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## ABSTRACT

This special edition of "The Networker" contains several articles focusing on aging and cerebral palsy (CP). "Aging and Cerebral Palsy: Pathways to Successful Aging" (Jenny C. Overeynder) reports on the National Invitational Colloquium on Aging and Cerebral Palsy held in April 1993. "Observations from an Observer" (Kathleen K. Barrett) describes the development of a survey of older adults with CP. "Aging with a Disability: Educating Myself" (June Isaacson Kailes) notes that living 20 or 30 years with a disability produces wear and tear on many body systems and lists 21 areas of research need. "Personal Assistance Services" (April Marie Myers) describes a woman with CP's realization of the value of hiring a personal assistant. "Reflections on the Aging Process" (Maureen Arcand) discusses therapeutic developments in CP over the past 65 years, explores ways to compensate for CP problems that multiply with aging, and encourages commitment to advocacy. "Social and Emotional Dilemmas Faced by Older Persons with Cerebral Palsy" (Gary B. Seltzer) discusses age-associated changes in social relationships, ambulation and mobility, sexuality, fear about the future, and coping with life events. "Adults with Cerebral Palsy: Exercise and Fitness" (Margaret Turk) reviews the prevention aspects of regular exercise, focusing on stretching, strengthening, and conditioning. Other articles include "Old Dogs and New Tricks: My Struggle with Independence" (David Bauer); "Getting Older" (Michael B. Williams); and "Cerebral Palsy Academy To Stress Involvement of People with Disabilities" (Alfred L. Scherzer). (JDD)

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*"When I was born almost 65 years ago, unexpectedly survived but then failed to develop as my grandmother kept saying I should, no one could tell my parents what to expect. In my fifties when I began to sense changes in my ability to do things I had always done, again no one could tell me what to expect as I aged with cerebral palsy." So writes Maureen Arcand (pictured at left) in **Reflections on the Aging Process** which appears on page 14 of this issue.*

Maureen participated in the National Invitational Colloquium on Aging and Cerebral Palsy, held in conjunction with United Cerebral Palsy Associations' 1993 Annual Conference in Alexandria, Virginia last April. Colloquium participants included medical practitioners, researchers, service providers and persons with cerebral palsy who were asked to synthesize existing knowledge and to make a series of recommendations for research, clinical practice and public policy. A preliminary report from the Colloquium will be disseminated in January 1994, and the full report from the Colloquium will be available by Fall 1994.

## SPECIAL EDITION ON AGING AND CEREBRAL PALSY

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## AGING AND CEREBRAL PALSY: PATHWAYS TO SUCCESSFUL AGING

*A Report on a National Invitational Colloquium on Aging and Cerebral Palsy—April 1993*

by Jenny C. Overeynder, ACSW

### Background

In April, 1993, a group of practitioners, researchers, service providers and persons with cerebral palsy convened for two days in Alexandria, Virginia for a National Invitational Colloquium on Aging and Cerebral Palsy. The Colloquium was an outcome of the efforts of a Task Force on Cerebral Palsy and Aging that was assembled at the request of the New York State Developmental Disabilities Planning Council (NYS DDPC) in 1991. Consultation with professionals and people with cerebral palsy in New York State as well as input from adults with cerebral palsy at four public informational meetings in the state had raised major concerns about changes in physical functioning for this population as they age. The Task Force found that little is known concerning the interaction of aging and lifelong cerebral palsy and that most of the information is anecdotal.

The Task Force issued a report in 1992, *I'm Worried About The Future: The Aging of Adults with Cerebral Palsy* (Overeynder, Turk, Dalton & Janicki), which recommended that the NYS DDPC play a key role in facilitating and co-sponsoring a National Colloquium on Aging and Cerebral Palsy. The purpose of this Colloquium was to bring together experts from all parts of the country to discuss issues that are faced by persons with cerebral palsy as they grow older. Colloquium participants were asked to synthesize existing knowledge and to make a series of recommendations for research, clinical practice and public policy initiatives to address pertinent aspects of the aging process faced by men and women with cerebral palsy.

Adults and older persons with cerebral palsy played a key role in carrying out this endeavor, both in the planning stages as well as in their participation in the Colloquium. They contributed much anecdotal information and freely shared their personal experiences, thus adding legitimacy and integrity to the process. The Task Force decided which topics were of most concern and identified and invited persons in the nation with

relevant expertise to participate. United Cerebral Palsy Associations, Inc. (UCPA) extended an invitation to hold the Colloquium concurrently with its Annual Conference and Meeting in April 1993 in Alexandria, VA. UCPA was also instrumental in identifying a significant number of persons with cerebral palsy, who were willing to contribute to the discussions.

Financial support was received from the New York State Developmental Disabilities Planning Council, the National Institute on Disability and Rehabilitation Research, and the Administration on Developmental Disabilities. The Colloquium was sponsored by the Strong Center for Developmental Disabilities at the University of Rochester, the SUNY Health Science Center at Syracuse, the Center for Therapeutic Application of Technology, SUNY Buffalo, the New York Institute for Basic Research in Developmental Disabilities, the New York State Office of Mental Retardation and Developmental Disabilities, the New York State Office for the Aging, Catholic Charities of Brooklyn, the New York State Office of Advocate for the Disabled, the Ontario Federation for Cerebral Palsy, UCP of Queens, UCP of New York State, United Cerebral Palsy Associations, Inc, and the Waisman Center UAP of the University of Wisconsin-Madison.

### National Colloquium

Fifty people attended the two-day event. Colloquium participants were divided into three groups:

- I. Oral motor functioning/nutrition/swallowing/gastrointestinal functioning/communication;
- II. Motor functioning and other physical aspects, i.e. genito-urinary and reproductive issues/assistive technology; and
- III. Psycho-social/life transitions/women's issues/sexuality/health care access.

Each of these topical groups was chaired by a person who had held several conference calls with the group prior to the Colloquium to develop an outline for the discussions and to prioritize the topics to be discussed.

The following questions formed the basis for the Colloquium:

What is the current status of knowledge in each topical area? What are the gaps in that knowledge?

What are age-related changes that are unaffected by the presence of cerebral palsy?

What risk factors can cause the aging process to vary for persons with cerebral palsy?

What are the major secondary conditions associated with cerebral palsy in each of the topic areas?

What treatment and intervention strategies are most used for the prevention of secondary conditions and age-related problems?

What are the standards for best practices?

What research strategies should be promoted?

What are the implications for service, training and public policy initiatives?

What are the major barriers to access to health care by adults with cerebral palsy?

How can assistive technology contribute to solutions?

The objective of these discussions was to summarize the state of knowledge, to identify available "best practice" guidelines, to describe gaps between knowledge and practice, to present recommendations in the context of these gaps and to identify the resources, funding and legislation available to implement the recommendations.

### General Recommendations

The following recommendations were made:

1. To develop a plan that meets the needs of, and receives major input from, persons with cerebral palsy;
2. To establish a National Task Force to oversee the implementation of the Colloquium recommendations. This task force should have shared sponsorship, include a significant number of persons with disabilities, and have an adequate representation of relevant agencies;
3. To design and implement a health and wellness agenda that should include full access to existing programs, emphasize self advocacy and optimal functioning, and enable independent living as much as possible;

4. To develop educational materials to provide training and dissemination of information to health care providers, adults with cerebral palsy and caregivers;
5. To establish an information and referral network, including resource persons, across the country;
6. To stimulate applied research, with emphasis on women's issues, best practice guidelines, and studies of life-long impact of early intervention strategies;
7. To advocate for public policy changes to increase access to care and prevention of secondary conditions;
8. To establish linkages with professional, state and national organizations to stimulate those organizations to undertake activities addressing the needs of older persons with cerebral palsy.

### Follow-up

A detailed report of the Colloquium discussions is being prepared by the NYS DDPC Task Force on Aging and Cerebral Palsy and will be ready for dissemination early in 1994. The findings will be presented by workgroup members and Colloquium participants at various state and national conferences. UCPA, Inc. will assemble a national steering committee to begin the work of implementing the plan's recommendations. Briefings for legislators and key representatives of national organizations will take place in 1994.

*Jenny C. Overeynder is Director of the Training Program in Aging and Developmental Disabilities at the Strong Center for Developmental Disabilities, University of Rochester, N.Y., and Co-chair, Task Force on Aging and Cerebral Palsy, New York State Developmental Disabilities Planning Council.*

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## NATIONAL COLLOQUIUM ON AGING AND CEREBRAL PALSY RECOMMENDATIONS

### Prevention and Intervention

- Involve persons with cerebral palsy in regular fitness program, as appropriate to their capabilities.
- Promote clinical and self care practices that reduce or prevent secondary complications.
- Create opportunities for comprehensive health care services for older adults with cerebral palsy.
- Emphasize early detection of physical and psycho-social problems.
- Provide support to promote options and choices for older persons with cerebral palsy with regard to their participation in community, leisure, civic and other activities.

### Training and Education

- Provide training in currently available "best practices" to physicians and allied health care personnel. Develop guidelines for what constitutes best practices for this population.
- Provide advocacy training to persons with cerebral palsy and their family members so they can be more effective self-advocates.
- Provide training in appropriate assistive technology, as well as in psycho-social issues, faced by persons with cerebral palsy.
- Make all training materials available in a variety of modalities (e.g., printed versions, video versions).
- Establish a national information and dissemination network. Include persons with cerebral palsy who can act as role models and resources.

### Research

- Advocate for research funding to investigate the cost-effectiveness of providing appropriate prevention services, rehabilitation therapies, and chronic care management services to adults and older persons with cerebral palsy.
- Advocate for research into the advantages and problems of managed care delivery models and their ability to provide effective preventive services.
- Advocate for the funding of selected projects that focus on prevention.

- Give priority to projects that have immediate and practical application for individuals with cerebral palsy.
- Encourage research in:
  - Effectiveness of traditional methods for prevention of secondary conditions
  - Implications of interventions during childhood and adolescence on life-long functioning
  - Epidemiology-related issues
  - Gender-related issues
  - Community supports (i.e., natural support systems as well as supports in the service sector)
  - Oral-motor and gastrointestinal problems
  - Dietary/nutritional management
  - Management of bowel disorders
  - Prevention of dental problems
  - Management of incontinence
  - Optimal sexual functioning
  - Psycho-social implications of aging for persons with cerebral palsy
- Develop epidemiological approaches to measure the percentage of persons with cerebral palsy who are not receiving appropriate preventive care.
- Provide data to assist health care planners in the development of preventive services.

### Policy

- Include persons with cerebral palsy and their families in all aspects of planning, evaluation, and decision-making.
- Ensure that health care reform provides adequate coverage for adults and older persons with cerebral palsy.
- Develop and fund at least two comprehensive centers of excellence that provide services, research and training in aging and cerebral palsy.
- Develop a wellness educational model as well as an effective system to disseminate the information generated from that model.
- Provide information about and access to appropriate assistive devices.
- Develop a life-span approach in the service system.

## OBSERVATIONS FROM AN OBSERVER

by Kathleen K. Barrett

The National Invitational Colloquium on Aging and Cerebral Palsy, held in conjunction with UCPA's Annual Conference, brought together individuals from across the country who have contributed their time and energy to this emerging area of study. There were fifty participants and several observers. I was an "observer."

During the first session, both participants and observers introduced themselves. As the time to introduce myself neared, I remembered my experiences with the project. At the November 1987 Annual Conference of UCPA of California, I suggested a study of aging in persons with cerebral palsy (CP). The subjects were to be persons over thirty years of age. I wanted to know if the problems I was experiencing—aching joints, lower back pains, pinched nerves and a strained neck—were happening to other persons with CP. Did they experience feelings of depression? Did they have problems accessing the health care system? Did they have to constantly educate health care professionals? What exactly was going on with my fellow "baby boomers" with CP?

In 1987 also, I asked several people interested in the aging process and cerebral palsy to join a workgroup. My fellow members named our group, the "Barrett group." I really didn't like that name, but the "aging group" was worse!

Our goal was to develop a proposal for funding a study of this subject. Little was known and it wasn't an easy task, but we were all excited about exploring what we perceived as uncharted ground. Our study would not be patterned after a medical model. Instead, it would be driven and designed by persons with cerebral palsy. The members of our workgroup were Margaret O. Murray, past President of UCPA, Inc.; Susan Fleischman, MSW, Program Director of UCP of Alameda-Contra Costa Counties; Ernest Weinrich, UCPA, Inc.; Jean Kohn, MD, School of Public Health, University of California at Berkeley; Robert Segalman, Ph.D., statistical researcher, and myself. Bob Segalman had written several articles on this subject, one of which had been published in *Research Notes* published by the UCP Research and Educational Foundation. At that time, I had been a volunteer for 11 years, serving on local and state UCP boards as well as on several national committees. Ernie, Bob and I have cerebral palsy. Since



Bob and I both worked for the State of California, we took vacation time to attend the meetings. Bob was, at that time, experiencing pain in his hip.

Our group spent the first several meetings defining our universe. We would interview persons with CP over the age of thirty. How large should our sample be? Could we study both the physical and the emotional aspects? Did we want to ask about dental hygiene?

We agreed that our initial study would focus on the aging process and the changes that occur in a person's health and physical status. We asked questions that would capture changes or difficulties in the following areas: health, physical abilities, sexuality, access to and use of health services, satisfaction with health care. Questions asked had to be worded so that the responses could be measured and studied. In a survey of persons with cerebral palsy such as ours, quantifying individual responses, which could be subjective at times, would be difficult.

We met regularly for five months. We debated, argued and then came to agreement. The sample group would be 101 adults with CP who were older than 30. The study would concentrate on individuals known to the local affiliate: UCP of Alameda-Contra Costa Counties, located in Oakland, California. The decision to limit the study to one affiliate was difficult. Cost was a contributing factor in limiting our study.

Another point of discussion was whether to seek federal funding. We decided to seek private

foundation monies, believing that it would be easier to keep the focus on what people with cerebral palsy are experiencing if the study were privately funded. Therefore, in May 1988, we submitted a proposal to the private, community-based Catherine Lyle Murray Foundation. Founded by Mr. and Mrs. Clark O. Murray, this foundation gives small grants to projects that enhance and enrich the lives of persons with disabilities. One of our workgroup members was Mrs. Margaret O. Murray ("Peg"), but this alone did not assure us of full funding. Our proposal asked for \$11,300, a large amount for this foundation. Funding of our project by their Board of Directors would mean others, no more or less deserving, would wait.

In June of that year, UCP received official notice that we had received the full amount from the Murray Foundation. Kathleen Lankasky, Public Information Officer for UCP of Alameda-Contra Costa Counties, was hired to conduct the interviews, and Roberta O. Grady, R.N., Ph.D., of the University of California at Berkeley was employed to direct the research and write the report. A questionnaire developed by Bob Segalman was the basis for the final study questionnaire.

Although not required by the study design, our workgroup hoped that the study would result in an inservice training video being developed for health care providers and also that more articles, such as Bob Segalman's article on this topic in the Winter

1987 UCP Research and Educational Foundation *Research Notes*, would be written by adults with cerebral palsy.

In May 1989, our study was completed and ready for presentation. With assistance from Jean Kohn, MD, and Margaret Murray, the Academy of Cerebral Palsy and Developmental Medicine allowed us an eight-minute time slot during one of the sessions at its annual conference in San Francisco in October 1989. The sheer number of questions asked afterwards told us that we had indeed hit upon an area that needed further exploration. Now, three years later, there was a National Colloquium on Aging and Cerebral Palsy, of which Bob Segalman, Ph.D., and I were observers.

And so, when I introduced myself at the Colloquium, I simply stated my name and my affiliate. I couldn't put into words the enormous feeling of accomplishment I felt—not for myself, but rather for the five members of what we had named, in 1987, the "Barrett group." Thanks, Doctor Kohn, Susan, Emie, Bob and "Peg." Thanks so very much.

*Kathleen Barrett recently retired from her position as Personnel Analyst for the California Personnel Board. In addition to being a licensed glider pilot and freelance writer, she is also a recently appointed member of UCPA's Professional Services Program Committee, a current Board Member of UCP of Alameda-Contra Costa Counties, CA, and former member of the UCP of California Executive Committee.*

## AGING WITH A DISABILITY: EDUCATING MYSELF

by June Isaacson Kailes

*(A shorter version of this article was published in the United Cerebral Palsy Associations' January 1990 NETWORKER.)*

People with disabilities are now experiencing problems that combine those of aging with those unique to a life spent living with a specific disability. We have all been told, "As you get older, you slow down physically, and you can't do as many things as you could when you were younger." For most of us who grew up with a disability, who could not do as much as our peers without disabilities, this warning was rather meaningless. Others with disabilities who did listen to this warning certainly did not expect that the aging process would be accelerated. However, people with disabilities

are experiencing unexpected declines in their energy and activity levels as they age. We are exhibiting signs of aging earlier than people of our age without disabilities. Yet, existing public policy and health and human services are not dealing with this issue.

When I, a person with cerebral palsy, would speak my concerns to friends who were medical professionals, I felt that my descriptions sounded vague and slightly bizarre. When I explained, "I'm not walking as fast, my balance is not as good, I have more spasticity and many more aches and pain," all I received were blank looks. I decided to initiate my own informal survey of friends and colleagues with disabilities. My results confirmed that I was not alone. After careful review of my situation, I decided to seek some additional professional opinions.

Because I had work experience in rehabilitation and neurology, I felt confident that I could find the appropriate resources. I was wrong! The process was disconcerting, despite the fact that I live in Los Angeles, with its plentiful medical resources. I found doctors who specialize in children with cerebral palsy (CP), but I was not able to identify anyone who specializes in adults with CP. After a costly and probably unnecessary MRI of the brain, the advice I received from several health professionals was to concentrate on strengthening specific muscles. Other than that, no one had anything more definitive to say.

I then sought the help of my out-of-town network and obtained names of additional professionals. When a business trip took me to the city in which he practiced, I connected with the doctor whose name was most frequently mentioned. He had some very different but specific and helpful advice regarding energy conservation, exercise, and mobility aids. He felt muscle strengthening would not be that helpful because the unevenness in cerebral palsy comes from imbalance in the degree of damage in the brain's motor cortex. That is, the firing pattern of electrical impulses in the motor cortex is asymmetrical, and it is not going to change. Therefore I could strengthen muscles as much as I wanted, but eventually they would return to being unequal in strength. In his opinion, the time and energy spent in exercising were not worth the very temporary, if any, results.

At this point, I felt I had found some answers for myself. But if I, a disability policy specialist, had to go through this rather extensive search for advice and information, I wondered what was happening with others who were asking similar questions. I also wondered what would happen to the upper extremities of others with cerebral palsy whom I saw walking so slowly and laboriously on crutches. Was walking so supremely valued by the medical community, family, and society that the long-term effects of wear and tear on upper extremities were better ignored, despite the consequences of accelerated deterioration?

#### Confirmation and Validation

The publication of Roberta B. Trieschmann's (1987) important book, *Aging With Disability*, confirmed for me and many others that our concerns were real and legitimate. Trieschmann substantiated the issue that has become a reality for many of us: People with disabilities are now experiencing problems that combine those of aging with those unique to a life spent living with a specific disability.

The combination of aging and disability is an unexplored, undiscussed, and unacknowledged area. Why is this such a new and unanticipated issue? I am told that in the past people with disabilities just never lived that long, and thus little is known about aging with an early-onset disability. My peers and I are the first generation of people with disabilities who are approaching middle age, retirement, and beyond in great numbers. People with disabilities have been taught how to live with a disability but not how to plan to age with a disability or how to prevent a disability from increasing via the aging process.

Before the publication of Trieschmann's book, peer input was the only validation and support people with disabilities had to assure each other that the accelerated aging we seemed to be experiencing was something real. Her book also alerted disability advocates that we must make room for yet another issue on our already full advocacy agenda. We have to insist that health and social service providers allocate a substantial amount of effort to issues of aging with a disability.

Trieschmann correctly points out that many of us consider our disabilities to be static (spinal cord injury, polio, cerebral palsy, spina bifida). A progressive component to our disability was not anticipated. Now, however, we are experiencing the natural process of aging superimposed on other impairments that have imposed a range of physical, emotional and financial penalties on our daily lives.

Apparently, the process of aging relates not only to chronological age but also the age at which one was disabled. Depending on one's lifestyle, genetic heritage, and type of disability, living 20 or 30 years with a disability produces wear and tear on the muscles, skeletal system, and other body systems. Most people with major physical disabilities of 30 years' duration note some tenderness and soreness in joints, muscles, and tendons that have been carrying an extra load because of impaired physical functioning in other parts of the body. Heavy use or over use of certain body parts (e.g., one's arms) to compensate for lost motor ability in others (e.g., one's legs) can lead to problems over time. As people with disabilities age, the physical penalty appears to increase.

#### The Absence of Rehabilitation Research

Trieschmann explains that rehabilitation is not a high-prestige clinical specialty because it does not focus on dramatic new discoveries leading to

"cures." Nor does it focus on the development of new procedures that "solve" problems, as do specialties like surgery, cardiology, radiology, and oncology. In the medical research world, research focused on practical issues such as helping people with disabilities to lead more satisfactory lives is considered a "weak" science. More prestige is given to "hard sciences" such as cellular, molecular, and biological research.

Rehabilitation medicine continues to focus on management of newly acquired disabilities. Hence there is little knowledge to offer the person who lives with a long-term disability. The gap between the needs of people with disabilities who are aging and existing programs to help minimize the impact of the aging process is immense. Research on "living and aging with a disability" is a very low priority! The only groups given the slightest attention in the area of aging with a disability are people with spinal cord injuries or survivors of polio (e.g., Trieschmann, 1987). What about people with other types of disabilities? Future research in this area must be broadened.

One way to accomplish this is to apply some of the core principles of the independent living movement. This movement emphasizes self-direction and control in contrast to more traditional model in which the

"client/patient" is highly dependent on experts. We ourselves accomplish service coordination to the greatest extent possible. People are not labeled "cases" to be managed, as in "case management." We are people who need to achieve and maintain a sense of empowerment in order to oversee our own service acquisition and coordination. To people with disabilities, playing a role in self-care is key. The authoritarian role of the physician in diagnosis and treatment is deemphasized. In the independent living movement there is a healthy distrust of the traditional belief that medical providers always know best. The movement challenges those doctors and other health professionals who have a tendency to be dogmatically prescriptive and judgmental in telling people with disabilities what to do and how to live their lives.

We must insist that factors that mitigate the effects of aging and early-onset disability be studied and the findings then applied. The relationship between people with disabilities and their physicians, as well as other health professionals, must become a partnership based upon mutual respect and shared problem solving. We with early-onset disability must make our needs known in the areas of service provision, research, education (especially prevention), and advocacy.

\* \* \* \* \*

Researchers and those who set research priorities must be convinced that people with disabilities are a large and growing segment of the population (because the population is aging and because people with disabilities are living longer) and that there is a great need for answers to questions like the following:

#### Medical-Functional Research

- What is the role of nutrition, exercise, stress management, and other lifestyle issues in aging with a disability?
- Does the presence of a disability accelerate the rate of aging or alter the manifestations of the aging process?
- In what way do decades of living with a disability alter the general aging process from the course it would have taken in the absence of disability?
- If aging is different as a result of disability, is the difference a generalized syndrome that cuts across most disabilities, or are there specific patterns or problems associated with certain disabilities?
- Are the rates of aging and its manifestation different for those who acquire their disability in early adult years in contrast to those who acquired it in their later years, in childhood, or at birth?
- What factors (e.g., amount and duration of

extra labor, general state of health, genetic makeup) contribute to musculoskeletal deterioration in persons with early-onset disability?

- Will examination of the medical records of those who have died after living with disability show that there is a combination of variables, a pattern, that differentiates long-term survivors from those who died early on?
- Will the study of medical records, including radiological reports and films of people with disabilities, uncover short-term and long-term patterns of change?

#### Questions Concerning Preventive Education

- What proactive preventive steps could be taken early in life to prevent or slow the specific effects of aging with disability?
- Is "use it or lose it" a sound strategy, or would voluntary curtailment in the intensity and scope

of certain activities at an earlier age translate into fewer musculoskeletal difficulties in later years?

- Are there trade-offs that need to be decided upon early in life—for example, choosing the rigors of walking with crutches or instead opting for use of a wheelchair to prevent upper extremity muscle deterioration, particularly if one's career depends on upper extremity muscles?
- At what point should a program to conserve energy or prevent increased disability start?
- What is the effect of exercise on preventing increasing disability for specific types of disability groups?
- Is physical conditioning more important for people with disabilities than for the general population? To what extent is a decline in energy and strength accelerated by performing repeated activities of daily living and mobility (which, for people with disabilities, are like athletic events) without being in proper physical condition?
- Does active and consistent participation in sports for people with disabilities accelerate musculoskeletal difficulties or slow them because of enhanced physical condition and health?

#### Questions Concerning Nutritional Research

- Do nutritional issues need increased attention for people with disabilities?
- Would strategies followed in sports nutrition regimes have a positive or negative effect on people with disabilities?
- Are peak performance diets even more relevant for people with disabilities, since living with disability often means continual body strain

and stress? For example, those without disabilities who have been athletic all their lives and who have continued to eat properly seem to age less rapidly and are healthier than their nonathletic counterparts. What implication does this have for people with disabilities?

- What is the effect of excess body weight on the development of increased impairment?
- Does a high fat, high protein, high sugar diet have greater impact on a person with a disability as opposed to others?
- Is calcium supplementation even more important for people with disabilities than for the general population?

#### Advocacy Issues

In addition to demanding attention from the research community, we must also advocate that policy makers address the following issues:

- Integrating an aging and disability focus into the practice of allied health professions.
- Reworking and coordinating fragmented social legislation that, although not intended to, keeps people poor and requires that they remain so if they expect any assistance.
- Demanding an array of community-based long-term services that embrace the values of empowerment and self-determination and that assist us in continuing to work and to stay in our homes. The issue of community-based long-term services, although frequently viewed as just a senior concern, is our issue also. If our function declines, we still want to work and to remain independent, free to manage our own lives in our own homes.

In summary, our new awareness of the effects of aging with a disability is accompanied by an increasingly urgent need for information, answers, and services. We must be heard and must forcefully demand that medical, health, and social service providers, as well as public policy makers, devote time and dollars to filling the many gaps in knowledge and services surrounding the issues of aging with a disability.

#### References

Trieschmann, R., 1987. *Aging with Disability*. New York: Demos.

[This publication may also be ordered by mail through the UCPA Materials Mailing Center, P.O. Box 10485, Lancaster, PA 17605-0485. Discounted cost of \$29.95 includes shipping and handling.]

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## PERSONAL ASSISTANCE SERVICES

by April Marie Myers

*It would take almost twenty-five years for me to realize how unproductive my philosophy of life was and how limiting my narrow view of independence would be to my future.*

I grew up believing that a disability was something that an individual had to overcome in order to be successful. I am a person with cerebral palsy who, as a child, saw only two choices of lifestyle for people with disabilities: Either you pushed yourself full speed ahead doing everything for yourself, or you sat back and allowed other people to attend to your needs.

At a very early age, I decided to seek a life of independence through determination and persistence. No matter how difficult the task was for me or how long it took me to complete, it was important to my fragile self-esteem for me to be able to proclaim that "I did it myself." It would take almost twenty-five years for me to realize how unproductive my philosophy of life was and how limiting my narrow view of independence would be to my future.

In my youth, my drive to achieve made me a strong student leader and helped me graduate from college with honors. It also gave me the desire and survival skills that allowed me to leave my family in Maine and move to Washington, DC. In Washington, I was able to launch my career and experience living alone in my own apartment for the first time.

In the eyes of my family, friends, and colleagues, I was the shining example of how mainstreaming could work and what people with disabilities could accomplish when they put their minds to it. I had all the basic components of a life that society expected from its non-disabled members.

Perhaps even more important to me was the fact that I never asked anyone to help me. I was "Super-Crip" and, except for an occasional hug, I did not need anything from anyone. I appeared independent and strong to all of the people who passed through my life.

Fortunately, my first job out of college was working for a Center for Independent Living as their Coordinator of Peer Counseling. This experience taught me some valuable lessons about the true meaning

of independent living and enabled me to gain important insights into myself.

The first thing that I discovered was that I can be a hypocrite. While I was effective in training other people with disabilities in how to be assertive and resourceful, I went home at night to struggle with making do for myself. Although I never defined the worth of the people around me by their quantity of physical accomplishments, I still viewed my personal independence in terms of finding a way to do everything for myself.

Two and a half years later, I accepted a different position working for another Center for Independent Living. One of my responsibilities at my new job was overseeing Personal Assistance Services (PAS). I recruited and provided orientations for people interested in working as Personal Assistants and maintained a PAS Registry. I also trained persons with disabilities on how to identify their needs for PAS and held workshops on how to manage Personal Assistants.

I often worked more than forty hours a week, attended computer classes at night, attempted to go to the health club three times per week, and tried to keep a part-time boyfriend entertained. Even though life was busy, I seemed to be managing all right on my own—until I woke up late one Saturday morning and took a long, painful look at my apartment.

I first noted the table covered with papers and unopened mail, then I surveyed the piles of laundry that had been strategically placed to the sides of the room—out of my path of travel. As I made my way to the bathroom, I felt the dirty floor under my bare feet and tried to remember the last time I cleaned the bathtub.

As a result of my "Super-Crip Complex," I confronted my mess by reaching the same logical conclusion that I had for the past three years: I immediately cancelled all of my plans in order to stay home and clean for the entire weekend.

When I proceeded to the kitchen to

make a pot of coffee and find something for breakfast, I was greeted by a sinkful of dirty dishes and an empty refrigerator. My environment appeared so depressing that I crawled back into bed in hopes that a few hours of sleep would make my life seem more manageable.

As I lay in my bed unable to fall back to sleep, I realized that my present lifestyle was not working and that I had to make some changes. I wondered what to change and how would it improve my life. My first consideration was what I could give up in order to have the time and the energy to appropriately care for my home.

Certainly, it did not make sense to stop attending the computer class which I had already paid for and was taking in hopes of reducing the time I spent on paperwork. If I no longer participated in aerobics and swimming, it would affect my health as well as my self-image. And I know myself well enough to know that sacrificing time with my friends would make me feel lonely, isolated, and depressed.

Clearly, lowering my quality of life would not produce a positive solution, and I would never consider requesting assistance from a friend. After pondering my situation for a couple of hours, I discovered that my dignified answer had been sitting on my desk at work all of this time. I could hire a Personal Assistant from the PAS Registry.

What a revolutionary concept for myself! I would not be relying upon someone else to care for me, something that would make me feel like a burden. Nor would I be assuming a hopeless or helpless role. Rather, I would be hiring and paying an individual to assist me.

I finally concluded that my independence and pride would be assured, as long as I was in control of the services. Besides, many of the most successful and productive people in the world have others perform time-consuming activities of daily living for them.

I began to reminisce about the jewelry which my mother used to assist me with

putting on and how my girlfriends in college would help me with my hair before we went out on the town. Then, my thoughts turned to the holidays and the impossible task of wrapping gifts.

It occurred to me that there could be a whole new world waiting around the corner for me. I interviewed my first Personal Assistant a week later and spent the next year discovering the empowering role that Personal Assistance Services can play in my life.

Initially, I thought of the routine household chores which I would benefit from having assistance with. Later I developed a list of activities which were either impossible for me to do or were unsafe for me to attempt alone, such as cutting my nails, standing on a chair to change a light bulb, and lighting the pilot light in the oven. All these are essential duties which any self-sufficient adult must complete by one means or another.

At this point in my life, the cost of a couple of hours per week of Personal Assistance Services has become as basic an expense as food, shelter and transportation.

*April Marie Myers recently joined UCPA as Principal Trainer for Project PASPORT TO CHANGE, a three-year project to train persons with disabilities and their families to educate policy makers on the need for Personal Assistance Services.*

***I never asked anyone to help me. I was "Super-Crip" and, except for an occasional hug, I did not need anything from anyone. I appeared independent and strong to all of the people who passed through my life.***

#### **ADULTS BORN PREMATURELY HAVE STORIES TO TELL**

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## OLD DOGS AND NEW TRICKS: My Struggle with Independence

by David Bauer

*Only after a long string of bloodied knees and severe headaches did I conclude that if Martha and I had any sort of future, we would not reach it riding bicycles.*

When I was 14 years old, I wanted desperately to ride a bicycle. I spent months attempting to navigate my brother's bike down the cement driveway beside our house, but the results were always the same. I'd glide a few feet, lose my balance, fall, and scrape my knees or bang my head on the driveway.

My determination stemmed not from a fascination with bikes, but from love. My neighbor Martha, also 14 years old, had suggested that I learn to ride so that we could take trips together. Only after a long string of bloodied knees and severe headaches did I conclude that if Martha and I had any sort of future, we would not reach it riding bicycles.

At no time did it occur to me that a bike was simply faster and easier than walking. The technology embodied in a bike held little interest for me unless the rewards of that technology were immediate, tangible and achievable. Technology was simply a means to an end. Without Martha, I had zero interest in bicycles.

In my mid-fifties, my balance and coordination deteriorated to the point that walking became extremely difficult. After several friends suggested that I might want to find a surer and more comfortable way to navigate, I bought an adult tricycle. The tricycle has been a godsend, enabling me to go to museums and movies with my wife, visit friends, go to the park to play chess, and engage in numerous other activities that I otherwise could not enjoy.

So even the low technology embodied in a bike adds immeasurably to my quality of life. The bad news is that in both my teens and my fifties, I have rarely struck out on my own initiative to discover the technology that can play such a major role for a person with a disability. I think my resistance stemmed

from a misguided notion of what independence is all about.

As an adult, I was content to look like a wounded duck as I walked around town because I was walking on my own. No training wheels, no tricycle, no Amigo for me, thank you very much. I'll do it on my own two feet. This, I thought, is independent living at its highest and purest form.

The problem was that I was walking to an increasingly fewer number of places. And when I got to where I was going, I was tired, disheveled, and in a foul mood. My independence was providing only the opportunity to sit home, logging more and more hours in front of the boob tube. Instead of opening new frontiers, independence was narrowing my horizons.

The turning point came when I realized that independence doesn't necessarily mean that I have to do everything myself. Bikes, Amigos and any other convenience are OK, particularly if they take you farther and faster than your feet ever did. If none of my nondisabled friends thought they were sacrificing their independence by riding rather than walking, why should I? I don't know why I had such trouble with this concept, but hey, when you're busy being independent, who has time to think?

*David Bauer is an economist who, upon retirement from the U.S. Department of Treasury, was persuaded to work part-time as a Consultant on Aging and Cerebral Palsy for UCPA's Community Services Division.*

*Instead of opening new frontiers, independence was narrowing my horizons.*

*My resistance stemmed from a misguided notion of what independence is all about.*

## GETTING OLDER

by Michael B. Williams

My name is Michael B. Williams, I am fifty-four years old, and I have severe cerebral palsy that affects both my mobility and speech. These are the bare-boned facts that have governed a life that has, up until recently, been relatively hassle free.

As a young adult, I was almost never sick. The only contact I had with doctors was to get an occasional dose of antibiotics. These visits required only the briefest of communications that could be dashed off on a typewriter, at home, before my appointment. Turning forty, a minor tragedy in most men's lives, was not a big deal to me. I still felt fine and was able to go about my daily routine and encounter relatively few minor medical intrusions.

Fifty has been another matter entirely. Before the big five-0, I was able to get around my house walking, using my electric wheelchair only for going on long excursions outside my house. Of course, I would take an occasional tumble, but I would get right back up and go about my business.

Hitting fifty has demonstrated that I'm not half the man I used to be. I have suffered several compression fractures to my back. These have necessitated rethinking my mobility problems. I no longer walk around the house, but use an electric wheelchair all the time. A routine eye examination turned up a case of hypertension. I now take medication for that. But the most startling thing about turning fifty is that I am now a candidate for all sorts of industrial strength medical tests, and these have brought me into a frightening intimacy with the medical establishment.

Consider the one I had the other day. I had flunked a colon screening test twice in a row. The doctor decides it's time for a serious look-see and sends me off to a specialist. Now, I hate meeting new doctors. I find very few know anything about cerebral palsy, and they view my inability to communicate by normal speech as a sign of mental retardation. But this specialist is different, and he likes the communication aid I'm using. With it I am able to tell him about any difficulties I may have

with the various tests he has proposed. He wants to do a colonoscopy. I say the prep on that will be too hard and the procedure itself is too invasive. We compromise on a barium enema but agree that if it shows anything, he can perform a colonoscopy on me.

After a day of not eating anything except liquids and sitting on the toilet the whole time, I'm ready to take the test. I feel weak, look like hell, am thinking like a bozo, and am trying to control my laxative-assaulted bowels while trying to drive my wheelchair. I'm not having fun.

Then I meet the x-ray team. They make me even more grumpy. They know nothing about cerebral palsy and even less about communication disabilities. Because I realize I will be flat on my back, I do not bring my speech synthesizer, as I won't be able to access it. I have with me instead a card with the letters of the alphabet printed on it. I hope these people can spell.

With the help of my wife, they get me on the x-ray table and then tell my wife to leave. With my wife out of the room, they put my letter card on my wheelchair, well out of my reach. I find this chilling. These people have no intention of communicating with me.

They proceed to have their way with me. They yell at me for not relaxing as the tube goes in. These people should be aware that people with cerebral palsy can't relax on command. I want to tell her, but have no way to do it. Then the liquid goes in—fast. More yelling about being tense. This is getting ugly. Then I'm left alone, and I start leaking. I try to hold it in to no avail. I start yelling, somebody comes, but they don't notice what the problem is. I start pointing wildly to my letter card, but nobody understands.

This goes on the whole time. When the session is over and my wife is let back in the room, I tell her nobody would listen to me. One of the technicians tells her, "We got along fine." What we have here is a failure to communicate.

By the way, the results were negative.

*Michael B. Williams has a Master's Degree in Library and Information Studies. He lives with his wife and son in Berkeley, CA.*

**The most startling thing about turning fifty is that I am now a candidate for all sorts of industrial strength medical tests, and these have brought me into a frightening intimacy with the medical establishment.**

## REFLECTIONS ON THE AGING PROCESS

by Maureen Arcand



*Those of us now reaching our sixties and above have lived our lives on the edge because information about CP was always a few steps behind us.*

To be asked to write for this very important issue of the **NETWORKER** is an honor and an opportunity. After over ten years of trying to bring attention to the matter of people growing older with cerebral palsy, this is the second big opportunity I've had in a matter of months to have the topic talked about. The other was as the oldest woman participant in the Colloquium on Aging and Cerebral Palsy, an experience that gave me a new goal.

Those of us now reaching our sixties and above have lived our lives on the edge because information about CP was always a few steps behind us. When I was born almost 65 years ago, unexpectedly survived, but then failed to develop as my grandmother kept saying I should, no one could tell my parents what to expect. In my fifties when I began sense changes in my ability to do things I had always done, again no one could tell me what to expect as I aged with CP.

The papers from the Colloquium are meant to lay the groundwork for future action. To do that, we need to look at the progress that has been made, and my own experience will illustrate that. I have always been grateful that my parents used good common sense from the beginning, since there were no professionals to advise them. My disability

had no name until age three when a chiropractor called it "spastic paralysis." With his help, I began to walk.

Until the age of seven, I had no therapy at all; none, that is, but my inclusion in the family and neighborhood. There was no hard pushing—just acceptance and encouragement. Looking back, it seems that I always had an innate ability to find other ways of doing things, and that ability turned out to be a key factor all my life. The earliest example of this was that I learned to roll on the floor to get where I wanted to go before I could walk. The neighborhood children caught the spirit and did things like throwing the ball at my extended bat, so I could hit it.

School was different. My first effort at going to school—when the teachers didn't have the time or help to cope with the problems that having me in the class created—was a disaster. The best thing that ever happened was my transfer in second grade to a "School for Crippled Children" in a city thirty miles from home. It meant being away from my family five days a week, but I had a teacher who understood me and believed in my abilities, classmates who also had physical limitations, and the first physical therapy I ever had. (There was no speech therapy until fifth grade.)

You may think the therapy I could have used as a child was actually available, but that we just didn't know about it then. Please, consider the fact that the city I went to school in was Madison, Wisconsin, and that each year I was checked by doctors at the University Hospital. That same University is now the home of the Waisman Center with its famous CP Clinic, Developmental Disabilities research and teaching facilities, and more recently its Project on Aging and Developmental Disabilities.

People with CP reading this will undoubtedly compare their own childhood to mine, as did many at the Colloquium. I heard people in their forties describe

early diagnosis and intense childhood therapy, and in the next breath tell me they seem to be experiencing the effects of aging about ten years earlier than I did. They grew up in a period when the approach was "no pain; no gain," and youngsters were instilled with the idea that being able to walk was the most important ability in the world. With full and active lives, their bodies are now beginning to age. They are developing such things as arthritis, bladder problems, and changes in speech and swallowing. They want answers, but the professionals don't have the answers yet.

The fact of the matter is that we can not stop living while we work to get the answers. In every phase of my life, I found the answers by doing and learning from each experience. When I married, had children, raised them for the most part as a single parent, became involved in my community, and moved into the working world, it was always with the cerebral palsy, not in spite of it. When I had my first baby, I knew only one other woman with CP who had had children. My own body proved it could do it: not once but six times. I found ways of caring for them, maintaining a home, and teaching them to cope with my CP, too.

I took that experience into the community as an organizer and advocate, into paying jobs including nine years in the Independent Living Movement, into local politics, and now into helping us all find the answers we're looking for. I picked up answers all along the way. After hearing for years that my speech could not improve as an adult, I proved it could when I got out and spoke up for other people. People learned to listen and not let the CP get in the way. Because people remember and identify me by the CP, it became an asset.

All of us, no matter how long we have lived with CP, have had different experiences and learned from them. Many of us have had problems with health care providers not recognizing that CP affects our whole bodies. The problems can only multiply as we get older and recognizing

the interaction of aging and CP becomes more difficult. For those who are employed and find we have less and less energy, do we need to look at reduced work schedules or early retirement? Are there others of us who have always walked but who now find that we can't walk as far as we used to? Will our pride let us conserve the energy we have by using a motorized chair or scooter? If we find it harder to get words out either because of shortness of breath or because our tongue and throat muscles are not working as they used to, how will we compensate? These are questions we will be asking ourselves as individuals.

The important question, and the one that should dominate our thinking, is how can we help each other? Somehow we must come together to work in groups to secure funding for research so that we build a base of information that people who come after us can build on. Schools training health care professionals must be convinced to teach more about CP, because no matter where in the system they work, health care practitioners are likely to encounter people with CP.

Reading this issue of the NETWORKER devoted to Aging and Cerebral Palsy may be the first indication some have that these questions exist. Don't let it frighten you. It really is exciting to realize that people are now living long enough to have to ask them, and even more exciting is the fact that now you know that you are not alone. There are others looking for the same answers you seek. Some of us will still be on the edge, ahead of the answers, but this time let's learn to share what life teaches us.

*Maureen Arcand consults and lectures on ADA implementation, disability awareness, and aging and cerebral palsy. She is currently working as a consultant on aging and cerebral palsy for the Wisconsin Council on Developmental Disabilities. Prior to this she was a consultant on ADA Implementation and Training for Dane County (WI) and, for nine years, was an advocacy specialist for ACCESS for Independence.*

*I heard people in their forties describe early diagnosis and intense childhood therapy, and in the next breath tell me they seem to be experiencing the effects of aging about ten years earlier than I did.*

## SOCIAL AND EMOTIONAL DILEMMAS FACED BY OLDER PERSONS WITH CEREBRAL PALSY

By Gary B. Seltzer, Ph.D.

Many of the participants in the Colloquium on Aging and Cerebral Palsy were older persons with cerebral palsy. We met as professionals and non-professionals to synthesize the very limited literature on the non-medical aspects of aging and cerebral palsy, to supplement the literature with personal accounts of life experiences, and to formulate recommendations. The group members had expertise in research, training, policy and mental health. This article will highlight some of the major concerns discussed by the group. The group generated a considerable amount of material, the organization of which has been a challenge. I have attempted to retain the richness of insights while summarizing the major issues effectively. Any time one summarizes, however, one runs the risk of overgeneralizing. Although I have tried to control for this problem, I suspect I have not eliminated it.

### Definition of Cerebral Palsy

The inadequacies of the prevailing definition of cerebral palsy were a major concern expressed by participants. The current definition describes cerebral palsy as a *non-progressive* disorder. Cerebral palsy can be thought of as non-progressive in contrast to other neurological disorders, such as Parkinson's or multiple sclerosis in which there is progressive neurological deterioration. However, cerebral palsy does affect the aging process. Persons with cerebral palsy tend to experience "aging" at an earlier age than most people. For example, many persons with cerebral palsy develop osteoporosis at 40 years of age, about 15-20 years younger than ordinarily the case, which in turn may lead to secondary complications such as hip fractures. These progressive losses of functional abilities in middle and older age are unanticipated by many persons with cerebral palsy who thought that they had a non-progressive disorder.

The present definition of cerebral palsy has been shaped primarily by the biomedical aspects of the disorder. In addition, most descriptions of the definition refer to the developmental consequences of the disorder on children, neglecting the life-long effects of cerebral palsy on the individual. One alternative approach to defining and describing cerebral palsy would be a life-span perspective. Research that utilizes this approach has found that different systems age at different rates. Development involves any age-related change, biological, social, psycho-



logical, and otherwise, from conception to death. Depending on the particular function being studied, aging, as a process of development, may involve stability, growth or decline. Thus, after a person has reached middle or older age, s/he can also experience gains in abilities, such as in some aspects of intelligence or declines in function, such as in walking. By using a life-span approach to define and understand the life-long consequences of cerebral palsy, people with cerebral palsy, researchers, program planners, policy makers and others are more likely to include the normative adaptive changes as well as pathological age-related changes associated with cerebral palsy and do so from a functional perspective inclusive of an array of biomedical and psychosocial perspectives.

### Transitions and Psychological Adjustment

A major theme expressed throughout the work group by participants was the need for persons with cerebral palsy to be able to anticipate the type, severity and course of age-associated changes that are likely to occur in middle and old age. They needed this knowledge to exercise some control over aspects of their life affected by age-associated changes and cerebral palsy. These include social relationships, problems with ambulation and mobility, sexuality, fear about the future, and coping with life events such as retirement.

Maintaining meaningful social relationships becomes increasingly difficult as we age and our peer group dwindles in size. A buffer to these losses is often the younger generation with whom we tend to become increasingly intimate. Persons with cerebral palsy are less likely to have married and had children, who otherwise would provide social support to them. For persons who also have mobility and/or speech difficulties, the isolation can be very difficult. It may help to anticipate these diminishing

social supports in older age and to support meaningful social relationships in early adulthood.

The work place is often where social supports and other resources are developed. Not surprisingly, the transition to retirement provokes a variety of concerns in persons with cerebral palsy: concerns about health care benefits, loss of income, loss of contact with friends at work. Optimally, the transition to retirement needs to be paired with an expectation that there is a positive role or activity to which the individual is retiring. Oftentimes, the lack of financial and social resources mitigate against retiring to a new set of activities. Sometimes pre-retirement planning can provide support for this transition.

However, in many instances, the person with cerebral palsy may not want to retire but is persuaded or forced to retire by physical limitations and the lack of flexibility in the work setting. Health care personnel, for example, may strongly recommend retirement because of increasing physical limitations. Sometimes these limitations could be compensated for if health care personnel were aware of rehabilitation programs that focus on teaching the employee and employer how to make modifications in the work place. However, some employers, who recognize the difficulties the employee with cerebral palsy is experiencing, refuse to or cannot modify the job requirements. Under these circumstances and even when retirement is optional, persons with cerebral palsy may lose one of their most valued social roles, work, and the accompanying social relationships.

Social isolation is also related to the topic of sexuality and women's health issues. The difficulty in finding a life partner or a partner at all limits sexual contact and intimacy for some persons with cerebral palsy. Women with cerebral palsy often have to struggle with their own and others's stereotypic image of what is sexually attractive—is it looking like "Miss America"? Moreover, many women with cerebral palsy have to negate the recurring statements and expectations they hear that suggest that they need protection from sexual experiences. Be-

cause they are not expected to marry and have children, they are not expected to be sexually active. These expectations have life-long social implications. They also have health care implications. Generally, women with cerebral palsy lack access to gynecological and other gender specific health care, a need that becomes increasingly important for health maintenance as they age. Even when available, though, some women with cerebral palsy may not seek this care because of the way they have been physically and psychologically treated by the medical establishment throughout their lives.

Self-neglect is a related problem. Among the elderly, the occurrence of self-neglect is very high and may be even more of a problem for middle-age and older persons with cerebral palsy who are isolated, failing in daily functional abilities but denying it, and who fear contact with social service and other agencies.

For some persons with cerebral palsy, the transition from being able to walk independently to walking with devices or not walking at all seems to have profound psychological effects. Among the group members, there was unanimous agreement that they had been raised with the maxim that being mobile was the key to "passing." They had been socialized to believe that "if you walk, then you can pass." The increasing mobility impairments experienced in older age not only provoke feelings about "passing," they raise fundamental concerns about independence. For the present generation of middle aged and older adults with cerebral palsy, dependence means more than giving up some freedom and social status; dependence raises the threat of being placed in an institutional setting.

Given these threats to their independence and freedom, it was not surprising that group members expressed much fear about growing old. A group symbol for this fear developed around the use of a scooter, an Amigo. Should one interpret the use of an Amigo as a tool that promotes independence or as a symbol of one's growing old and needing help? One group member, only partially in jest, wished that someone would develop "CP years, similar to dog years or cat years." He wondered further "what's a person with CP like at 31, 41, 51?" He then drew an analogy between a "normal" person having \$1000 and a disabled person having only \$100. If you take away \$10, the "normal" person has \$990 and the disabled person has only \$90 left. The moral of this analogy may be that as one ages with cerebral palsy, one needs to support his/her shrinking resources by borrowing what one can from assistive devices and technology.

(continued on Page 22)



## ADULTS WITH CEREBRAL PALSY: EXERCISE AND FITNESS

by Margaret Turk, M.D.

Exercise and fitness have been considered an important part of daily routine and preventive medical care since the 1960's. The virtues of exercise have been noted in books, pamphlets, and television and radio shows, as well as the scientific literature. Benefits include more efficient muscle, heart, and lung function (fitness), weight reduction, improved mood, and improved sleep to name a few. To this end, health clubs have become a part of American culture, and parks are filled with exercise-conscious individuals. However, the audience for articles on fitness and the advertisements for health clubs, not to mention the individuals in the parks, are usually people without disabilities. It has only been recently that exercise and fitness have come to be recognized as an important issue for people with disabilities. The scientific literature does report the benefits of some exercises for people with certain disabilities, and we can learn from these studies. There are also general principles of exercise that can be applied to all individuals.

Adults with cerebral palsy have become more vocal regarding their health issues in the past few years. Many questions revolve around increased fatigue, lack of flexibility, and pain. In fact, health care providers who work with and care for persons with CP recognize that there are some common complaints adults often voice in the areas of endurance and musculoskeletal pain. Some of the complaints are not unlike those of nondisabled adults as they age, although adults with CP may note these at a younger age. (This age differential is suspected, but not yet proven.) A strong, scientifically based study is underway, but is not yet completed, to report the percentages of problems and the risk factors associated with each. Nonetheless, a growing number of health care providers appreciate that adults with CP do have these concerns and complaints, that the complaints are real, and that there are some interventions which can be tried. More importantly, there may be some prevention strategies in the area of exercise and fitness that may delay the onset of these problems or ameliorate them before they become problematic. This article will deal with the prevention aspects of a regular exercise program.

Considering what we know about aging in general, issues of flexibility and endurance should be addressed through adulthood to maintain a level of activity. In a person with CP (who is likely to use more energy to complete routine tasks and who often has had to deal with the inflexibility of spasticity for a lifetime), these issues may come to bear at a younger age than his/her nondisabled counterpart. Therefore it would make some sense to begin an individual and independent exercise program early in life that could be done on a regular basis to either achieve a higher level of activity or maintain a desired level of activity. And, if a program were not started during teenage years, it would make sense to start a regular exercise program as an adult either as a prevention strategy or to address some existing areas of concern. However, a person's functional capability will dictate what exercises can be done independently or with assistance, and will also dictate accessibility to endurance and fitness activities in particular. Because of joint deformities and unusual joint alignments from spasticity, typical repetitive and weight-bearing activities (running, walking, weight lifting to name a few) may be more harmful than helpful.

Also, as should be the case for anyone embarking on a new exercise and fitness program, advice should be sought from a knowledgeable physician to ensure that no other unknown, adverse conditions are present. A physical therapist knowledgeable about cerebral palsy will also be helpful in development of and instruction in a progressive program. Although there are no specific reports in the literature on exercise for adults with CP, general principles of exercise can be followed. The three types of exercise are described below: stretching, strengthening, and conditioning.

### Stretching

Probably the most important type of exercise is stretching to improve flexibility. This is important for all adults, with and without disabilities. As we age, we need to stretch more to maintain our functional level. People with spasticity are probably more at risk than others for losing flexibility, despite keeping up a relatively active lifestyle. Thinking that walking or riding a bike will improve flexibility in and of itself is misleading, however.

Each type of exercise is directed toward a specific goal: walking and riding a bike have more to do with fitness than with flexibility or strengthening. However, flexibility or strengthening may improve the activity by preventing possible injuries (sprains and strains in particular).

Stretching should be done slowly, without bouncing. The stretch should also be prolonged, holding the extreme tolerated stretch position. Stretching should always be done before other exercise, competition or sporting activity. Having the assistance of another person will make the stretching easier and sometimes more beneficial.

People with CP often have a regular stretching routine twice a day: it can alleviate early morning muscle or joint pain on arising and can decrease that pain after a long day. Sometimes using ice or heat before the stretching can be helpful. The muscle groups that should be stretched depend on the individual, but commonly include hamstrings (posterior thigh muscles), adductors (inner thigh muscles), and calf muscles. Adults with CP will probably remember some of these exercises as a part of their childhood physical therapy program. The difference, of course, is that the individual becomes responsible for the exercise, not the therapist.

### Strengthening

Strengthening exercises are not as universally beneficial for persons with CP as are flexibility exercises. Many individuals with CP cannot isolate muscle groups and therefore move their extremities in "patterns" of extension or flexion; that is, they cannot bend their ankle to bring their foot up toward their face (dorsiflexion) while their knee is held out straight (extension). Consequently, it would be very difficult to try to strengthen some muscle groups because they cannot be controlled specifically enough to be active in the exercise. There are some individuals who can isolate movements for strengthening exercises, but do not use these muscle groups in regular activities; the long lasting benefit (or harm) of a strengthening program to these individuals is not known. Other individuals with CP, who can isolate muscle groups for exercise and in daily functional activities, will benefit from participating in strengthening programs.

A strengthening program for persons with CP with muscle groups having no or mild spasticity can be successful. However, the effect of strength-

ening exercises in adults with CP is not well studied. To embark on such a program would require good discussion with knowledgeable health professionals initially. The type of strengthening exercise and the equipment needed will be determined by the initial evaluation and the goals. There could be some risks for muscle and joint complaints without knowledgeable direction. Certainly an ongoing program can be maintained at home or, where possible, in a health club. The program needs to be changed as gains are made, although there is a limit to the amount of improvement that can be achieved.

To maintain an improved strength status, strengthening exercises must be done routinely. A general activity program (like walking) will maintain an improved strength level within the limits of the activity; continued strengthening exercises must be continued for strengthening gains in muscles not used in that activity or not used to the maximum level.

### Conditioning

A general conditioning program is probably the most neglected form of exercise for people with disabilities. People with disabilities have been shown to use more energy to perform some tasks than their nondisabled counterparts. In fact, the scientific literature reports that, because of higher energy use, children with spastic diplegic CP choose a slower walking speed than children of the same age who are not disabled. There is also mention of adolescents with developmental disabilities changing their mode of mobility because of fatigue from high energy use. The literature does report improved fitness in individuals with disabilities who participate in conditioning programs. Theoretically, then, persons with CP should benefit from such an exercise program.

A structured conditioning program consists of a warm up period (lasting about 5 to 10 minutes), an activity period that can raise and maintain the heart rate above the resting heart rate (within certain parameters called the target zone) for about twenty to thirty minutes, and a cool down period (about 5 to 10 minutes). There are three requirements: (1) no heart problems so the activity can be managed, (2) ability to participate in some sustained type of activity, and (3) ability to monitor your heart rate.

Regarding cardiac status, a physician should be able to give the go ahead to participate in a

fitness program. There does not seem to be any higher incidence of heart problems in persons with CP, and family risks should be the same as for people without disabilities. Finding a sustainable activity that increases blood flow to the heart and large extremity muscles could be the most difficult. The best exercise involves any rhythmic, repetitive activity which can be continued for two or more minutes, without huffing and puffing afterwards. People without disabilities routinely participate in swimming, biking, or running/walking as a means of maintaining an activity level. These are choices as well for people with CP, although balance limitations, existing joint complaints, increased risk for joint pain, or accessibility may make these options not possible. Modifications to equipment may be possible, but may be avoided by professionals and health clubs because of liability concerns. Activities involving arms only can also be used but are less likely to raise the heart rate consistently.

As in strengthening activities, there is a limit to improving the efficiency of the heart and lungs. There is also a need to maintain the improved fitness by a three-times-a-week maintenance program. If you decrease your exercise program to once a week, half of your fitness will be lost in 10 weeks. Stopping altogether will result in complete loss of gained fitness in 5 weeks! A less aggressive approach can be attempted, with some benefit, from a general activity program, but not to the degree noticeable in a well outlined program.

**Getting Started**

Of course, starting any organized and strenuous exercise program requires a good evaluation and direction from a health care provider expert in this

area. The program will also have to be adjusted as gains are made. Once attained, physical fitness must be maintained by regular exercise. Exercise should become part of your lifestyle. If unavoidable circumstances keep you from exercising for a few days to a few weeks, start the program again at a lower level than when you quit.

Listen to your body! If you note any changes or symptoms that are disturbing, uncomfortable, or otherwise unusual for you, stop the exercise and consult your physician. In particular, any complaints of heart palpitations, chest pain, or dizziness should be addressed immediately. Other complaints of joint or muscle pain, nausea, or fatigue may have to do with your exercise plan. If those complaints persist after adjustments to the program, medical evaluation is indicated.

Exercise is a healthy response to aging and concerns about maintaining a functional level. Persons with CP often view an exercise program as one more encounter with a health care system that may not have been especially responsive in the past. In actuality, an exercise program should not ultimately be health-care based. Programs can be designed for home or health club and, in fact, they should be the model. The individual should be responsible for the exercise activity, both in initiating the concept and following through in the program. Most of all, exercise should be an enjoyable recreation!

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# CEREBRAL PALSY ACADEMY TO STRESS INVOLVEMENT OF PEOPLE WITH DISABILITIES

by Alfred L. Scherzer, M.D.

The American Academy for Cerebral Palsy and Developmental Medicine (AAPDM) has become increasingly aware of the need for more involvement from people with cerebral palsy and their families in its programs and activities. An ad hoc study committee was set up two years ago to evaluate how such involvement could best be organized. As many of you are aware, the Academy is an international multi-disciplinary professional organization whose purpose is information exchange and professional education of its nearly two thousand members. This is accomplished by means of an Annual Meeting at different sites around the country, regional courses, a regularly published newsletter, and an international professional journal, *Developmental Medicine and Child Neurology*.

Just recently the Academy endorsed the recommendations of an ad hoc committee and approved formation of a new Committee on Advocacy and Parent/Consumer Partnership. (This name is still open to possible revision.) Its purpose is to bring the interests and needs of people with cerebral palsy and their families directly into the organization through the Committee and Board of Directors. It is planned to have both local and national representatives meet with the Committee at the time of each Annual Meeting. Also, a consumer forum will become a regular feature of the Annual Meeting.

In order to develop suggestions of how best to involve people with cerebral palsy in the Academy, a breakfast meeting was held on April 30th in Washington, D.C. at the UCPA Annual Conference with a group of persons with cerebral palsy who were attending the Task Force on Aging and Cerebral Palsy. Representatives of the Academy included Michael Alexander, M.D., President, Ernie Weinrich, Leon Sternfeld, M.D., and Alfred Scherzer, M.D., Committee Chairman.

Suggestions included appointing a person with cerebral palsy (or the parent of a child with cerebral palsy) as an *ex officio* member of the board, and having a consumer membership category, with a different fee schedule. At the Annual Meeting, the group endorsed having local consumer representa-

tion on the committee as well as representation from national service organizations.

There were many suggestions of subjects to be included in the AAPDM program. Above all was the need for the Academy to reach out to the medical profession in general, and to specialty groups in particular, to sensitize professionals to the needs of people with disabilities. Specific suggestions in this regard included:

1. Develop printed instructional materials to orient professionals in dealing with persons who have cerebral palsy;
2. Produce video materials with guidelines for working with persons who have cerebral palsy; these would stress special needs such as speech and motor problems, and would aim to sensitize professionals to the individual life styles and social situations;
3. A central hot line should be established for immediate professional guidance and assistance in patient management;
4. Through Academy auspices, presentations should be made to medical specialty groups by persons with cerebral palsy concerning general medical needs;
5. Regional courses should be more frequently scheduled as a means of reaching out to local practitioners;
6. The Academy should use its influence in an organized way to work toward changes in medical school curricula that would sensitize physicians early on to the needs of people with disabilities;
7. A listing should be available of physicians who have disabilities and who might be especially sensitive;
8. Means for more broadly circulating the Academy membership listing should be explored as well.

Other topics for Academy consideration were the following:

1. Newly developing information on physical aging of people with cerebral palsy—especially the need for informing people at an early age;

4. Sexuality and reproduction issues in relation to persons with disabilities;
5. Regular updates on medication use and interactions;
6. Financial and health delivery issues, including standards for care, dealing with prescriptions/equipment for insurance claims;
7. Advocacy for standards and uniformity of vendors, equipment, and treatment modalities.

This meeting also presented an opportunity to further strengthen the newly developing Academy/UCPA Coordinating Committee. This venture is an attempt to extend the mutual contact which has existed over many years in which Dr. Sternfeld, as UCPA Medical Director, served as a liaison on the Academy Board of Directors. Many have felt the need for greater direct involvement between the two organizations. A first meeting of this joint committee was held in January in Washington to prepare an agenda and future strategies. It was dramatically clear at the April meeting that more direct involvement by persons with cerebral palsy would greatly benefit both organizations! This will be vigorously followed up in future deliberations.

*Alfred L. Scherzer, M.D., is Chairperson of AACPD's Committee on Advocacy and Parent/Consumer Partnership.*

**SOCIAL AND EMOTIONAL DILEMMAS...**

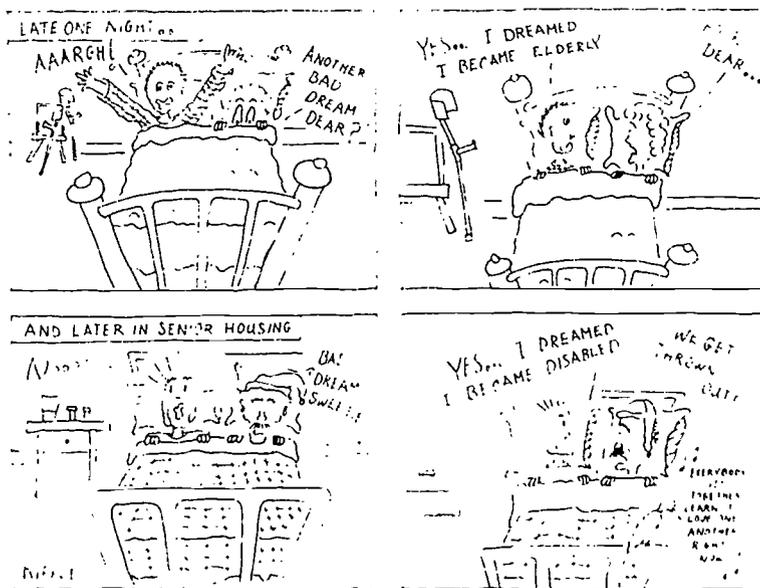
*Continued from Page 17*

**Conclusions**

The dynamics of a group of persons with cerebral palsy and professionals working together on the above topics was incredibly powerful. Not only did it produce noteworthy insights and recommendations, it also gave participants an opportunity to share their thoughts and feelings with each other. Because of the dearth of role models and the recency of persons with cerebral palsy living until old age, this type of group process fostered introspection and sharing that should be replicated in other settings.

One note of caution: The content of this article is heavily influenced by the composition of the group who met as part of the Colloquium. Some of the problems described may represent a skewed picture of what the non-medical issues are for the larger population of older persons with cerebral palsy. Persons with cognitive limitations and persons with severe seizure disorders, for example, were not represented. Thus, not only is there a need for more knowledge about the complex issues raised in this article, but we need to become more inclusive of diversity within cerebral palsy. In so doing, we also need to begin to investigate the diverse patterns of age-related changes that exist among all older persons with cerebral palsy.

*Gary B. Seltzer, Ph.D., is Associate Professor in the School of Social Work at the University of Wisconsin and Director of the Aging and Developmental Disability Clinic at the Waisman Center.*



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## BROWSING THROUGH THE BOOKSHELF— David Bauer on Books

### **Aging with a Disability**

By Roberta B. Trieschmann, Ph.D.  
Demos Publications 148 pages

Aging in the United States is a growth industry. Baby boomers of the late 1940's and early 1950's are about to mature, and this grand event has energized corporate America, government and nonprofit groups such as AARP into providing assistance to ease and enhance the greying of America.

Partly because of their small numbers, baby boomers with disabilities have not been as fortunate as their nondisabled counterparts in obtaining assistance with the aging process. Until recently, disabled people in their 40's and 50's were "rare birds" indeed, although advances in medical treatment coupled with the impact of the independent living movement are increasing the number of older adults who are asking, often demanding, help with aging.

Help has have been slow to materialize and Roberta Trieschmann in *Aging with a Disability*, presents a superb review and analysis of the political, social and economic constraints that can make aging such a painful process for people with disabilities.

Writing in 1987, Trieschmann concluded that instead of a health care system, the United States had opted for a "sickness treatment business" that focuses on biological-organic dysfunctions and frequently ignores psychosocial and environmental factors that play an important role in determining a person's wellbeing. A society that treats a pressure sore with surgery and immobilization but ignores accompanying problems of depression and financial resources is, she reasons, poorly equipped to provide the comprehensive services needed by persons with disabilities who are aging.

In a recent interview, Trieschmann said that the myopia of the health care system in the United States had gotten worse. She praised the Clintons' health care package and the drive for universal coverage, but criticized the continuing emphasis on a technical/medical approach to aging and disability that she discusses in her book.

The current system, she argues, is deficient not only because it cannot adequately address the problems associated with aging and disability but also because it is directly responsible for huge increases in medical costs. A technical approach to health care

views a patient as a collection of body parts, each of which can be competently treated by a specialist. The proliferation of medical personnel raises the cost of treatment but at the same reduces prospects for complete recovery because the totality of an individual's needs are lost in the confusion.

Trieschmann goes further. Her book strongly questions the effectiveness of the corporate partnerships and hospitals that now deliver a sizeable portion of the nation's medical care, and she now advocates that all medical practioners be salaried employees of not-for-profit organizations.

Trieschmann's prescriptions for restructuring health care will not be well-received by all readers even though some form of her proposals to cut costs seem likely to be embodied in federal health care legislation.

Her analysis of the problems that aging with a disability can create will find a wider audience. Trieschmann's book grew out of a grant from the Paralyzed Veterans of America, and the aging of people with spinal cord injuries and, to a lesser extent, polio, receive major attention. But the methodological framework within which she discusses fatigue, muscle weakness and atrophy, stress, infection, hypertension and other conditions will be valuable to people with cerebral palsy and other disabilities.

Trieschmann also discusses some of the issues such as the likelihood of suicide and alcohol and drug abuse that unfortunately are not usually mentioned in literature on aging and disability. Suicide does not appear to be a major cause of death among older people who acquired a disability early in life, although Trieschmann insists on the need for more statistical data, as she does for many aspects of aging with a disability.

Trieschmann is a clinical psychologist who uses case histories as well as an impressive array of medical and studies to buttress her analysis and recommendations. Her book is required reading for anyone interested in aging and disability.

*David Bauer is an economist who, upon retirement from the U.S. Department of Treasury, was persuaded to work part-time as a Consultant on Aging and Cerebral Palsy for UCPA's Community Services Division.*

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