those involved, keeping in mind who works for whom.

b. Adopt a family-centered model.

c. Get medical, educational, rehabilitation, and social services systems to work together.

d. Make it easier to try, before you buy assistive technology, particularly AAC devices.

Dodds[34] described his dream for future service delivery as follows: When someone needs help, they call a well-publicized, toll-free number. Each caller is asked what they (or the person they are calling for) are having trouble **doing.** For example, writing a letter. A list of available services is shared that can address the problems (e.g., help with positioning, ways to hold a pen, special computer modifications and predictive programs, and so on). Then, the caller is asked which options they are interested in trying and when and where the team can go to see the person.

Equipment

AAC devices: Desired features

Without question, one of the most significant developments for individuals with CP has been communication devices that use computers and voice synthesizers. Manufacturers in AAC serve a market that is small and has limited resources. . . us! Yet, in just under two decades AAC manufacturers have provided the field with an ever increasing choice of devices, strategies, and techniques for people with CP. Unfortunately, the expectations surrounding assistive technologies, particularly AAC devices, are not always fair or realistic. For example:

- Some expect a device to behave like an appliance. You buy it, plug it in or charge it up, prepare some vocabulary and symbols, push a button and voilà it communicates—just like a toaster. And it never breaks down. NOT!
- Some expect a device to be the long awaited "Answer." It becomes everyone's focus. While others are playing outside, learning to read or finishing 3rd grade, the person with CP is learning to use a device. NOT!
- Others act as though a communication device is some kind of prize to be won. The prerequisite may be hitting a switch 9/10 times or using a communication board in X number of contexts. NOT!
- Finally, and too often, the coveted prize may be awarded after years of family members, school boards, rehabilitation agencies, medical insurance companies and a cadre of others practicing the "art of confrontation." NOT!

Actually, an augmentative communication device is just what it is—a mechanical thing (with some electronics). It only does what it does when someone wants it to. Ideally, but not always, that someone is the person who has difficulty communicating. AAC devices can and do contribute enormously to a person's total communication system. However, unlike the human brain, an electrochemical organ that generates impulses that cause cognition, language, movement, speech, sight, hearing, and feeling to occur almost simultaneously, a communication device operates in a linear fashion with certain limitations. That's why it is never the only "thing" a person with speech impairment needs to communicate effectively.

How powerful a device can be in a social interaction! You can add a little comment here or a question there using voice. How satisfying to store a speech or prepare your homework or write a paper. How wonderful to be able to express your basic needs, tell a joke, or talk on the phone. Of course, no one is satisfied; and we are a far cry away from having a device that interprets someone's thoughts and speaks or writes them immediately.

As partners in the field, manufacturers and clinicians are being led by the desires and dreams of people who have severe communication impairments. It is their vision we follow. I first heard a request for the *Brain Interpreter* ten years ago.

> Someone in a nursing home had noticed that a young adult who had been comatose for 6 months after a serious automobile accident, was beginning to wake up. He was transferred to a rehabilitation hospital in Baltimore and I was asked to consult.
>
> He had a tracheostomy and gastrostomy, was quadriplegic, had visual problems, and could not sit, talk, or eat. I introduced myself, telling him I tried to find ways for people who couldn't talk to communicate. I asked him if he had given any thought to what he might want? Truthfully, I didn't expect a response! However, I am forever glad I asked.
>
> Using a rudimentary alphabet board, he slowly spelled (or misspelled) "Something to read my thoughts and speak!" "Well," I said (with enormous excitement). "We aren't quite there yet, but lets get going!"

Along the way, we all have contributed ideas. On page 6 there is a compilation of visions from people interviewed who

(cont. on page 6)

Equipment *(cont. from page 5)*

responded to the question, *"What features do you think could be added to AAC devices that would make them better for AAC users with CP?"* They said, "We would like . . .

- **Displays**
  a. that are readable, even outside, in strong sunlight.
  b. that accommodate a range of pictures and photos and graphics.
  c. sharper dynamic displays.
  d. that allow us to enlarge text
  e. that take into account the visual problems of people with CP and offer some accommodations with contrast, color, position and presentation of materials.
- **Speech output**
  a. that offers us a wider range of options (inflection, volume, voices)
- **Rate increases**
  a. with faster ways to participate during spontaneous conversations
  b. that reflect new thinking, e.g., why not rethink directed scanning. Using a joystick approach is an old technology!
- **Modularized systems**
  a. that give us a way to bring (or not bring) along your speech, printer, phone, low tech display, word processor, and note pad.
  b. that have components designed to be compatible with school/ job.
  c. that are easily integrated with other system components, like wheelchairs.
- **Better interfaces and access**
  a. such as eye gaze to computer.
  b. such as head gear that is acceptable to the people who use it.
  c. that really increase the rate.
- **Changes in the shape and size of devices**
  a. so they could adapt to the person's position and needs. Why not package components in gelatinous material?
  b. so some are much smaller and weigh less.
- **User friendly devices**
  a. that allow independence.
  b. that lower the cognitive load so people can learn them as part of normal life
  c. that lower the cognitive load so people can think about their message and not the method.
- **Strong waterproof, and reliable devices."**

SOME BASIC REFERENCES

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Trefler, E., Hobson, D., Taylore, S., Monahan, L. & Shaw, C. (1993). **Seating and mobility for persons with physical disabilities.** Tucson, AZ: Therapy Skill Builders.

Bigge, J. (1991) **Teaching Individuals with physical and multiple disabilities.** New York: Macmillan Publishing Co.

*UCPA offers excellent publications (stories, poetry, biographies, and books about romance, natural supports, inclusion, pregnancy and parenting) written by parents, individuals with CP and others.
UCPA, 1522 "K" Street, NW, Suite, 1112,
Washington, DC 20005.

Governmental

International Cerebral Palsy Society (ICPS)

The International Cerebral Palsy Society (ICPS) was founded in 1969. Today, the membership includes national and regional organizations as well as individuals from countries around the world. The Secretariat is located in London. The goals of ICPS are to:

- Respond appropriately to the needs of the world communities.
- Work toward prevention.
- Work toward mainstreaming people with cerebral palsy and related disabilities.

ICPS has affiliated organizations in regions around the world and seeks to attract members from various backgrounds including parents, teachers, therapists, psychologists, social workers, physicians and people with disabilities. Members of the organization share an interest in the field of cerebral palsy prevention and rehabilitation.

A major focus of ICPS is to disseminate information and provide training tailored to the needs of local members. To date, the Society has organized over 73 meetings (study groups and seminars) in 26 different countries. Examples of topics covered include:

- Research on brain development and prevention of disability.
- Discussions on various treatment approaches.
- Information about early intervention, schooling, housing, adulthood, architectural planning, mental retardation, fund-raising and sexuality.

Two conferences planned for 1994 focus on important issues. The first, *Aging and Cerebral Palsy*, will be held from March 26-30 at Cambridge University in England. The second, entitled *The Child in the World of Tomorrow - The Next Generation* is scheduled in Athens, Greece from June 2-5, 1994.

Mr. Jack Weinstein, ICPS's current Chairman, just returned from an ICPS Executive Committee meeting and indicated their interest in opening a dialogue with ISAAC *(the International Society for Augmentative and Alternative Communication)*. A collaboration between ISAAC and its Chapters and ICPS and its affiliates could be of great benefit to people with CP from around the world who have communication difficulties.

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University & Research

Drooling

Many people who have CP also have oral motor dysfunction, causing a spectrum of problems which include:

- Speech dysfunction.
- Feeding and swallowing difficulties with danger of aspiration.
- Drooling.

Severe drooling without speech impairment is virtually unknown. Not surprisingly then, many people who use AAC techniques have a drooling problem. Drooling, or sialorrhea as it is known in the medical literature, is an unintentional loss of saliva and other contents from the mouth.

Drooling can be a communication problem.

Drooling can be a communication problem. Society considers drooling disagreeable and abnormal when it persists past early childhood. Thus, people's response to an older child or adult who drools is often social avoidance. In addition, electronic technology, which gives individuals with CP opportunities to communicate, participate, and achieve, must be drool proof. As a result, some people who drool put up a seemingly relentless, Herculean effort to STOP. This is often not possible, and they are likely to suffer a loss of self-esteem and frustration.

In 1990 a Consortium on Drooling was held at the Kluge Children's Rehabilitation Center. Members included distinguished representatives from engineering, technology, and health care fields. The subsequent Proceedings,[35] a 1993 review article by Allaire and Blascoe,[36] and an annotated bibliography[37] synthesize the current knowledge about drooling. Did you know? . . .

1. Saliva protects the teeth from decay and tissues from disease. It acts as a lubricant for swallowing, facilitates taste and promotes digestion. It provides a cleansing action in the mouth and reduces breath odor.
2. Saliva is produced by several glands: submandibular, sublingual, parotid, minor palatal and mucosal.
3. Most people who drool do not produce excess saliva. Instead, they are not swallowing. Reasons can range from a lack of attention to a complete inability to swallow.
4. Drooling can be caused by both oral motor dysfunction and intraoral sensory deficits.
5. Drooling is classified as mild (saliva collects at the lips), moderate (on the chin), and severe (on clothing).
6. Prevalence data for drooling have not been gathered or reported. However, an estimated 10 percent of children with CP drool to an extent it "interferes with daily social and practical functions." An unknown number of adults are further disabled by their drooling.
7. Adults with CP and parents of children with CP have expressed fears about surgery, skepticism about drugs and disappointment and frustration with positioning and behavioral interventions. Their skepticism is not unfounded. The literature provides no comparisons of different treatment strategies. It is difficult to ascertain what options are best for a particular individual.

Intervention Approaches

Drooling management should promote a better quality of life and improve social interaction. Current treatment approaches include:

- **Handling techniques**. The goal is to facilitate swallowing by enhancing head control, normalizing muscle tone and stabilizing body position. Neurodevelopmental treatment (NDT) approaches, positioning techniques, and oral stimulation techniques to enhance sensorimotor feedback are employed. Unfortunately, "there is a striking paucity of clinical research to document the effectiveness of these techniques for oral-motor dysfunction and specifically for drooling control."
  Note: The potential advantage of oral appliances combined with therapy is just beginning to be understood. Dr. H. Haberfellner from Austria has used oral appliances in his population of children with CP with good results. His appliance combines sensory input and motor training in one orthodontic device.
- **Behavioral interventions.** Goals are to promote awareness of saliva and encourage regular swallowing. Behavioral techniques prompt individuals to swallow at regular intervals. For example, portable devices may deliver an auditory or tactile cue as a signal to swallow. While most studies report an initial cessation of drooling, it is never completely eliminated and carry-over is typically incomplete. This raises the question of true efficacy beyond the first few months after treatment.
- **Surgery.** The goal of surgery is to decrease the amount of saliva by 1) interrupting the nerves which innervate the production of saliva as in tympanic neurectomy or 2) excising or removing certain salivary glands while simultaneously moving the position of the ducts more posteriorly in the throat and thereby making swallowing easier. Dr. William Crysdale of the Hugh MacMillan Rehabilitation Centre in Toronto reports good success in over 600 patients with severe to profuse drooling. His clinic, a model for all, has been in existence for 20 years and uses an interdisciplinary team comprised of a surgeon, dentist,[38] and speech/language pathologist.
- **Drugs.** The goal of pharmacologic therapy is to reduce secretions. It is most likely to be effective when salivation is excessive, an uncommon finding in the CP population. Unfortunately anticholinergic drugs not only decrease drooling, but have widespread side effects (e.g., restlessness, irritability, delirium, mild sedation, blurred vision, dryness of the mucous membranes.) Recent optimism with drugs, such as glycophrrolate, warrant[39] well-designed clinical studies.

One important goal is to establish measurement protocols that will enable researchers to measure outcomes and compare treatment approaches. To do so, the frequency of swallow and the quantity of saliva must be ascertained across natural settings, all day long. Techniques are being developed to evaluate:[40]

- ☐ Salivary overflow. A patch worn on the chin that will act as a filter and allow severity levels to be extrapolated by measuring calcium ions. Note: This is less invasive that a chin cup.
- ☐ Frequency of swallowing. A portable device that listens for the "sounds of swallow." A microphone and computer track swallowing throughout the day.

A database is being developed at the National Clearing House of Drooling.* This will assist researchers at participating sites to study a large number of children longitudinally. As a result, variables predicting drooling and potential for treatment success may be determined. In the meantime, try the following coping strategies.[40]

- **To absorb saliva.** Use a scarf (all natural fiber works best). Or, put a piece of disposable diaper or menstrual pad in clothing (bib or scarf) for better absorption. Or, use a cotton wrist band.
- **To protect skin.** Use a cream that is designed for ileostomy sites (e.g., Alovesta cream).
- **To reduce odor.** Remove article first. Spray high powered deodorants (Odor-nil) on articles of clothing, e.g., before recess.

*The Clearing House of Drooling, c/o Kluge Rehabilitation Center, 2270 Ivy Road, Charlottesville, VA 22907 (804) 982-3808.

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YOUR RESOURCES

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