



Augmentative Communication News

May, 1990 Vol.3, No.3

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keeping it!

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Institute on Disability at the
University of
New Hampshire

UPFRONT

Many adults with severe and profound mental challenges (SPMC) have spent a majority (if not their entire life) in large institutions. Those who are younger may (or may not) have benefited from public laws and/or policies insuring them an education in "least restrictive environments." For the most part, they too have lived their lives set apart. Obviously, our experiences determine to a large extent who we are, what we expect and believe, what we know, and how and if we learn. People with SPMC generally require support throughout their lives. Independence is not a realistic goal. However, for most of us, **interdependence** is a much more desirable option anyhow!

Not every society has the resources, or the inclination, to be concerned about quality of life issues. However, as the 90's emerge the "era of normalization" and integration for persons with severe disabilities will continue to expand. Augmentative communication (AAC) has a major role to play because communication is required for participation in domestic, recreational, vocational/educational and community activities. Thanks to the clinicians, researchers, parents, and administrators I interviewed. Their willingness to share information is much appreciated. (*See list of resources and references, page 8*).

In this issue, **For Consumers** summarizes characteristics of the population. The **Equipment** section describes materials and (*cont. pg. 2*)

For Consumers



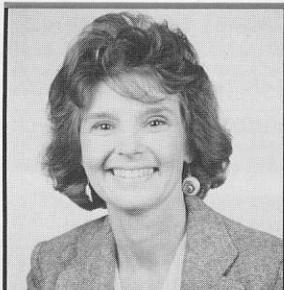
In pursuit of
opportunities &
interdependence

Approximately 1 to 3 percent of the world's population is profoundly retarded.¹ Although I am not aware of studies describing adults with severe/profound mental challenges (SPMC) who could use AAC, demographic studies of children in the U.S. suggest 75 percent of those aged 5 to 21 years who might "benefit from AAC" are mentally retarded, two-thirds of whom are severely or profoundly retarded.² It is likely (*because children grow up*), a large number of adults with SPMC also might benefit from the use of augmentative communication aids, techniques, symbols and instructional strategies. Integrated, functional approaches to communication using AAC techniques are showing encouraging results.

Information about the Population

1. Severe and profound retardation implies a very slow rate of learning accompanied by a rapid rate of forgetting.
2. Most adults with SPMC have had very limited experiences. Thus, their "world knowledge" is minimal.
3. Adults with SPMC can and do learn. Not surprisingly, evidence suggests these individuals are more capable than imagined. They have strong preferences, make definitive choices, and can act meaningfully on their environment.
4. The intellectual functioning of individuals with mental retardation, as well as their potential to learn new skills, increases as a result of their participation in more stimulating experiences and (*cont. page 2*)





Upfront (cont.) technologies currently found useful, and **Clinical News** focuses on exemplary practices and intervention principles.

The **Governmental** section provides important information about U.S. Work Incentive Programs for adults with all types of disabling conditions. Finally, **University & Research** highlights the Institute on Disability in New Hampshire.

Remember, the Hotline number is (408) 649-3050. Thanks to those who returned the service delivery questionnaire sent with the March issue. There's still time! Results will be summarized in the July issue and shared in Stockholm in August. Keep in touch!
Sarah Blackstone, Ph.D., Author, ACN

For Consumers (cont. from pg. 1)

active involvement in their living and working environments.

5. Many are able to work, with support, in meaningful employment situations. However, few do. In the U.S., for example, the 1980 census revealed 95% of persons from ages 16 to 64 receiving care in homes and schools for the mentally handicapped were not working.³

6. Sheltered workshops do not prepare people to work in non-sheltered environments. Statistics show less than 2 percent ever make it out of a sheltered workshop into the real world of work.⁴ Similarly, educational programs that prepare students to function in "special" classrooms often fail to teach the skills required for participation in integrated adult service options.

7. Persons with SPMC are among those who benefit most from supported employment participation. They experience dramatic increases in earning power after par-

ticipation in supported employment programs. Of the options investigated, work crews were least effective as a supported employment alternative.⁵

8. Many do not speak at all, or, are not understood. Most individuals with SPMC, however, have a system of communication, albeit idiosyncratic, maladaptive, nonlinguistic, and situation specific.

9. Persons with SPMC often are provided with very few opportunities to communicate. In fact, communication (and other means of control over their environment) may not be perceived as an "adaptive behavior" by caregivers.

10. Caregivers (who are often underpaid, and minimally trained) can easily develop the belief that individuals who do not communicate in obvious ways have no desires or preferences. Based on such beliefs, caregivers often reduce their socializing with these individuals, make choices for them and perform all their self-care functions. "Learned helplessness" is the result.

11. Skill generalization (transfer of training) and skill maintenance can not be assumed from one context to another. Instruction, therefore, needs to occur in settings where behavior is expected.

12. This lack of generalization also makes it possible for persons with SPMC to learn to use different approaches (i.e., gestures, communication wallet, communication device) for different circumstances, without becoming confused.

13. Behavior and communication problems are probably the most often cited reasons for segregating adults with severe and profound mental retardation. Because maladaptive behaviors may, in fact, be communication acts, AAC intervention can play a major role in developing more appropriate com-

munication behaviors and decreasing behavioral problems

14. The geriatric population (including those with SPMC) is increasing in proportion to younger folks and is a growing concern of human services agencies. The human aging process is associated with an increasingly distorted understanding of the nature of communication and a lack of motivation to communicate. As a result, the efficacy of communication intervention strategies with aging individuals, with a range of disabling conditions is being evaluated.⁶

Today's and Future Challenges

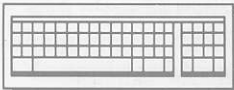
Those interviewed described the typical adult with severe mental retardation as an individual in a sheltered workshop and non-habilitative group home with staff that are poorly paid and minimally trained. Those who are medically fragile; those with severe behavioral problems, profound retardation, dual sensory impairments, and/or multiple handicaps are still living in institutions.

Adults, unlike children, do not yet have a mandated right to education/work, live in the community, and participate in society. Adult service delivery systems are difficult to understand and negotiate. Still, the social, communicative, and domestic histories of adults who in the past may have been deprived of even the most basic human experiences, are being rewritten. . .

S L O W L Y.

The future promises not only a more humane approach to persons with severe disabilities, but an approach that recognizes their legitimate right to participate, to whatever extent possible, in their communities. If AAC professionals work with persons with SPMC and those who support them, to create communication opportunities and establish a means of environmental control and social interaction, the "typical" adult with SPMC may be described quite differently in the year 2000.

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Equipment

A full range of options

Augmentative communication techniques and aids are introduced when more efficient and effective ways to exchange messages are required. Persons with SPMC currently use a range of communication options, which include: speech, gestures, signs, communication books, wallets, mini-boards, wall boards, texture rings, remnant books, calendar boxes, electronic devices, switches, environmental control units, computers, and so on. As with other populations, each individual's communication system is comprised of multiple modalities. Some desirable features are noted in Table I.

Table I. Desired features

- Low symbolic load
- No or limited memory requirements
- Intelligible in targeted contexts
- Assists individual to accomplish tasks
- Portable, light weight, easy to transport
- Easily accessed & available, as needed
- Affordable
- Has setting specific vocabulary
- Easy to program

Access to the Environment and Communication

Activating a switch with a body part or a vocalization can have a direct effect on an individual's experience (e.g., *turn on/off a fan, vibrator, light, music, T.V., blender, hair dryer, food processor, toaster, and so on*). There are a number of ways to assist persons with SPMC to control electrical appliances.

The following publications are particularly valuable for adults:

Levin, J. & Scherfenberg, L. (1990). *Breaking barriers*. Minneapolis, MN: Ablenet

Levin, J. & Scherfenberg, L. (1987). *Selection and use of simple technology in home, school, work, and community settings*. Minneapolis, MN: Ablenet

Note: Control units and switches can be purchased from companies listed at the end of this section.

If motor impairment precludes direct access to communication displays, consider manual scanning. Present an item the learner likes. Put finger on item (visual scanning) and/or say item (auditory scanning) and wait for a signalling response.

Later, introduce a single distraction (non preferred item/activity). You are providing "choice making opportunities." Remember, accessing techniques have different cognitive, sensory, and motor requirements. See ACN issues on Light Pointing (Vol. 1, #2), Auditory Scanning (Vol. 1, #5) and Visual Scanning (Vol. 2, #4).

Messages

The gestures, vocalizations, body language and signs of persons with SPMC often are difficult to interpret. More intelligible representational systems are needed. Tangible symbols (objects, attributes of objects, textures), graphic symbols (logos, pictographs), and speech output aids have been successfully used. Vocabulary is chosen after direct observation of daily activities and arranged in ways meaningful to the individual (NOT necessarily by category). In addition to "wants and needs," those interviewed recommended using social niceties, comments, and questions. Table II lists examples of frequently used vocabulary on speech output aids.⁷

Table II. Sample vocabulary

Come here	Go away
Leave me alone	Shhh, Be quiet
I like your shirt/pants	Excuse me
You look nice	Time to go
Where is he/she?	Happy Birthday
What's new?	I'm trying
How are you?	I want more
Will you talk to me	When is my bus coming?
You're getting on my nerves.	
Can you take me?	

Light Tech

Environmental Displays remain in the setting (e.g., restaurant, bathroom, weight room). Symbols are specific to the setting and the task. Displays may be used by one or several individuals. Wall boards, mini-boards, and the communication tools listed below can also have great instructional value:

CUE BOARD: A step-by-step set of instructions (using pictures, objects, textures) to assist a person to accomplish a task.

SCHEDULE/CALENDAR BOX: Aids depicting the day's activities. Each activity is represented by a photo, picture, object or part of an object. For example, using a calendar box, the individual gets/ touches symbol, participates in the activity, returns symbol and gets one representing the next activity. Note: Rowland and Schwegert's Tangible Symbols Systems: Symbolic communication for individuals with multisensory impair-

ments has lots of examples. Available from Communication Skill Builders, P.O. Box 42050, Tucson, AZ 85733. \$69 (videotape).

Individual displays may be worn or carried. Mini-boards and communication books are examples. Here are some other ideas:

WALLETS: Symbols are placed in the wallet. Initially, use a single generalized symbol. Additional ones can then be added, and several wallets developed for different situations. Crestwood Company (6625 N. Sidney Place, Milwaukee, WI 53209) offers a variety of reasonably priced "Porta Books" with "Talking Pictures" appropriate for adults. If carrying or wearing a wallet "is a hassle," put the wallet and a symbol with high motivational value near the person. Gradually move it closer. Note: the wallet holds money, which also can be motivating.

JANITOR KEY CHAIN: A ring can be attached to a belt with a telephone loop cord. with 1 or more symbols (e.g., pictures, textures, representational objects like a "stop sign" or a disk painted red indicating stop). Note: Feel and Match Textures (3 1/2" disks of different textures) are useful if you put word/picture on other side. Available from Flaghouse, Inc., 150 N. Mac Questen Pkwy, Mt. Vernon, NY 10550. \$5.30 per set of 16.

FAN DISPLAYS: Fasten pages with a rivet. Place symbols on pages so they are seen when fan opens.

REMNANT BOOKS: Use a photo album with peel back pages. Before the end of an activity, put a "remnant" in the book (3 or 4 to a page). Each page represents a day and is labelled accordingly. Remnants can be: napkin from a restaurant, ticket from a bus, grass from the park. Write something next to it. The items become "symbols" of the activities. Many begin initiating use of book, start making choices, and "talking" about things not in the "here and now." After a week or so, clean it out.

High Tech

Speech output devices increasingly are being used with success. Here are some things to consider:

- Technology often raises partner's expectations and leads to more interaction and more validity ascribed to interaction by caregivers.
- The effect of the speech output on comprehension and use of aids is not documented, however, Durand, Ronski, & Schweitzer (see resources), among others, are investigating.
- Speech output aids are often not useful in noisy environments or when "natural" modes of communication are effective.

What is being used? The User programmable Wolf is preferred for its durability, use of levels, vocabulary size, portability (e.g., *in a backpack*), low cost. The Intra-Talker, Macaw and Parrot are easy to program. For those with severe motoric involvement, the Talking Screen and Aud Scan (cont. pg. 4)



(cont. from page 3)
programs are occasionally used.
Also, mentioned was the VOIS 136,
and the TouchTalker.

User Programmable Wolf (Ask them about their new **Whisper Wolf, Scan Wolf, Volks Box, and curriculum packages**) AdamLab, Wayne Co. Intermediate School District, 33500 Van Born Rd., Wayne, MI 48184)

Parrot and Macaw (look also at their switches and mounts) Zygo Industries, P.O. Box 1008. Portland, OR 97207

IntroTalker, Touch Talker (check out the environmental controls, switches also) Prentke Romich Co, 1022 Heyl Rd., Wooster, OH 44691

Talking Screen and AudScan (this is software for IBM compatibles) Words +, Inc. P.O. Box 1229, Lancaster, CA 93584

VOIS 136 (now 160), Phonic Ear Inc., 250 Camino Alto, Mill Valley, CA 94941

Finally, below are additional sources for switches, appliance control units, and other useful products
Ablenet, 360 Hoover Street, N.E., Minneapolis, MN 55413

Adaptive Aids, P.O. Box 57640, Tucson, AZ 85732

Don Johnston Developmental Equipment, P.O. Box 639, 1000 N. Rand Rd., Bldg. 115, Wauconda IL 60084

Handicapped Children's Technological Services, Box 7, Foster, R.I. 02925

TASH, 70 Gibson Drive, Unit 12, Markham, Ontario, Canada L3R 2Z3

Note: Bill Lynn, who has worked with this population for years has two products he's offering: 1) Plans for reinforcement timer using parts from Radio Shack: Simtech Publishing, 587 Northfield Rd, Northfield, CT 06778. Available for cost and 2) Switch mechanisms for special needs: A project manual. Available from National Clearinghouse for Rehabilitation Training Materials, 115 Old USDA Building, Oklahoma State University, Stillwater, OK 74078. (405) 624-7650, \$6.50 plus shipping.

On the Horizon

Exciting computer applications are being developed at the Bioengineering Program at the Association for Retarded Citizens. Three systems designed to allow individuals with the most severe handicaps to control their environment and communicate with others are:

- 1. **Voice Control:** permits person with SPMC to activate environmental appliances by voice
- 2. **Sound-to-speech translation.** A portable system that permits user to utter unintelligible sounds that are then translated into conversational speech.
- 3. **Eye gaze/headpointing:** a portable environmental control aid. User directs gaze or head at visual symbol on a display and the system responds by speaking or by activating an appliance.

For additional information contact Dr. Carrie Brown, ARC/US, 2501 Avenue J, Arlington, TX 76006. (817) 640-0204.



Clinical News

Intervention perspectives

AAC intervention requires consideration of variables related to individuals with communication problems, their partners, the context, tasks, and available communication modes. It's always complicated. Intervention with adults with SPMC is particularly challenging because:

- Adults have been alive for decades and have behavior patterns and patterns of interaction that are "well established" and "resistant to change."
- Adults with SPMC learn very slowly
- People who support them in their community, homes, work environments and participate with them in recreational activities may not see communication as a desirable or adaptive behavior.

Principles for Intervention

Table III is a list of best practices for AAC intervention with adults with SPMC.⁸ To summarize, intervention must be functional and delivered in natural settings. Goals must be embedded in and designed

Table III. Best practices in AAC

- 1. Teach functional skills.
- 2. Teach in natural settings. Don't set up separate communication programs.
- 3. Teach communication as an embedded skill.
- 4. Involve natural communication partners. Teach them to provide opportunities, recognize signals, as well as implement augmentative aids, strategies, and techniques.
- 5. Provide appropriate chronological age materials and activities
- 6. Provide opportunities to practice skills in natural settings
- 7. Increase number/type of environments in which individual participates.

to support an individual's participation in daily activities with natural communication partners.

The Process of Intervention

Readers are referred to selected references for more indepth descriptions of intervention processes and examples of useful assessment and observational tools. Below is a list of seven steps to consider:

1. Look at the individual's communication opportunities and think about how to expand them within and across environments using various adaptations (e.g., assistive devices, adaptive equipment, instructional strategies, removal of architectural/electronic barriers, and changes in attitude.)

2. Delineate the communication requirements of targeted tasks/activities.

3. Observe partner behaviors during interactions with the individual. Suggest realistic adaptations.

4. Determine what person currently does to communicate. Suggest adaptations that can be implemented in natural contexts.

5. Provide mechanisms for instruction and support of job coaches, co-workers, group home staff, volunteers, families, etc.

6. Assist in providing equipment, education, and instructional strategies.

7. Determine effectiveness of intervention strategies using functional outcome measures.

Assessment and evaluation strategies involve a discrepancy analysis, i.e., comparison between requirements of a task and those elements an individual is unable to do. Intervention involves changing the individual's behavior and, more importantly, the environment. AAC professionals facilitate positioning and access, develop vocabularies and scripts to implement aids and techniques and instruct partners on the use of equipment and techniques to facilitate adaptive communication patterns.

Specific Strategies

Several areas of concern were identified by those interviewed:

1. Making successful transitions. Adult intervention begins in childhood. Professionals involved in service delivery systems for adults with SPMC can be overheard complaining that elementary school professionals, parents, and pediatric health-care specialists "baby" learners with severe disabilities, make them overly dependent, limit their opportunities, teach skills that have little functional value, don't allow them to fail, and so on. *It's more difficult to undo maladaptive patterns than "do it right in the first place."* Remember. . .

Cue dependent, passive, noncommunicative adults with behavioral disorders are not born. **They are made.**

Systematic and longitudinal planning and coordination facilitate transitions that occur without unnecessary trauma and loss of skills. At least by age 16, goals should be built in that relate to the next five years. Plans should be formulated

with regard to housing, supported employment options, community, domestic and leisure activities. AAC techniques and aids are a means to insure participation.

Pooling the resources of public educational systems, vocational rehabilitation programs, developmental disabilities services, and social security agencies can make good things happen. Projected adult service providers should attend IEP meetings, and begin negotiations for adult services. Some feel by age 18, only 10 percent of a student's day should be spent in the school building.

2. Infusing communication across domains. Communication intervention for adults with SPMC is embedded across four functional domains: vocational, domestic, recreation, and community.* Adaptive aids and techniques can (*and will*) be different across domains. For example, a learner may use a computer during leisure activities to access software and facilitate attending, joint focus, and social interaction. However, it may not be a useful tool in other domains.

Vocational A range of options exist: day activity centers, sheltered workshops, adult schools, and supported employment options (e.g., enclaves, job sharing, mobile crews, job coaches). Supported employment should enable individuals with severe disabilities to participate successfully in a meaningful job in the community. It is supposed to be a primary service option for adults with severe mental retardation.

Supported employment reportedly is more cost effective than other options, e.g., maintaining a sheltered workshop. However, U.S. studies show persons with SPMC comprise less than 8 percent of the total number of participants. Persons with autism, cerebral palsy, and sensory impairments represent

*An example is Schnorr, R. et al. (1990). *The Syracuse Curriculum Revision Manual: A group process for developing a community referenced curriculum guide.* Available from Paul Brookes Publishing Co. P.O. Box 10624, Baltimore, MD 21285.

only 4 percent.⁹ Table IV contains examples of some employment sites and jobs successfully held by individuals with SPMC who use AAC.

Table IV. Examples of Jobs

Settings	Job activities
Cafeteria	Dishwasher: Unload and put away forks/spoons
Nursing Home/Hospital	Food preparation: Hit switch to turn on foodprocessor Put items on trays Fill water jugs, juice cups Assemble admission packets
Laundry	Sort/fold laundry. Turn pressing machine on Put clothes on hangers
Offices	Cleaning, stacking, collating
Stores	Sort items in stock room Put on hangers
Barbershop	Sweep up, fold towels
Nurseries	Plant seedling
Pet stores	Feed animals
Motels	Collect towels/sheets Load vending machines

A major role of the AAC team is to support the job coach, who supports the individual. Think about how a job coach perceives his/her role because it will affect an individual's communication opportunities. If the focus is "helping do the job," the coach is likely to emphasize task analysis, cueing, and reinforcement strategies. However, if the job coach also sees his/her responsibility as facilitating primary relationships between the individual, the employer and co-workers in order to develop a natural system of support, strategies will be more communication oriented (e.g., talking about how clients communicate, how to talk with them, how to recognize signals, and what to do if bizarre or aggressive behavior occurs.)

Domestic Several types of living options exist for individuals with SPMC: Family home, apartment sharing, foster home, group home, nursing home, small residential facility, and institution. Smaller living arrangements are preferable. Shane¹⁰ reported the greater the number of disabled people residing in one setting, the less likelihood of interaction among the residents.

Those interviewed shared many examples of group homes run and managed in ways that are both integrated and individualized. Many group homes, however, are not really "homes." How the staff see their

role has an impact. Is the "building" their place of employment or the home of those who live there? Is their role to "take care of basic needs" or facilitate participation?

Reichle¹¹ describes a technical assistance program for group home staff in Minnesota. The university-based group offers longitudinal, learner specific technical assistance (weekly training). Case management is community based. Another program¹² places student facilitators in nearby group homes. Students and residents even co-manage and operate a Bed and Breakfast business.

Note: Training program should teach professionals how to tap community resources (i.e., ask for money) to supplement state and federal monies so they can run programs that benefit clients.

Community and Recreational. Shopping, yard work, bowling, taking walks, going to church, sporting events, a restaurant, and so on are opportunities for community participation, recreation, and social interaction. In one facility, group home staff asked (*and got*) a local organization to buy health club memberships for their clients. Remember, few interactive opportunities are created by sitting at "home" or watching T.V.

3. Training support staff. Table V. is a list of considerations when working with the partners of persons with SPMC. (*cont. on page 6*)

Table V. Suggestions for Staff Training

- Listen to what staff say they want and/or don't want
- Remember in many cases, staff has chosen to work in a segregated environment
- Discuss what communication is
- Show them how to create opportunities
- Demonstrate how to interact with somebody who does not speak
- Demonstrate how they can provide choices
- Teach staff to respond to learners when they use augmentation, but not discount any of their attempts to communicate. For example staff should not instruct individual to "use your board" if a natural gesture has been understood.
- Remind staff. Many individuals have difficulty with attention and tend to focus on 1 aspect of a situation
- Keep in mind that prompting strategies: verbal instructions, hints, models, cues (color coding, position, highlighting), physical guiding are cues that may inhibit learning.



(cont. from page 5)

Readers are referred to a case study by McNaughton and Light focused on staff training.¹³

4. Dealing with "excess behaviors." Behaviors deemed unacceptable by society such as screaming, hitting, throwing, masturbating in public, injuring oneself are "excess" or "challenging" behaviors. Their existence often preclude participation. Research in this area suggests these behaviors are communicative. Once the intent is understood, alternative ways of communicating can decrease these "acting out" behaviors. Successful communication intervention for learners with socially motivated excess behavior requires teaching efficient, adaptive alternative or replacement behaviors across settings. See Table VI for a summary of 3 major causes of excess behaviors with some suggested strategies.

5. Identifying reinforcers. It can be difficult to determine what, if anything, some adults are interested in. "Food" is not always motivating. Institutionalized adults may not be "interested in communicating about basic needs" because they are auto-

Table VI. Excess Behaviors: Common Causes and Solutions

- 1. ESCAPE AND AVOID TASK DEMANDS** (Note: Behavior is often aggressive.)
Strategy: Give the individual a communication technique that is easy, accessible and can be used at a distance. Natural gestures like a "stop" hand signal or a "no" head shake are effective. So is a key chain with a spiral telephone cord. Attach a piece of wood painted red or a "stop" sign. In some situations, manual signs are okay because they are always readily accessible. However, they are often produced in an idiosyncratic manner and rarely work across domains. Note: Communication wallets, booklets don't work well because individuals can not get at them fast enough.
Strategy: Increase the number of directives staff gives the individual that involve doing something "he/she wants to do." Most of the time staff are telling people what they "need to do." Individuals learn to associate staff requests with undesirable tasks.
- 2. OBTAIN GOODS AND SERVICES**
Strategy: Use graphic modes that depict specific, preferred items. For example, a picture of a diet coke or the McDonald's logo. Provide opportunities for individual to ask and receive what they request.
- 3. GET/SUSTAIN ATTENTION.**
Strategy: Teach individual to go up to someone and stand in front of person. (Note: This is effective, but a difficult situation to set up for instruction.)
Strategy: Teach individual to vocalize. (Note: This is difficult as they may not imitate appropriate types of vocalizations).
Strategy: Touching. (Note: This can be a problem if misinterpreted by receivers)
Strategy: Use a battery powered pocket pacer with a beeping sound, worn on a belt clip.

matically taken care of. One study¹⁴ found swinging was a more effective reinforcer than food or praise for 4 out of 5 subjects. In another example, staff put representations of the individual's scheduled activities in the pages of his favorite magazine. As he leafed through the pages, they called attention to the activities. Finally, a man who only responded (by laughing) if a

caregiver dropped something, was taught to use a picture to request staff "do something silly" (e.g. put on a weird hat).

Final note: If we take the time to listen and learn from our clients and provide them with opportunities to participate and with a means to access communication, intervention can make a real difference in their lives.



**Governmental
Work Incentives**

At a recent conference, professionals raised concerns saying individuals with severe disabilities will lose their "benefits" if they "made too much money." **That doesn't need to happen!** Here are some important facts. Note: The reference is excellent!

The Employment Opportunity for Disabled Americans Act (P.L. 99-643) encourages individuals who are receiving Supplemental Security Income (SSI) and Medicaid to work and/or pursue training and education.¹⁵

For more information, contact your local Social Security Office and ask for the Work Incentive Specialist (Note: they are supposed to have one!)

- 1. People who receive SSI can earn money on the job and keep all or part of their monthly SSI payments (*Section 1619a*).
- 2. People can keep Medicaid benefits as long as they need them to continue working, even if they are no longer getting a monthly SSI payment. (*Section 1619b*).
- 3. People can deduct expenses for services or items they pay for, which are directly related to enabling them to work and are needed because of a physical or mental impairment. This may include a personal atten-

dant, a special piece of equipment, special transportation costs.) (Impairment Related Work Expenses IRWE).

- 4. People can also save money for a special reason that will assist them on their job or help them achieve their vocational goals (e.g., education, special training, special equipment.) (*Plan for Achieving Self Support PASS*).

Note: Anyone can help write a plan (PASS) and have it approved by the Social Security Administration (SSA).

Below is an example of how the Work Incentive Equations works.

Gary receives an SSI payment of \$380 per month and has Medicaid coverage. He has no other income. He was been offered a part time job for \$160 per month. **WHAT WILL HIS MONTHLY INCOME BE?**

1. \$20 automatically excluded from monthly job salary (\$160) = \$140
2. \$65 also excluded as "earned income" = \$75 left
3. minus \$25 for monthly transportation costs (IRWE expenses) = \$50 left
4. Calculate 1/2 of remaining amount = \$25. This is total amount of salary remaining **after exclusions.**
5. Subtract \$25 from amount of SSI payment (\$380 - \$25 = \$355)

ANSWER # 1: Gary would receive \$355 SSI plus his salary (\$160 minus the amount taken out for taxes) = **\$515** (minus taxes).

ANSWER #2: if he had a PASS for \$25 (e.g., for a communication aid) he would receive his entire SSI payment of \$380 plus the \$160 income (minus taxes = **\$540** (approximately)

Note: In any case, he would continue to receive Medicaid coverage.



University & Research

Institute on Disability at University of New Hampshire

The Institute on Disability was established in 1987 at the University of New Hampshire-Durham through the collaborative efforts of the Bureau of Special Education, Community Development Services, Division of Vocational Rehabilitation, the Developmental Disabilities Council, and the University of New Hampshire. In 1989 it was awarded a University Affiliated Program status in association with the Dartmouth Medical School and other state agencies.

The Institute on Disability, directed by Dr. Jan Nisbet, is collaborating with multiple agencies to conduct 4 major projects. Projects enhance the Institute's mission, i.e., to improve knowledge, policy, and practice related to the economic and social participation of persons with disabilities. Specifically, goals are to foster more and higher quality integration of persons with disabilities in their New Hampshire communities. Examples of current projects are:

1. Project I.N.S.T.E.P.P. (Integrating Neighborhood Schools - Training Education Personnel and Parents). Co-directed by Jan Nisbet and Cheryl Jorgenson, project associates are Stephen Calculator and Carolyn Rudy. This collaborative, 3 year project between the Institute and the Center for Health Promotion and Research is designed to help local school districts integrate students with severe disabilities into regular classes in their home school. Twenty school systems will receive training in:

- 1) integrating students with severe disabilities into neighborhood schools with typical peers,
- 2) developing a functional community-referenced skills curriculum,
- 3) providing integrated related activities through a transdisciplinary approach, and
- 4) involving parents in the educational process.

Over the past 2 years, staff and parents from 10 districts have participated. Each district has a long

term plan in place for full integration of all students to their neighborhood schools and has begun that process with 1 or more student.

2. State-wide systems change: New Hampshire's commitment to students with severe disabilities. Co-directed by Stephanie Powers, Robert Kennedy, and Jan Nisbet. This 5 year project is funded in cooperation with the Bureau of Special Education. Twenty-four school districts or programs receive on-site technical assistance by regional consultants. This includes workshops and awareness activities with teachers, administrators, school boards, and parents/families to decrease disincentives and increase the capacity of LEA's to support students with severe disabilities.

3. Following the lives of young adults with disabilities in New Hampshire. Directed by Jan Nisbet and coordinated by Stephen Lichtenstein, this four-year descriptive research study and training project is surveying 300 young adults regarding their employment and residential status. Information is being provided on employment opportunities, training, participation in leisure/recreation, level of independence, use of community services, and integration. Preliminary findings are concerning. Although

over 90% were enrolled during their last year of school in a vocational education class, less than 10 percent had related goals in their I.E.P. Fifty percent held jobs in high school. However, less than 10 percent had any involvement with adult services. Students with severe disabilities generally received certificates for completing school.

4. Project School to Work. Directed by Jan Nisbet with project Coordinator, Patty Cotton. The focus will be to provide successful transitions from school to the adult world by identifying alternative support strategies for young adults with disabilities. This project builds circles of natural support among the employers, coworkers, family, friends, and community members of persons with severe disabilities to increase their vocational, leisure, living, and community options.

Other research projects at the University of NH in the AAC area:

- 1. Identifying best practices in delivering AAC services to students with severe disabilities (Drs. Calculator and Jorgensen)
- 2. Determining opinions among AAC team members regarding what constitutes important communication goals. (Drs. Calculator and Jorgensen)
- 3. Perspectives on communication competence in AAC use (Dr. Calculator in cooperation with Drs. Linda Hoag, Jan Bedrosian, and Barry Molineaux.)

For additional information about the Institute, contact Jan Nisbet. For information related to AAC, contact Stephen Calculator. (See list of Resources for addresses).

13 States Receive 1990 Awards for Assistive Technology

STATE	LEAD AGENCY	STATE	LEAD AGENCY
Alaska	Millie Ryan, Div. of Rehab., Dept. of Educ. (907) 465-2814	Oregon	Tim Latta, Dept. of Human Resources, Voc. Rehab. Division (503) 378-3830
Indiana	Constance Brown, Dept. of Human Services, Div. of Rehab. Services (317) 232-1409	Tennessee	Earnest Campbell, Dept. of Mental Health/Mental Retardation (615) 741-2361
Iowa	Univ. of Iowa, Div. of Devel. Dis.	Vermont	David Baker, Agency of Human Services Planning Division, (802) 241-2228
Massachusetts	Nancy Robbins, Commission for the Deaf & Hard of Hearing, Central Office (617) 727-5106	Virginia	Dale Hanks, Dept. of Rehab. Serv. Office of Planning, (804) 367-0264
Mississippi	Mark Smith, Dept. of Human Serv. Div. of Rehab. Serv. (601) 354-6272	Wisconsin	Susan Kell, Dept. of Health & Soc. Serv. Div. Voc. Rehab, (608) 266-2179
Nevada	Donny Loux, Rehab. Div. PRPD, (702) 885-4440		
New Mexico	Terry Brigance, Dept. of Educ., Div. Voc. Rehab. (505) 827-3522		
North Carolina	Ricki Cook, Dept. of Human Resources, (919) 733-3364		

CONGRATULATIONS TO ALL!

Consumer involvement, equipment loan programs, information dissemination & consumer awareness mechanisms were among the highlighted features.



Resources (Your Network)

Paul Alberto, Special Education, Dept. of Special Education, Georgia State University, Atlanta, GA 30303 (404) 651-2310.

Stephen Calculator, Dept. of Comm. Dis.-PCAC, University of New Hampshire, Durham, NH 03828 (603) 862-3836.

Al Cook, Assistive Device Center-SCUS, 600 J Street., Sacramento, CA 95819. (916) 278-6422.

Mark Durand, Dept. of Psychology, SUNY-Albany, Albany, NY (518) 442-4845.

Bill Lynn, Communication Services, State Dept. of Mental Retardation, Region I Northwest Center, 195 Alford Park Road, Torrington, CT 06790 (203) 482-0196.

Patricia Mirenda, Special Education Dept., Douglas College & University of Nebraska, P.O. Box 2503, New Westminster, BC, Canada, V5L 3B2. (604) 527-5400.

Jan Nisbet, Institute on Disability, University of New Hampshire, Durham, NH 03824 (603) 862-2310.

Joseph Reichle, Communication Disorders and Special Education, University of Minnesota, 164 Pillsbury Drive, S.E., Minneapolis, MN 55455 (612) 624-3322.

Mary Ann Romski, Yerkes Primate Center, 954 Gatewood Rd., Atlanta, CA 30322 (404) 243-8287.

Patti Green Roth, Project Inform. UCPA, Inc. 1522 K Street, NW, #1112, Washington, DC 20005 (202) 842-1266.

Lynn Scherfenberg, Ablenet, 1081 10th Ave. Minneapolis, MN 55414 (800) 322-0956.

Mauren T. Schweitzer, Assoc. of Retarded Citizens-Delaware, 240 N. James St., Suite 100, Wilmington, DE 19804. (302) 998-8090.

Louise Kent Udolf, Udolf & Udolf, 5400 Memorial Dr., Suite 406, Houston, TX 77007-8257 (713)880-9674.

References

¹ Mercer, J. (1973). The myth of 3% prevalence. In G. Tarjan, R. Eymann, C. Meyer (Eds.), *Sociobehavioral studies in mental retardation*. Wash., D.C.: AAMD.

News

A Notice of Proposed Rule Making appeared in the Federal Register on April 16, 1990 inviting "public comment" for Title 2 monies (P.L. 100-407). **BEFORE MAY 31, WRITE A LETTER** specifying what you think the priorities for grants should be. For example:
Dear Ms. Berland:

In response to the request for public comment to the Notice of Proposed Rule Making in the Federal Register on April 16, 1990, I suggest supporting: Blah Blah Blah (i.e., your favorite project) Please note these priorities address the communication needs of more than 2 million Americans who are now unable to express themselves sufficiently to participate in educational, vocational, leisure, community, and domestic activities. Thank you. (etc.)
Send to: Betty Jo Berland, NIDRR-Dept. of Educ., 400 Maryland Ave, Switzer Bldg.-Rm 3422, Washington, D.C. 20202-2016.

² Blackstone, S. (1989). Augmentative Communication. In Lahm, E. (Ed.) *Technology with low incidence populations: Promoting access to education and learning*. Reston, VA: Center for Special education technology, CEC. (800) 873-8255.

³ Kraus, L.E. & Stoddard, S. (1989). *Chartbook on disability in the United States*. An InfoUse Report. Washington, DC: U.S. National Institute on Disability and Rehabilitation Research.

⁴ Bellamy, G., Rhodes, L., Bourbeam, P. & Mank, D. (1987). Mental retardation services in sheltered workshops and day activity programs. Consumer benefits and policy alternatives. In F. Rusch (Ed.) *Competitive employment: Delivery models, methods, and issues*. Baltimore, MD: Paul H. Brookes.

⁵ Kregel, J, Wehman, Banks, P. (1989) The effects of consumer characteristics and type of employment model on individual outcomes in supported employment. *Journal of applied behavior analysis*. 22:4, 407-415.

⁶ Haney, J., Wilson, J., Halle, J. (1988). Adults with mental retardation: Who they are, where they are, and how their communicative needs can be met. In Calculator, S. & Bedrosian, J. *Communication assessment and intervention for adults with mental retardation*.

⁷ M. Schweitzer (April, 1990). Pers. comm.

⁸ S. Calculator, (April, 1990). Pers. comm.

⁹ Kregel, J. & Wehman, P. (1989) Supported employment: promises deferred for persons with severe disabilities. *JASH* 14:4, p. 293.

¹⁰ Shane, H., Lipshultz, R., & Shane, C. (1982). Facilitating the communicative interaction of nonspeaking persons in large residential settings. *Topics in language disorders*. 2:73-84.

¹¹ J. Reichle. (April, 1990) Pers. comm.

¹² L. K. Udolf. (April, 1990) Pers. comm.

¹³ McNaughton, D. & Light, J. (1989). Teaching facilitators to support the communication skills of an adult with severe cognitive disabilities. *AAAC*. 5:1, 35-41.

¹⁴ Sandler, A. & McLain, S. (1987). Sensory reinforcement: Effects of response-contingent vestibular stimulation on multiply handicapped children. *American Journal of Mental Deficiency*, 91 (4), 373-378.

¹⁵ Cohen, R., Green Roth, P., & Morris, M. (in preparation). *A new way of thinking - getting to work, understanding SSI benefits for people with disabilities*. UCPA, Inc. Community Services Division 1522 K Street, NW, Suite 1112, Washington, DC 20005.

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Calculator, S. & Bedrosian, J. (1988). *Communication assessment and intervention for adults with mental retardation*. Boston: Little Brown

Brown, F. & Lehr, D. (1989). *Persons with profound disabilities: Issues and practices*. Baltimore: Paul H. Brookes.

Journal of the association for persons with severe handicaps (JASH) (1989) 14:4 (entire issue will be of interest).

Reichle, J., York, J., Sigafoos, J. (in press). Implementing augmentative and alternative communication: Strategies for learners with severe disabilities. Baltimore: Brookes.

Summers, J. (Ed.) 1986. *The right to grow up: An introduction to adults with developmental disabilities*. Baltimore: Brookes.

York, J. & Rainforth, B. (1989). *Related educational services for individuals with severe disabilities*: Seattle: TASH.