



Uncertain Futures

AGING & CEREBRAL PALSY *CLINICAL CONCERNS*

The New York State
Developmental Disabilities Planning Council

Uncertain Futures

AGING AND CEREBRAL PALSY - CLINICAL CONCERNS

**A REPORT OF THE
WORKGROUP ON AGING AND
CEREBRAL PALSY**

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Publications of the Workgroup on Aging and Cerebral Palsy

- **I'm Worried About the Future.. The Aging of Adults with Cerebral Palsy**
- **Aging and Cerebral Palsy – Pathways to Successful Aging: A National Action Plan**
- **Uncertain Future: Aging and Cerebral Palsy – Clinical Concerns**

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Dedication

This report is dedicated to Dr. Frances Berko, who until her retirement in 1994, served as the New York State Advocate for People with Disabilities. It was Dr. Berko, who by her experience and example, relentlessly served as the primary advocate within the New York State Developmental Disabilities Planning Council for the work of the workgroup. Dr. Berko's own aging as a person with cerebral palsy, provoked much soul-searching and angst because we did not have the answers to her many concerns and questions. We hope that the work that will result from this and our other reports will finally produce those answers.

M.A.T., J.C.O., M.P.J.

Uncertain Futures

AGING AND CEREBRAL PALSY - CLINICAL CONCERNS

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Executive Summary

This is one of three reports resulting from the joint efforts of an ad hoc workgroup on cerebral palsy and aging and the National Invitational Colloquium on Aging and Cerebral Palsy held in Alexandria, Virginia in April 1993. In this report we address the clinical aspects of aging with cerebral palsy.

Little is understood of how the aging process affects persons with cerebral palsy. Most of what is known is either anecdotal or biased due to the types of persons who have been the subject of studies, most of which have generally involved persons who also have mental retardation, are nonambulatory, and to a large extent are dependent on others to take care of their daily needs.

Adults with cerebral palsy age in the same way as do other adults in the general population. There may be differences, however, in the way in which the consequences of the aging process manifest themselves. The presence of motor impairments and other associated conditions may adversely interact with the aging process and may result in atypical adult development and aging. At some point, the interaction of aging and life-long impairments may change the reserves that an individual with cerebral palsy has with which to respond to the physiological stressors associated with aging. Stressors that occur, especially in the later stages of life, may accelerate declines in functional abilities.

It is difficult to establish which of these stressors has the greatest impact and what can be done to slow or stop these changes. We do know, however, that environmental supports, such as assistive technologies, play an increasingly critical role in maintaining the balance among functional limitations associated with aging, life-long impairments, and independence for persons with cerebral palsy.

Adults with disabilities experience problems that reflect the normal aging process, as well as those unique to a life spent living with a disability. With the onset of middle age, many adults with cerebral palsy report changes in functional abilities that they did not anticipate. They had been led to believe that cerebral palsy is a non-progressive disorder and were not prepared for the fact that they can no longer easily do what they could do previously.

These unexpected losses and impediments pose a new threat to their independence. They are now faced with having to develop acceptable solutions to continue day-to-day functioning. In turn, they may have difficulty coping with the age-associated changes that are complicated and perhaps accelerated by cerebral palsy. Many of these difficulties may become more of a problem when these changes interfere with their day-to-day social concerns, interpersonal relationships, employment, parenting, and other demands.

Main Findings

Based on information drawn from discussions at the Colloquium and gleaned by the workgroup from a variety of sources, this report provides a review of the significant health, physical, psychological, and social functioning issues that have been identified and which need to be addressed in order to increase the body of knowledge regarding the effects of the aging process on adults with cerebral palsy. What were the major observations? We found that among adults with cerebral palsy:

- many experience motor function changes in mobility, strength, and endurance and that the problems stemming from these become more pervasive and may have an earlier onset than in persons in the general population.
- oral health problems increase with aging, but few persons with cerebral palsy (who are not part of state supported services) make routine visits to the dentist because of a variety of reasons.
- although little is known about the incidence of stomach and intestinal problems, there are concerns about nutrition, access to a balanced diet, and quality and quantity of food intake.
- both women and men report that they have genital and reproductive health concerns, that health care providers are often not equipped to help them, and that in many instances the

problems they experience are misdiagnosed or not properly treated.

- availability of responsive health care is a major problem.
- health care insurance is extremely difficult to obtain and, even when insurance is available, most clinics or physician offices are inaccessible.
- many may experience difficulty and frustration in making themselves understood because of speech articulation difficulties and that these difficulties may contribute to negative reactions from listeners and a lack of willingness to make the effort to carry on a conversation.
- many report changes in functional abilities, with the onset of middle age, that they did not anticipate and since they had been led to believe that cerebral palsy is a non-progressive disorder, most are not prepared for the fact that they can no longer easily do what they could do previously.
- the transition to retirement, with advancing age, can provoke a variety of concerns, including concerns about extent or loss of health care benefits, loss of income, and loss of contact with friends developed in the work place.
- some, because of either their physical condition or emotional fragility, are particularly susceptible to unwarranted exploitation or mistreatment.
- there is an expressed fear about growing old because some associate growing old with “pathological aging,” and with a loss of mobility, personal competence, and independence.

Major Recommendations

The report also raises a variety of research or clinical considerations. The major recommendations cited in the report concern a need for

- increased availability and accessibility of health care resources and providers trained and knowledgeable in the problems of aging and cerebral palsy,
- more substantial information for adults with cerebral palsy so they can be informed consumers of health and social services, and
- an expanded emphasis on research in medical issues pertaining to the aging of adults with cerebral palsy.

1 INTRODUCTION

“When I was born almost 65 years ago, I 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.”

This report is the result of the joint efforts of an ad hoc workgroup on cerebral palsy and aging and the National Invitational Colloquium on Aging and Cerebral Palsy held in Alexandria, Virginia in April 1993. The ad hoc workgroup was chartered and supported by the New York State Developmental Disabilities Planning Council. This report is one of three products developed by the ad hoc workgroup. The others are “I Worried About the Future... The Aging of Adults with Cerebral Palsy” and “Aging and Cerebral Palsy - Pathways to Successful Aging: A National Action Plan.”

Background

Adults with cerebral palsy form a varied population. As is true for other people, most adults with cerebral palsy work and participate in the normal activities of their community. In many instances, they do not need any special services to help them live their lives.

In other cases, because of the nature or involvement of their disability, some adults with cerebral palsy may have specific limitations in their ability to function. They may live in the community and work and participate in community life, but may need some special supports or accommodations. Some receive those supports from their families or friends. Others receive these supports from formal services provided by broad-based or specialized community agencies.

Yet still others, more severely impaired due to the nature of their disability, may live in congregate settings that range from group homes to nursing facilities. Many could and should live in more independent settings. However, attitudinal and physical barriers and lack of community support systems prevent them from doing so.

Little is understood of how the aging process affects persons with cerebral palsy. Most of what is known is either anecdotal or biased due to the types of persons who have been the subject of studies, most of which have generally involved persons who also have mental retardation, are nonambulatory, and to a large extent are dependent on others to take care of their daily needs.

The workgroup was formed because the New York State Developmental Disabilities Planning Council recognized that so little was known about how the functional abilities of persons with cerebral palsy are affected by aging and wanted to know what could be done to prevent or at least forestall expected decline. Library research revealed that there was little if any substantive information about how older individuals with cerebral palsy maintain or lose function as they age.

Little information was also available to guide and develop the best practices to help health care professionals treat age-associated problems. Little or no easily accessible information was available for practitioners who are willing and have the expertise to treat those problems. Almost nothing was known about whether any networks existed of older persons with cerebral palsy who could serve as role models and provide reassurance or personal advice.

Begun in 1992, the workgroup reviewed the existing literature, carried out extensive interviews with experts and persons with an interest in this topic, and held public forums across New York State to collect as much information as it could. The result of this effort was its first report, "I'm Worried About the Future... The Aging of Adults with Cerebral Palsy" (Overeynder, Turk, Dalton & Janicki; 1993). One of the major recommendations of the workgroup was to convene a colloquium of experts, persons with cerebral palsy, and other interested parties to examine the workgroup's findings and draw together additional information and expertise.

Thus, in April 1993, a group of practitioners, researchers, service providers and persons with cerebral palsy convened for two days in Alexandria, Virginia for the National Invitational Colloquium on Aging and Cerebral Palsy. The purpose of the 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 workgroup decided which topics were of most concern and identified and invited persons throughout the nation with relevant expertise to participate.

United Cerebral Palsy Associations, Inc. (UCPA) extended an invitation to the workgroup to hold the Colloquium concurrent with its 1993 annual meeting in Alexandria, Virginia. UCPA was also instrumental in identifying a significant number of persons with cerebral palsy who were willing to be key participants and contribute to the discussions.

Financial support was provided by the National Institute on Disability and Rehabilitation Research, the New York State Developmental Disabilities Planning Council, and the Administration on Developmental Disabilities. The Colloquium was sponsored by a number of organizations, including the Strong Center for Developmental Disabilities at the University of Rochester Medical Center, the SUNY Health Science Center at Syracuse, the Center for Therapeutic Application of Technology at SUNY Buffalo, the New York State 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 Persons with Disabilities, 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.

The National Colloquium

The National Colloquium was organized as an invitational event. Some fifty persons attended the two-day meeting. Colloquium participants were divided into three discussion groups:

1. Oral motor functioning/nutrition/swallowing/ gastrointestinal functioning/communication.
2. Motor functioning and other physical aspects/genito-urinary/reproductive issues/assistive technology.
3. Psycho-social/life transitions/women's issues/sexuality/health care access.

Each discussion group chairperson held several conference calls with the group prior to the Colloquium to develop an outline for the discussions and set priorities for topics to be discussed.

The following questions formed the basis for the Colloquium:

- What is the current status of the 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 are associated with variations in the aging process 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 older 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.

The products

One of the products of the Colloquium is a policy report calling for action on a variety of issues related to aging and cerebral palsy. This report, “Aging and Cerebral Palsy: Pathways to Successful Aging - A National Action Plan” (Overeynder, Turk & Janicki) outlines the recommendations of the Colloquium and calls for a national plan of action. The UCPA has adopted the national action plan and has begun to work to implement its many recommendations. Copies can be obtained from the address shown on the inside cover.

This companion report, “Uncertain Future - Aging and Cerebral Palsy: Clinical Concerns,” explores complementary information to the national action plan. We examine some of the physical and psychosocial aspects of the aging process as they are experienced by adults with cerebral palsy. Because of the current limited state of knowledge about this topic, this report also outlines questions in need of further study and highlights the areas of clinical or personal concern that need attention.



2 CEREBRAL PALSY AND AGING

"I'm 35 years old. I am just beginning to feel changes in my body, changes that I know are due to my cerebral palsy. I shared these changes with my peers - increased tightness in my shoulders and neck, heartburn, and bladder weakness. I realized that I wasn't alone with these symptoms, that other adults with cerebral palsy experience the same. This frightens me, because I think that no one knows what to do about it."

What is aging?

Aging is a conception-to-death progression of developmental changes that ultimately lessen a person's ability to cope successfully with internal needs and with the demands of the environment. During the early stages of aging (infancy, childhood, adolescence) skills and capabilities continue to increase; in the middle stages (i.e., adulthood) maintenance of function is the focus. Disease, trauma and other challenges can cause a decline in function at any stage. It is in the later stages of life that function declines significantly as a result of aging (if disease is not a factor at any of these stages).

The underlying assumption of this report is that the pattern of aging as a process is the same in persons with life-long disabilities as it is in the general population, although the data to substantiate this assumption are not available.

To understand the aging process, one must focus on all the changes that occur in the person from the moment of conception until the moment of death. Aging is not simply a process of becoming older, less functional, and dying. Growth, development, acquisition of skills, maintenance of skills and functional capabilities, repair and replacement, and ultimate decline, are all parts of aging.

As adults age, they are generally less able to respond to stresses in the environment as rapidly and effectively as when they were younger. Numerous diseases can affect a person's stress response and may interfere with the body's ability to generate an appropriate response. However, it is important to remember these diseases are not caused by aging but may occur more commonly among persons who are older. Ultimately, the person becomes biologically "overwhelmed" by those stresses and dies.

In the past, many researchers and clinicians regarded aging itself as a "disease," something to be cured. There is now a more general acceptance that some of the changes often seen with increasing age are signs of disease (e.g., dementia, osteoporosis, and arthritis), rather than signs of the aging process itself. A recent theory suggests that changes associated with aging are due to genetically driven processes, and are best described as resulting in these manifestations: successful, or usual, or pathological.

- **Successful aging:** The successful ager has a positive genetic inheritance that is unfolding in a positive environment. Little if any, major functional change occurs in the person at least until the early to mid-70s. Except for an occasional acute illness, the person who is aging successfully has no chronic disease to limit his/her functional capabilities.

- **Usual aging:** The usual ager has a positive or neutral genetic program that is unfolding within a neutral or slightly negative

environment (i.e. an environment that puts a person at some increased risk for dysfunction). The risk of developing disease or dysfunction is present and will be manifested; it does not however, seriously or overwhelmingly impair the individual. Function, while less than that of a person who is aging successfully, is still at a relatively high level. Disease may be present but does not present serious functional limitations.

Pathological aging: The pathological ager is at risk of serious functional limitations for genetic and/or environmental reasons. Disease is typically serious, may be of long-standing duration, and may be of multiple types. Function is obviously impaired and may be poor enough to require continuing home-based or institutional care. Independence is severely limited.

With increasing age, a shift usually occurs in the type of diseases to which a person is susceptible. Acute illnesses become less common (except for viral infections such as “flu”), while chronic conditions become more common. The likelihood increases for developing cardiovascular, neurological, respiratory, or kidney disease, and cancer, in part because of changes taking place in the immune system.

It is important to remember, however, that while a disease is more likely to develop in the older person, that disease probably is not caused by the aging process. Distinguishing between age-related change and change caused by disease is very difficult in any population. The distinction between “successful” and “usual” aging is often not as sharp and unambiguous as one would like.

Aging, the conception-to-death series of changes, is generally assumed to follow the same sequence in all people. However, the rate by which these changes manifest themselves can vary widely. As in the general population, persons with lifelong conditions such as cerebral palsy experience growth, development, maintenance of function, and finally, loss of function. The three-part descriptors of aging (successful, usual, and pathological) also apply to them.

What is cerebral palsy?

Cerebral palsy is a life-long motor dysfunction that resulted from a one-time injury to the immature brain in a fetus or an infant. As a result, central control of muscle function is adversely affected for the remainder of an individual's life. The brain injury is static; it is not progressive (that is, it does not change or get worse). However, the dysfunctions or disabilities associated with cerebral palsy can be static, progressive or regressive; that is, they can remain constant, increase or decrease. These changes are due to biological, environmental and therapeutic influences on body structure and function.

Cerebral palsy affects approximately 2 of every 1000 individuals or approximately 500,000 persons of all ages (prevalence) in the United States. Approximately one out every 1000 live-born babies are born with cerebral palsy. This results in about 3,500 to 4,000 new cases of cerebral palsy in the United States per year (incidence).

Cerebral palsy is a life-long neurologically-induced motor impairment; it is a condition, not a disease. Appropriate medical management and treatment, rehabilitative therapies, adaptive strategies, recreational activities and assistive technology enable persons with cerebral palsy to communicate and participate in regular educational programs, develop special interests and skills, find and hold jobs, live independently, marry and have children, retire and in general, to be active, productive members of their communities.

In the United States, the national United Cerebral Palsy Associations, Inc. reports that although about 40 percent of persons with cerebral palsy are less than 20 years of age, a substantial number of persons with cerebral palsy are now in their 50s and 60s and some are in their 70s and 80s. As in the general population, the life expectancy of persons with cerebral palsy is increasing and is, with the exception of those individuals who have the most severe degree of physical or mental impairment, approaching that of the general population.

Types of cerebral palsy

Cerebral palsy is defined by motor dysfunction and described by muscle tone and coordination and by body part involvement. Typical terms used to describe muscle tone and function are spastic (increased tone), athetoid (uncontrolled or extraneous movements), spastic athetoid, ataxic (poor coordination), and hypotonic (decreased tone). Body part involvement is present in the spastic form and may involve one or both sides of the body.

- **Spastic type.** This is the most frequently occurring type of cerebral palsy in the U.S. and is characterized by tightness of the muscles or increased (high) tone. In spastic diplegia, there is a characteristic “scissors gait” or cross-over of the legs because of the spasticity or tightness in the legs. A person with spastic hemiparesis is usually very functional and achieves a high level of independence. Spastic quadriplegia is a generalized and more severe form that often manifests with other associated conditions. Most people with cerebral palsy are either mildly or moderately affected; only a small portion are severely affected.

- **Athetoid type.** The athetoid type of cerebral palsy is characterized by generalized involuntary and irregular movements of large muscle groups, but most notably of the head, face, and arms. Balance and gait are unsteady. Most people with this form of cerebral palsy are ambulatory, though they move with varying degrees of difficulty. Self-care skills are often more impaired. Hearing impairment and speech difficulties are the most common conditions associated with athetoid cerebral palsy.

- **Spastic athetoid (mixed) type.** A combination of spastic and athetoid can occur. It can be seen in moderately to severely affected persons, often with notable associated conditions.

- **Ataxic type.** The ataxic type of cerebral palsy is characterized by unsteadiness and difficulty with rapid or fine movements. This form is usually associated with a problem in the cerebellum, the motor coordination center of the brain. Pure ataxia is rare; if it does occur, it is often related to genetic causes. Ataxia is found in association with other forms. Nonetheless, it is not common.

- **Hypotonic type.** Hypotonic (poor muscle tone) cerebral palsy is very rare. Often hypotonia in infancy is a precursor to the spastic or athetoid forms. Within the first year of life, spastic, athetoid, or spastic athetoid tendencies become more obvious. There are instances in which a diagnosis of hypotonic cerebral palsy is erroneously made rather than the more correct diagnosis of mental retardation.

The disability continuum

Cerebral palsy is a condition, defined by one's ability to control movement and posture. There are conditions associated with cerebral palsy that are also the result of the single injury to the immature brain and that may also determine or limit one's ability to function. Moreover, over a person's lifetime, there may be secondary conditions or age related changes that may modify those persons' functional status.

A primary disabling condition is one that is caused by a disease or disability, and is often manifested by a functional limitation. This functional limitation can be either physical or mental. Cerebral palsy is an example of a primary disabling condition. The lifetime effects of the primary disabling condition span the continuum of all disabilities.

There are associated conditions, those conditions that are a residual effect of the injury or pathology, and are linked to the primary disability. In persons with cerebral palsy, they can include seizures, mental retardation, learning disabilities, and sensory problems such as hearing loss.

A secondary condition is a disease, injury, functional limitation, disability or handicap that occurs at any point during a person's life and is the result of the existence of the primary disabling condition. These conditions are seen more frequently than might be expected by chance.

The primary disabling condition can be a risk factor for any given secondary condition. In addition, the presence of the primary condition often alters the standard intervention for the prevention or treatment of the secondary condition. Moreover, the fact that a person is aging and has lived for many years with a disability may also put that person at risk for developing secondary conditions. In cerebral palsy, a pressure sore resulting from an ill-fitting wheelchair is a secondary condition.

Decreasing endurance with age in persons with cerebral palsy may also be a secondary condition, since there are only limited opportunities for those persons to exercise; but is also an effect of aging. In most instances, traditional intervention or prevention strategies to ameliorate the effects of aging or secondary conditions may need to be modified for persons with cerebral palsy.

How does aging affect persons with cerebral palsy?

Adults with cerebral palsy age in the same way as do other adults in the general population. There may be differences, however, in the way in which the consequences of the aging process manifest themselves.

The presence of motor impairments and other associated conditions may adversely interact with the aging process and may result in atypical adult development and aging. It is assumed that some decline will be due to the aging process, some to the effects of the primary disabling condition (including associated conditions) or secondary conditions, some to the interaction of the two, and others to unrelated or co-existing diseases.

The interaction of these factors (aging, lifelong motor impairment and associated conditions, secondary conditions and age-related disease) may lead to decreased over-all function. There is little published information about the interaction of the aging process, the primary disabling condition, any associated conditions and secondary conditions, among adults with cerebral palsy. There is also not much information about the impact of commonly practiced interventions with persons with a disability over a lifetime.

It is difficult to establish which of these factors has the greatest impact and what can be done to slow or stop these changes. We do know, however, that environmental supports, such as assistive technologies, play an increasingly critical role in maintaining the balance among functional limitations associated with aging, life-long impairments, and independence for persons with cerebral palsy.

Thus, there is a clear need for more knowledge that will help explain the causes of age-related and functional changes in persons with life-long disabilities, as well as the role of environmental supports. As greater numbers of adults with cerebral palsy grow older and as they become more vocal in expressing their concerns about their aging bodies, health care professionals are becoming more aware that they don't know what constitutes the "typical course of aging.'

Are the consequences of the aging process different from peers who do not have cerebral palsy, or is it the same but with greater chances of disease or dysfunction? Is the process of aging among persons with life-long motor disabilities the same as among family members and other adults in the general population? If different, is this difference inherent in the neurological impairment? How is aging affected by interventions in childhood and adolescence, and by activities of daily living?

The discussion that follows covers a range of secondary conditions and problems experienced by adults with cerebral palsy and raises a series of questions that warrant further investigation.



3 CRITICAL ISSUES

“I’m 61 years old and I’ve been a professional physical therapist for more than 35 years. Over the past few years, I’ve noticed some gradual changes. I’ve noticed increased pain in my joints since the onset of arthritis, when I was in my forties. I had to have surgery for hip replacement when I was 56 and it took me nearly a year and an half before I was fully recovered. I now notice new difficulties in balance, but I continue to exercise in order to maintain flexibility. I’ve also developed progressive obstructions in my lungs and two years ago I found that I was born with a congenital heart defect. Quite honestly, I think that the most pressing need right now is for our professions to develop better treatment and interventions for persons with cerebral palsy of all ages.”

Persons with cerebral palsy have always been told that their condition was the result of a one-time injury to the brain and was “non-progressive;” that is, it would not get any worse. However, new information is available to show that the presence of this condition over a lifetime may lead to unexpected problems. Some persons may begin to develop functional and social problems at a relatively young age. But, when they seek help to address these problems, they often encounter an unresponsive or uninformed service system.

Based on information drawn from discussions at the Colloquium and gleaned by the workgroup from a variety of sources, this section reviews some of the issues that have been identified and which need to be

addressed in order to increase the body of knowledge regarding the effects of the aging process on persons with cerebral palsy. The first part of this section reviews issues and concerns related to health and physical functioning. The second part of this section reviews issues and concerns related to social and psychological functioning. In both instances, we review what has been identified within the areas of concern and raise research or clinical considerations.

Musculoskeletal concerns

Many adults with cerebral palsy indicate that musculoskeletal complaints are the most prominent problem they experience and about which they have major concerns. What do we know? We know that motor function (mobility, strength, endurance) changes during the maturation process in persons with cerebral palsy. These changes are also a part of the maturation process in persons who do not have a lifelong disability. However, when there is the co-occurrence of cerebral palsy, musculoskeletal problems may become more pervasive and often have an earlier onset than in persons in the general population.

Changes in mobility and functioning

Adults with cerebral palsy are at risk for having decreased function in their mobility as they age. They can expect some changes in muscle flexibility and it is likely that muscle strength and endurance will decline without routine maintenance activities, much as it does for their non-disabled peers. They can be at risk for falling and developing fractures or related problems. They may require more help with activities of daily living, in transfers, in assistance with personal hygiene, in dressing or with other every day requirements.

Often, spasticity seems to be more pronounced, frequently related to pain and fatigue. Knowing whether the changes are age related or secondary to a significant pathological process is often a problem,

both for the person with cerebral palsy and for the health care provider. At times, these changes may be related to deconditioning as it is in the general population; at other times a significant problem like cervical spine stenosis (a narrowing of the spine canal at the top of the spinal cord) may be the reason for the change.

A person with cerebral palsy may need more time to get around as he or she gets older. This may present the need for assistive devices, such as canes, walkers or wheelchairs. It may mean developing new ways of getting around, getting in and out of a bathtub, getting in and out of a car. It may also mean that person needs to plan his or her daily activities in a different way. In order to adapt to these changes, it is important to know what adaptive equipment is available and how to procure it.

The questions raised include:

- How does spasticity act as a risk factor for decreased function over a lifetime?
- What are the reasons for spasticity/motor function getting worse? Is it the norm or is there a specific cause? If it is the norm, are there prevention strategies to maintain function?
- What does assistive technology have to offer to overcome problems with mobility?
- What are the changes in equipment needs over time and over a lifetime?
- What exercise regimen best maintains strength and endurance for day-to-day activities?

Pain and fatigue

Musculoskeletal complaints can arise from a variety of causes. Commonly, pain is attributed to presumed “arthritis.” However, there often is no clinical evidence of such arthritis or that the arthritis is the cause for pain. We do not know whether persons with cerebral palsy are at greater risk for developing age-related arthritis, and if they are also prone to an earlier onset of this disease. Often the pain is related to soft tissue injuries in muscles, tendons, ligaments, or nerves. Compression of peripheral nerves (that is, entrapments) can also cause pain. These conditions are likely to be the result of the way a person performs an activity and often may be the result of repetitive movements over time.

There is no information about the risks for developing pain or about preventing it, especially over a long period of time. Unfortunately for adults with cerebral palsy, there are many instances that their complaints about persistent pain are either ignored, or minimized (i.e., “You can expect this to occur and there is nothing we can do about it”).

Fatigue is a recurrent complaint for adults with cerebral palsy, particularly as they get older. As in the general population, fatigue may signal the onset of a general slowing down of the person; however, it may also signal the onset of a particular medical problem. Older persons with cerebral palsy may sometimes experience pain and fatigue together. Often this is ascribed to “depression” or psychosomatic issues.

There is little information about strategies to maintain endurance over a lifetime for an adult with cerebral palsy. Issues of energy conservation are often dismissed. Choices regarding equipment or technology use as well as exercise often are made by an adult with cerebral palsy using imposed values of family members or care

providers. It is quite possible that these value judgments are based on data available for the general population, but that they are not in the best interest for the adults with cerebral palsy.

The questions raised include:

- Do persons with cerebral palsy experience musculoskeletal or arthritic related pain earlier in the life cycle than their peers?
- Does excessive fatigue jeopardize the ability of older adults with cerebral palsy to function adequately on their jobs? If so, how can they be assisted to minimize the effects of that fatigue?
- Does weight-bearing on poorly functioning joints, aggressive therapeutic mobility activities, repetitive movements, or poor preparation or maintenance for these activities lead to joint pain, muscle pain or weakness?
- Do people who are full or part time users of wheelchairs experience pain in the back, hips, knees, and shoulders? if so, what can be done to alleviate or minimize this problem?
- Is there an increase in the prevalence of peripheral nerve entrapment (e.g., carpal tunnel syndrome) causing pain in persons with cerebral palsy?
- What is the relationship between spasticity and pain as one grows older?
- Does chronic pain (i.e., pain persisting regularly and relentlessly for more than three months) occur more often among adults with cerebral palsy?
- How can assistive technology, selective exercise, or the use of special equipment be effective in the prevention of pain or fatigue in persons with cerebral palsy?

Osteoporosis and fractures

There is a marked concern about osteoporosis - a possible problem for adults who already have musculoskeletal problems. There is no research on adults with cerebral palsy and calcium loss, even though we know that medication for seizures impedes absorption of calcium. There are also concerns regarding the inconsistent recommendations about estrogen replacement.

Osteoporosis can be a problem for persons with cerebral palsy, while they are still young, as well as when they grow older. As a secondary condition, it has been noted to occur early in life in this population and is related to limited activity (particularly when there is a lack of weight bearing coupled with lack of muscle activity), poor nutrition, certain medications, or endocrine problems. In addition, older persons with cerebral palsy are also at risk for developing age-related osteoporosis. The interrelationship between these two etiologies is unknown.

The most significant complication of osteoporosis is fractures. Fractures resulting from secondary osteoporosis often involve a person's limbs, and may be related to transfer lifting techniques or to injuries when an arm or leg may get caught when moving through a doorway in a wheelchair. Frequently the person or the care provider is not aware of the fracture having occurred and it is only discovered by accident. Fractures resulting from age-related or post-menopausal osteoporosis are traditionally found at the spine or the hip in the general population. This is likely to be the site of injury for the older person with cerebral palsy as well. The most common causes for fractures in adults at any age are falls.

The questions raised include:

- Are there different causes or contributing factors for osteoporosis in older persons with cerebral palsy as compared to the general populations?
- In treating fractures, what is the impact of surgery, casting or splinting on changes in function?
- Are persons with cerebral palsy at greater risk of developing age-related osteoporosis than persons in the general population?
- Do typical intervention and treatment strategies for osteoporosis and arthritis work for persons with cerebral palsy?

Impact of previous treatment

The long-term impact of the treatment that adults with cerebral palsy received in their younger years has not been studied. Concerns about such impact stem from two beliefs. The first involves a belief that vigorous applications of therapy (weight bearing on poorly aligned joints, stress to joints or muscle tendons from poorly controlled movements, and such) may have a long term deleterious effect. Also, long term effects of surgical interventions from a functional and personal/social basis are being questioned. While no research yet has confirmed or disconfirmed these beliefs, there is anecdotal evidence supporting the notion that these practices bear further scrutiny.

The second belief concerns the cessation of therapies that may have been applied during the developmental period. Many adults with

cerebral palsy, when they were younger, received physical or occupational therapy of long-term duration. As they reached late adolescence or young adulthood and were able to make their own decisions about treatments in which to participate, many decided to discontinue these therapies. Others may have been participating in routine therapies as a part of their school programs. As they aged out of these programs, usually by age 21, those services were discontinued, often without any concern or planning for maintenance or prevention programs. This lack of continuity of routine therapies has raised sufficient concern that too bears further scrutiny.

There is also a concern that treatments may have been initiated, not because the individual with cerebral palsy requested or consented to it, but for other self-serving reasons. In some cases such treatment was initiated without consideration of the needs of the person, but to address the convenience needs of the parent or caregiver. The individual with cerebral palsy was encouraged to walk with or without a mobility aid rather than using a wheelchair, or was positioned in a way that looked comfortable to the caregiver, simply to suit the caregiver. Thus having learned to walk and made to feel that it was crucial to do so may have resulted in limited mobility options in later life, or the change in positioning may have looked better to the caregiver, but resulted in pressure sores for the individual.

Many experts in the field are beginning to question the long held beliefs regarding intervention and the bases for the use of certain treatment modalities. It is imperative to take a hard look at what those treatment modalities are, how or whether they need to be modified, and what the future implications of current treatment methods may be.

The questions raised include:

- What are the best intervention strategies to promote optimal functioning over the course of a person's life (e.g., a specific description of the treatment, intensity, course over time, continuity and mix of services)?
- What are the long-term implications of therapies or medical and surgical interventions instituted at a young age?
- What is the life-time impact of medication, orthopedic or neurosurgical procedures, exercise, assistive technology or conditioning activities?

Oral motor problems

The act of eating and swallowing is a complex physiological task. Some adults with cerebral palsy, especially those with severe impairments, experience great difficulties with this function. In these instances, they are also at risk for developing dental problems.

Upon getting older, these problems tend to be aggravated by two related factors. The structure and overall health of dentition worsens, primarily as a consequence of disease and poor early dental care, and the amount of saliva produced diminishes as a result of aging (the amount of decrease may be exacerbated by various medications). These situations cause further problems because teeth are necessary to chew and saliva is needed to mix with food in order to facilitate the swallowing process. As a result, the already existing eating and swallowing problems get worse, and may result in a number of secondary conditions.

Eating and swallowing

Persons with cerebral palsy may have difficulty with chewing, swallowing or choking. These problems range from mild to severe. They may exhibit slow, delayed, or “unsafe” swallowing (or dysphagia), and may therefore choke or aspire food or liquids. Problems with chewing and swallowing will obviously have an effect upon the types of foods a person may choose to eat. These limited choices, in turn, may have an effect upon nutrition, weight maintenance, and overall health.

Often, complaints about eating and swallowing difficulties are not taken seriously or dealt with adequately by health care providers. But, when they are taken seriously, unfortunately routine testing (e.g., using a barium swallow) may not show any definitive results. Consequently, the application of intervention strategies (or even the decision not to try anything) may be based on inaccurate or inadequate information.

The questions raised include:

- • What are the changes in swallowing patterns that occur over a person’s lifetime?
- • How useful is a modified barium swallow in detecting dysphagia?
- • How can we determine which treatment strategy is most effective in alleviating feeding and swallowing problems over a long period of time?

Dental problems/malocclusion

Oral health problems increase with aging among persons with special dental care needs. A high incidence of dental problems exists for

persons with cerebral palsy and yet very few of them make the routine visits to the dentist that are normal practice for the general population. For the most part this can be attributed to difficulties in access to care, lack of the availability of trained dental professionals who are comfortable with treating adults with special needs, and restraints due to reimbursement levels.

Bruxism (or tooth grinding) can result in fractured teeth and difficulties for the restorative dentist. Malocclusions (or problems with “bite”) are prevalent in adults with cerebral palsy due to abnormal muscle functioning, such as facial grimacing, abnormal chewing and swallowing patterns, and tongue thrusting. In addition, although it is generally believed that temporal mandibular joint (TMJ) problems among adults with cerebral palsy are no more prevalent than among other adults, they usually occur more frequently among those adults who have malocclusion or poor dentition. Preventive and/or orthodontic therapy may not have been possible in adolescence due to behavior management problems or other factors.

The presence of these oral problems also can impact a person’s ability to eat and/or swallow. For example, loose or broken teeth, periodontal disease, oral cancer, broken and/or ill fitting dental prostheses, all interfere with chewing and swallowing. Oral hygiene is often inadequate due to the lack of fine motor skills and lack of cooperation by caregivers. This can lead to dental plaque, halitosis, dental decay, infection and the early loss of one’s teeth.

A 1994 study, sponsored by the Centers of Disease Control and the Massachusetts Office of Disability Prevention, titled “Impact and Consequences of Secondary Conditions as a Public Health Issue in Massachusetts,” surveyed 739 users of the state’s independent living centers to determine the extent to which they experienced a variety of secondary conditions. The survey asked whether in the past six months the respondents had experienced any secondary conditions, whether they felt the condition had limited their activities, and whether they had visited a health care facility for this condition. The study showed that of 54 adults with cerebral palsy, dental problems were reported to be the most prevalent secondary condition and that such problems were the primary reason for visiting a health care facility within the past six months.

A common misperception is that the loss of teeth and poor oral health are normal by-products of the aging process for older persons with cerebral palsy. However, these problems are less related to normal aging and more a function of barriers to effective oral hygiene. One significant problem is that there is a dearth of adaptive aids to help with oral hygiene. However, most dental problems can be prevented with routine dental care and a good daily preventive program. Many adaptive aids are available and oral hygiene education for both the adult and, when appropriate, his or her caregiver is essential.

Dental professionals need to be educated and trained in diagnosis and treatment planning for work with adults with cerebral palsy. Although certain barriers to care will still inevitably exist, modifications to offices and treatment protocols can be made to make patient visits more efficient and successful. Other barriers may be more difficult to overcome; these include lack of sufficient trained dental professionals, lack of funding for dental care, and state Medicaid dental program policies regarding reimbursement.

The questions raised include:

- What is the incidence of tooth decay, TMJ, malocclusion and other oral problems among adults with cerebral palsy and if the incidence is higher than the norm, why?
- How can general dental treatment strategies be adapted for use with adults with cerebral palsy when special care techniques are warranted?
- What can be done to increase the number of dental practitioners who can provide routine dental care for persons with cerebral palsy?

Gastrointestinal concerns

Little is known about the incidence and experiences of adults with cerebral palsy with stomach and intestinal problems. Some persons with cerebral palsy report problems with heartburn, hemorrhoids and constipation.

Gastroesophageal reflux

Gastroesophageal reflux is the backward flowing or return of the contents of the stomach or intestines. Reflux of stomach contents can be painful and a cause of discomfort to some adults with cerebral palsy. It can cause esophagitis (i.e., heartburn), gastritis, and ulcers. These problems can be exacerbated by certain medications (e.g., particularly antiseizure and anti-inflammatory medications). Although there is a long held belief that skeletal deformities (e.g., scoliosis) may have an effect on gastrointestinal functioning, there is little evidence in the professional literature to substantiate it.

These reflux problems can often result in vomiting, poor general nutrition, and retarded physical growth. The cause and occurrence of gastroesophageal reflux among persons with cerebral palsy is unknown. In addition, the treatment options and their success rates among adults with cerebral palsy are not well described.

One special problem related to gastroesophageal reflux is aspiration (which is fluid or food going into the airways). This can result in recurrent bouts with pneumonia, specialty in persons who are severely physically disabled.

The questions raised include:

- What are the etiology, the prevalence, and the risk factors for gastroesophageal problems?
- What are effective treatment guidelines for problems with aspiration?
- How does the presence of scoliosis impact on gastrointestinal functioning?

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Constipation

Constipation, the inability or difficulty with passing fecal matter from the bowels, is a problem for many individuals with cerebral palsy, whether or not they are older. This problem is generally the result of a hardening of the stools. It is often related to insufficient dietary intake of fiber and fluids, as well as to a lack of routine physical movement to change intra-abdominal pressures.

Certain medications can also aggravate the problem. Through diet modification, bowel medication manipulation, or other bowel management strategies, regular evacuation can be achieved. However, care providers often accept regular evacuation in diapers as the best outcome. Possibly, other techniques or equipment should be considered that may allow timed evacuation on a toilet, thus promoting personal dignity, improving social acceptance, and avoiding skin irritation.

The question raised includes:

- What are effective bowel-management protocols for older adults with cerebral palsy, taking into consideration level of impairment?
- What techniques or technologies could be drawn upon to provide for bowel continence?

Nutrition

Many adults with cerebral palsy expend large amounts of energy in maintaining their mobility. They are also at risk for nutrition-related problems owing to many complex and interrelated physical, environmental, and psycho-social factors. Thus concerns about nutrition are significant.

Traditional methods of calculating needed dietary intake are related to a variety of factors, including metabolism, anthropometric measurements, and exercise. These methods, which result in recommended Regular Daily Allowance (RDA) needs, are based on the general population and have not been adapted for adults with special needs related to neuromuscular disabilities. Thus, there is reason to believe that the dietary intake prescriptions drawn from these methods are not applicable to persons with cerebral palsy. It is likely that the traditional model based on a combination of weight control, diet, and exercise requires some modification, or that the prescriptions should be adapted to accommodate special situations.

It is difficult to determine when the energy and nutritional needs of a person with cerebral palsy are being met, particularly among persons with severe impairments. An uncertainty is how someone should change his or her nutritional intake based upon the presence of acute or chronic illness (e.g., aspiration pneumonia) or a change in functioning. Further, since adults with cerebral palsy have fewer options for exercise than adults in the general population, a steady weight gain can not be offset by a prescription for more physical activity.

Thus concerns about nutrition, access to a balanced diet, and quality and quantity of food intake may take on special meaning when an individual may have difficulties in feeding him or herself, shopping for food, or finding someone who can help with determining nutritional needs.

The questions raised include:

- How does lack of adequate nutrition impact on the general health status of older persons with cerebral palsy?
- What are the energy needs during rest, daily activities and mobility over a lifetime?
- How does the RDA (Regular Daily Allowance) need to be modified for people with cerebral palsy?
- What are the energy and other nutritional consequences of recurrent aspiration pneumonia, and other frequent illnesses?

Urologic concerns

Both men and women with cerebral palsy can have problems with urinary incontinence and retention. These urinary problems can be neurologically based, secondary to existing spasticity, or may result from a lack of appreciation of bladder fullness. Some women with cerebral palsy may also experience urinary problems related to their menstrual cycle.

As can be expected, lack of control of continence can also cause embarrassment and difficulty in being fully independent. In particular, loss of urinary control or changes in urinary function need to be more fully examined as to possible causes, such as medication, spinal cord compression or other neurologic causes, urinary tract infection, or behavioral changes.

Besides biologic causes, there are other factors that may cause urinary problems. Among these factors are inability to void when needed because of unavailable or inaccessible toilet facilities, intake of very small or very large quantities of liquids, incomplete emptying of the bladder, infrequent voiding, and the use of external drainage devices. Among some adults with cerebral palsy and mental retardation, a lack of cognitive awareness of fullness and a lack of any voluntary control may result in reflex voiding.

Yet, urinary continence can be addressed by a variety of methods. Urinary continence requires an ability to appreciate bladder fullness, to indicate the need to void or to have a voiding pattern established, to control the process of voiding, and to transfer to a commode with or without help. These are all areas where an individual can gain control and prevent incontinence.

Adult men with cerebral palsy are likely to have the same problems with prostate enlargement and risk for cancer as other adult men as they age. However, there is no information to support or refute this, nor is there any information regarding diagnostic or treatment strategies among men with cerebral palsy.

The questions raised include:

- What are the risk factors for the development of urinary problems (e.g., urinary tract infections)?
- What are the best treatment options to promote bladder continence?
- Under what circumstances is a full evaluation with urodynamics warranted?
- Is the prevalence of benign prostatic hypertrophy or prostatic cancer the same among men with cerebral palsy as in the general population of age-matched men?

Reproductive concerns

There is limited information about reproductive issues that are specific to adults with cerebral palsy. Both women and men with cerebral palsy report that they have genital and reproductive health concerns, that health care providers are often not equipped to help them, and that in many instances the problems they experience are misdiagnosed or not properly treated.

Physicians or medical clinics generally make no special provisions for men and women with cerebral palsy with regard to genital and reproductive health concerns. This is evidenced when their offices and examination tables are not accessible or able to accommodate an adult with a disability. Even when special equipment is available, most practitioners are either untrained in its use or insensitive to its applications. Some may not be able to conduct a proper examination because of the individual's physical limitations (particularly, spasticity) or the limited amount of information that they elicit from the person with cerebral palsy who seeks their services. Because of this, some physicians are less apt to investigate changes or abnormal menstrual cycles in women or to conduct thorough examinations. Although information is limited, it appears that routine PAP smears, breast examinations (mammography in particular), and rectal exams to detect prostate enlargement and other problems, may not be done at the same rate among women and men with disabilities (who are not part of state regulated services) as among other persons.

Reproductive concerns raised vary among men and women with cerebral palsy. Men express concerns about impotence and the physical means to meet their sexual needs. Women seem to express more concerns about menopause and its manifestations as compared to women without cerebral palsy. They are concerned about the additional physical problems that middle-age brings, such as emotional changes and changes in level of energy. There are also concerns about the physical implications of menopause, for example, difficulties with removing a sweater or other wrap during hot flashes. In some, mood swings associated with menopause are also a concern.

As is the case with many adults in the general population, there are also concerns about birth control and the potential of contracting sexually transmitted diseases and AIDS. While some of these are reproductive health issues, others are intractably interwoven with issues of human sexuality, such as education about sexually transmitted diseases, reproductive health, PAP smears, and birth control (such as use or inability to use condoms). There are also the influences of cultural differences and their effect upon the acceptance of a man or woman with a disability as a sexual partner. Even more importantly, among adults with severe physical limitations, there are concerns about the use of a third person to facilitate sex.

There are concerns about fertility and ability to carry to full term and give birth to an infant. Women with cerebral palsy report they have an extremely difficult time finding someone who can help provide accurate and reassuring information about this concern. One question often asked relates to the "childbearing window." Many women ask "How long can I have children and will I have a more difficult time with childbirth due to my disability as I grow older?" Physicians, family planning clinics, and independent living centers need to be able to provide counseling to address these concerns.

Accessibility to health care around reproductive concerns is a major problem. Most persons with cerebral palsy find that health care insurance for persons with a disability is extremely difficult to obtain and that even when they have insurance most clinics or physician offices are inaccessible. In addition, some health care providers are lacking in knowledge about cerebral palsy, OB/GYN services are difficult to obtain, and many providers do not take stated concerns seriously (sometimes due to preconceived notions about intelligence, hypochondria, and the like).

"Patients" with a disability are often de-personalized by health care providers, and even when information is available, it is generally based on male subjects. With regard to reproductive health concerns, adults with cerebral palsy are often viewed as asexual and practitioner attitudes are generally based on the expectation that they are not sexually active.

The questions raised include:

- How can reproductive information, such as birth control, family planning, genetics, fertility, and satisfaction in sexual functioning, be made more readily available to adults with cerebral palsy?
- How should health care practitioners be advised and trained to provide a regular schedule of routine examinations related to reproductive health?
- Do women with cerebral palsy experience problems associated with menopause in a way that is different than among other women?
- Do men with cerebral palsy experience impotence or other reproductive problems in a way that is different than among other men?

Sexuality concerns

While not easily divorceable from reproductive health concerns, sexuality is included as a separate issue because of its social and emotional effects on adult development and aging. Adult women and men with cerebral palsy face many barriers to being a sexual person. This is due to the mythology within the population-at-large that de sexualizes persons with disabilities (that is, people who are disabled are portrayed as non-sexual beings).

Often persons with a disability may also hold a similar image of themselves. In large part, this has been reinforced by parental and other adults' attitudes as many adults were brought up thinking of themselves as asexual. Women may be diminished by this attitude and many remain single because their parents felt they should never get married. Thus, they never dated or expected to be seen as a sexual person and lacked expectations to become wives and mothers. Men, in turn, may have been identified as poor family providers and unable to assume the responsibilities of a lover, husband, and father.

As adults grow older, many sexuality issues may revolve around a number of concerns. Health-related concerns include worries about effects and utility of different types of birth control (e.g., side-effects of birth control pills, the difficulty in using condoms); fears generated by sexually transmitted diseases and AIDS; and with advancing age, unanswered questions related to more noticeable contractures, decreased mobility, possible impotence, and the impact of menopause upon sexual activity.

Another concern, expressed by both men and women, pertains to sexual performance. Some of this is affected by whether or not the sexual partner is a person with a disability. Some feel that there is less performance anxiety with a non-disabled partner because the partner is seen as helping out; others may feel more anxiety in such situations. When both partners have a physical disability, each may perceive problems with attitude and physical barriers. Further, these performance concerns may be associated with dysfunctional aspects of sexuality, which in turn are linked to low self-esteem and self confidence, and discordance with body-image.

The difficulty of finding a life partner (or an immediate partner) can limit sexual contact and intimacy, and with advancing age this becomes even more of a concern. Even within marriage or with a consenting sexual partner, privacy may be compromised when a third party has to be present to facilitate sex among adults with severe physical impairments. All of these barriers become more pronounced with advancing age - in fact, dating and engaging in sexual relations may become more difficult due to social isolation and as the pool of potential mates decreases with age.

Both men and women with cerebral palsy often have to struggle with their own and other's stereotypical image of what is sexually attractive. Moreover, many women and men with cerebral palsy have to learn to overcome the expectations and suggestions that they need protection from sexual experiences. Because often they are not expected to marry and have children, they are not expected to be sexually active. These expectations have life-long social implications.

Thus, expectations and desires related to being a sexual person are fraught with problems when one is confronted with a lack of expectations that one may be a sexual person, one's experiences are limited or non-existent, and with increasing age, when one's physical abilities are further diminished.

The questions raised include:

- What are some means to provide supports for the physical and psychosocial sexuality concerns and needs of older persons with cerebral palsy?
- How can assistive technology be useful in sexual situations?
- How can personal care assistants be more effective in areas of sexuality and sexual functioning?

Communication problems

Adults with cerebral palsy may experience difficulty and frustration in making themselves understood because of speech articulation difficulties. These difficulties may contribute to negative reactions from listeners and unwillingness on their part to make an effort to carry on a conversation. Their difficulties may also affect general attitudes expressed about adults with cerebral palsy. These attitudes may lead to the general impression that people with cerebral palsy are of low intelligence or interpersonally incompetent. In reality, many adults with cerebral palsy are intellectually competent.

When communication problems are present, they can be generally attributed to three major factors: motor production of speech, actual language and central processing difficulties, and the existence of hearing loss. Although any one of these factors may be the main underlying cause of communication problems, a small number of persons with cerebral palsy may experience a combination of all three problems. Motor production of speech is the most prevalent cause of problems, while hearing impairments may be a factor in some 20% of such instances. In addition, with increasing age pulmonary changes can have an effect upon breath control, affecting voice volume and capacity. To what extent this is prevalent among older adults is unknown.

Communication difficulties present an intricate set of problems. It is difficult to assess these problems accurately, because of the complex interplay between cognition and language production. Adults with cerebral palsy may also have "learning disabilities" which may have not been accurately diagnosed and remediated when the individual was in school. Therefore, adults may have some language integration and production difficulties.

These learning disabilities may further interact with problems of articulation, making speech and conversation a frustrating ordeal. However, recent innovations in augmentative technologies can offer a significant benefit in overcoming communication deficits. One problem with such interventions, though, is that once a young

adult has “aged out” of the school system, this type of assistance becomes less available.

In any event, communication difficulties need to be addressed. For example, a common concern among older adults is that symptoms and complaints are often difficult to communicate to health care providers and others. This may lead to frustrations with the health care system and a disincentive for contact until a health problem becomes an overwhelming acute issue or a chronic problem. It can also lead to misdiagnoses of illnesses and secondary conditions when health practitioners cannot fully comprehend the responses given.

Communication difficulties may and do pose significant barriers to employment, socialization, and conducting day-to-day business. While some of the attention needs to be focused on developing more effective and efficient communication devices, other attention needs to be directed toward training health care workers and others, who are apt to regularly come in contact with adults with cerebral palsy, to be more receptive and understanding communicators.

The questions raised include:

- How should health care providers be trained to take the time to listen to adults with cerebral palsy, without having any preconceived ideas about their intelligence or ability to make informed decisions about their care?
- Which augmentative communication devices would be most useful and how can they be made accessible and available?
- How do age-related changes in breath control impact on the ability to talk among adults with cerebral palsy?
- Is the incidence of learning disabilities, especially in the areas of communication, speech and language disorders similar to that in the general population?

Personal effectiveness concerns

Adults with disabilities experience problems that reflect the normal aging process, as well as those unique to a life spent living with a disability. With the onset of middle age, many adults with cerebral palsy report changes in functional abilities that they did not anticipate. They had been led to believe that cerebral palsy is a non-progressive disorder and were not prepared for the fact that they can no longer easily do what they could do previously. These unexpected losses and impediments pose a new threat to their independence.

Many adults are now faced with having to develop acceptable solutions to continue day-to-day functioning. In turn, they may have difficulty coping with the age-associated changes that are complicated and perhaps accelerated by cerebral palsy. Many of these difficulties may become more of a problem when these changes interfere with their day-to-day social concerns, interpersonal relationships, employment, parenting, and other demands.

Successful aging

Maintaining social networks, friendships and other relationships becomes increasingly difficult as we age and our peer group dwindles in size. Often, a buffer to these losses is having children or a spouse with whom we increasingly develop an interdependent relationship. Unfortunately, many adults with cerebral palsy are less likely to have married and have had children - the very people who otherwise would be able to assist them and offer informal supports. For persons who also have mobility and/or speech difficulties, this isolation can be very difficult because many adults have not been able to develop social networks outside of their immediate family.

Getting older also has an effect on vocational identities and plans for life following retirement. It contributes additional stressors to physical abilities and raises concerns about abilities to maintain health and maintain social relationships. It may also open up problems related to neglect or abuse - particularly among older adults with no sustainable social support structure - and make unresolved fears of the future more apparent.

With the absence of adequate role models for successful aging among adults with cerebral palsy, one potential consequence can be the adoption of a personal strategy of denial. For example, if we deny that in the future we can be adversely affected (that is, we will have diminished capacities), we are less likely to engage in behaviors that promote health and well-being, and even worse, we may engage in risk-taking behaviors. Another potential consequence can be "learned helplessness." In this instance, if we believe that no matter what we do our actions will not alter the outcome, we become at-risk for depression and sometimes suicide. Thus, aging among adults, whose psychosocial functioning may

already be disrupted or dysfunctional due to lifelong disability and for whom few or no role models exist for successful aging, may result in a risky “old ager.”

What are some of the areas that are impacted by aging within the realm of personal effectiveness? These areas can include responsibilities related to parenting, work and retirement, and living independently. Some areas of concern that are also impacted are issues of personal integrity (or abuse), passing (or not being identified as different), and fears of the unknown.

The questions raised include:

- What is typical “successful aging” among older adults with cerebral palsy?
- How can local support groups contribute to a better understanding of aging and coping with its changes and demands?

Parenting/family responsibilities

Parenting responsibilities among adults with cerebral palsy who marry and have children becomes an issue only if societal attitudes interfere with the parents’ abilities to parent in their own way, their physical condition begins to pose a barrier to attending to their child, or financial or other stressors lead to a breakup of the marriage. While these problems may seem particular to adults with disabilities, there are also problems that any married couple may encounter when they are parents. For example, middle age parents may experience conflicting demands from maintaining their own family and having to care for elderly parents -- an all not too uncommon phenomenon among adults in the “sandwich generation.” In addition, although most adults who become parents may not need special assistance, some - due to their physical condition - may require adaptive aids or homemakers to help them.

The interaction of age-associated changes that occur at a younger age than was expected and the demands of being a parent of a young child at the same time may pose some unique challenges. Some parents with cerebral palsy may need help in the physical care of their children when they are very young. As they and their children grow older, they may also become more dependent on their children than they would wish. This may be particularly true among adults who become parents later in their lives.

When a couple does have children and one spouse has cerebral palsy, the division of household labor and child care may become an issue. While this role issue is typical of all married couples, it may be a special concern when either of the two has a disability. The couple often has to make a choice whether the parent who does not have a disability should stay home and assist with the child care or whether they should go through the expense of hiring an aide to help. If both parents have to work, this becomes an especially difficult situation.

The questions raised include:

- What are some aids that can help families in which one or both parents have cerebral palsy?.
- How can agencies provide support services to aid families in which one or both parents have a disability that may interfere with parenting?
- How should supports be best made available to help a son or daughter with a disability provide care for both an elderly parent and his or her children?

Work and retirement

The work place is often where social supports and other interpersonal resources are developed. Not surprisingly, the transition to retirement provokes a variety of concerns for persons with cerebral palsy. These may include concerns about extent or loss of health care benefits, loss of income, and loss of contact with friends developed in the work place. 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. In most persons, retirement concerns revolve more about what to do as a retiree, particularly if the person's employer will provide an adequate pension or Social Security benefits will offer some level of support. Among persons with short work histories, who have worked for employers that do not have adequate pension plans, or for whom continued loss of physical abilities poses serious barriers to leaving their job, retirement may not even be a reality.

The latter problem may be very serious. For older adults with cerebral palsy who may not want to retire but are persuaded or forced to retire because of physical limitations and the lack of flexibility in the work setting, there may be no alternative. Particularly devastating may be the loss of health care coverage and the impact on personal dignity of accepting public welfare.

In such work situations, health care personnel, for example, may strongly recommend retirement because of increasing physical limitations. However, in many instances, these limitations could be compensated for if health care personnel were aware of programs that focused on teaching the employee and employer how to make

modifications in the work place. Unfortunately, some employers, even when they recognize the difficulties the person 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.

The questions raised include:

- What should be done to improve health care provider and employers' receptivity to providing supports in the work place for older workers?
- What should be done to provide retirement supports for persons who otherwise might become socially isolated and without activities?
- How can satisfactory retirement opportunities be expanded for persons with cerebral palsy?
- What can be done to encourage greater compliance with the Americans with Disabilities Act?

Housing

Where one lives defines in no small part how one views one's capabilities and role within society. Thus, having one's own home or place to live is extremely important. Accessible housing, whether renter or owner based, for an adult with cerebral palsy plays a major role in that person's ability to function independently and maintain his or her personal effectiveness. Accessibility, an issue for persons with minimal impairments, is even more of a concern for persons with significant motor impairments and associated conditions.

Properties chosen for use as a residence need to accommodate the needs of the individual when mobility and other movement may be a significant problem. The properties should be designed to permit ease of getting in and out of the front door, easy movement inside so that living space is barrier free, and containing the special features to make the house useable and livable.

Important also is autonomy and control over design (for example, layout, special or personal features, etc.), environmental features (such as temperature settings, lighting, colors), and use (for example, who comes and goes). In essence, "if it is your place, you should have the final say in what happens in it.

For persons who may be living in congregate care facilities, other problems may occur. If an adult may need to relocate because he or she is no longer able to function in his or her current residential setting, the emotional impact may precipitate a major functional decline or a major change in adaptive behavior. The problems become exacerbated if the individual who is being moved is not part of the planning and decision making process for the move. Under these circumstances, the need for care may increase and new symptoms may develop.

The questions raised include:

- How can housing be modified or made available that includes adaptive aids and is barrier free?
- How can persons with cerebral palsy be encouraged to optimize autonomy and control over their living space?
- How can agency policies be modified to protect the rights of adults who want to "age in place" in the residence of their choice?

Abuse and neglect concerns

One outcome of social isolation among persons with disabilities, which may increase with age, is self-neglect. Another is abuse when a person is in a dependent situation socially or for care needs. Many adults who live in less than ideal situations may be abused or subject to neglect. This may be particularly true in congregate care facilities where negative staff attitudes or work habits can contribute to advertent or inadvertent abuse or neglect.

In dependent care situations both men and women (though it tends to be more prevalent among women) who are severely physically impaired and who are physically handled may be the object of physical or sexual abuse. This may take the form of touching, fondling, or other more blatant forms of sexual abuse. Abuse may also take the form of constant intrusions, lack of privacy, and lack of sensitivity upon exposing the person during bathing and other general personal care routines. It may also result in depersonalization in care situations where the adult is treated as an object rather than respected as a person with a need for privacy.

Social interactions may unfortunately also afford an occasion for abuse. Unwanted sexual advances and rape have been reported by women with disabilities. Previous limited social experience often makes persons with disabilities uncertain in some social situations. Abuse of drugs and alcohol in social situations can also be a problem. Consuming excessive amounts of alcohol is often related to anger or depression. The over use or abuse of medications may be due to dependency upon prescribed medications. Such abuse is problematic because it can have long term consequences, not only in the impediments it may cause to effective personal functioning, but because excessive medication use may have unknown physical consequences of upon body systems.

Abuse appears to occur with greater frequency among older adults with disabilities than for older persons in the general population. Such abuse can be emotional, physical or sexual and should be brought “out of the closet” in order to eliminate the situations that cause persons with disabilities to be abused. Such abuse may also be the result of vulnerability of men and women with a disability, who because of either their physical condition or emotional fragility are particularly susceptible to unwarranted exploitation or mistreatment.

Self-neglect is also a significant problem, particularly among those older adults who have difficulties with mobility and physical control. Thus, difficulties with staying clean, getting good nutrition, and maintaining other hygienic and health features pose barriers to effective personal functioning. These problems are exacerbated when the individual is socially isolated or neglected by their family or other caregiver or a personal attendant. These special circumstances that confront many adults with cerebral palsy place them at risk for further health problems. One outcome of this type of self-neglect is that as they grow older, they may begin to fail in their ability to carry out tasks of everyday living, then denying that this is happening, and resisting contact with social service and other agencies.

The questions raised include:

- Are there effective abuse prevention strategies that can be implemented?
- What can be done to empower adults to prevent abuse, either emotional or physical?
- What are the adverse effects of the long term use of certain medications by adults with cerebral palsy?

“Passing” and staying mobile

Many adults with cerebral palsy express a fear about growing old. They associate growing older with the occurrence of signs of “pathological aging.” They have difficulty sorting out when to begin to use assistive devices and when, as they perceive it, to remain stubbornly independent and resist all types of therapeutic interventions. They feel that as they grow older, they have less of their existing “reserve” and are forced to use assistive devices and technology sooner than do their age-peers without a lifelong disability.

Passing implies that a person with a disability is able to “hide” the disability. It has little to do with really being accepted in society. Walking is sometimes believed to be the key to passing; this concept is promoted by well-meaning parents, educators, and health care providers early in life. Passing can also include choosing clothing to hide a disfigurement, using a tape recorder in a classroom to assist with note taking, or choosing activities in school based on proximity to limit difficult walking. The decision to use an assistive device may be difficult, because in the eyes of the user accepting its use may make the disability more obvious and may indicate a more dependent state.

To make things even more difficult, adults with cerebral palsy who begin to develop mobility impairments are faced with decisions to begin to use such assistive devices (walkers or wheelchairs) at a much younger age than peers who are not disabled. For the present generation of middle aged and older adults with cerebral palsy, this dependence on assistive technologies means more than giving up some freedom and social status -- it may raise the threat of a change in place of residence.

The questions raised include:

- How should young adults with cerebral palsy learn to anticipate what their needs may be as they grow older and how should they plan and prepare to meet them?
- How can parents be assured that their children's mobility encompasses more than being able to walk unassisted?
- How realistic is the fear of being placed in an institutional setting when one gets older, and one's mobility becomes more impaired?

Fears about the future

A major fear about growing older among adults with chronic conditions is that they will not be able to obtain health insurance. Most insurance companies will not accept persons with pre-existing conditions and specialized equipment or specialized long-term care is often not covered. Adults with cerebral palsy face problems even if a health care provider can be found who is willing to provide services and if the finances are worked out. These problems include the fact that their concerns are not taken seriously or the health care provider lacks knowledge about what to do.

Another fear is related to problems in accessing health care, particularly with changing needs associated with aging. It is difficult for adults with cerebral palsy to receive age appropriate health care as they grow older since in many instances most of their care has been based in pediatrics. This has sometimes resulted in infantilization and lack of respect for adults with cerebral palsy among health care professionals.

Another fear is of physical changes. Adults are likely to worry about the possibility that things will get worse in the immediate future. For persons who thought that they had come to terms with their disability, the possibility of future loss of function can upset their expectations that their lives had stabilized. There is a lack of knowledge about the future need for assistive devices and the long-term impact of increased disability. There is also a lack of persons as role models who have experienced similar changes. Many adults will readily admit that they have no idea what the future has in store for them since they seldom know an older person with cerebral palsy.

With increasing age, significant people in one's life also age. Caregivers (whether parents, spouses or partners, siblings, friends or relatives) also age and experience age-associated changes and possible limitations. This may mean that adults with cerebral palsy may no longer depend on the caregiver for assistance and support. This may cause uncertainties about the future and increase concerns about what supports may be available with advancing age.

The questions raised include:

- How can we identify role models who have experienced similar changes with aging, and how can we help them to share their experiences?
- How can we best assist persons with cerebral palsy plan for the future?



4 WHAT NEEDS TO BE DONE?

“I’m 35 years old and trained as a graduate level rehabilitation specialist I’ve used a wheelchair most of my life. I’m married, drive a specially equipped van, and hold a responsible position with a state agency. Recently my wife and I moved to this city so I could work for a state agency. Not knowing any local physicians familiar with the problems we have, I got an appointment at the clinic of the local cerebral palsy agency. While sitting in the waiting room, I was approached by a worker at the clinic who, not knowing me, commented about ‘how cute I looked in my tie and jacket’ This comment left me angry and frustrated, since I did not expect to be treated so rudely.”

What have we learned?

Little substantial information is available about how the aging process affects adults with a lifelong disability, such as cerebral palsy. We have heard that some adults experience age-related problems earlier than would be expected for their age. Nonetheless, we believe that most adults with cerebral palsy are generally healthy and, with greater attention to certain preventive health practices, could remain so as they age. As with other adults, responses to age-associated changes among adults with cerebral palsy vary from individual to individual. However, due to a number of factors some adults with cerebral palsy have fewer options to exercise with regard to the age-related changes that life brings.

We have observed that many adults with cerebral palsy have problems with movement and other musculoskeletal functions. We know that motor function changes in mobility, strength, and endurance occur during the maturation process in adults with cerebral palsy. These changes may have an earlier onset than among other adults and may be more pervasive. Yet, there is little consistent information about means to maintain mobility, strength and endurance over a lifetime for an adult with cerebral palsy. Interestingly, the long-term impact of treatment in younger years has not been studied even though anecdotal evidence indicates that some treatment strategies may be based upon faulty assumptions and may cause more harm than good.

We have observed that oral health problems increase with aging among persons with cerebral palsy. Yet, although a high incidence of dental problems may exist, we have also observed that most adults with cerebral palsy have great difficulty in seeing a dentist regularly. The reasons for this are complex. They include poor insurance coverage for services, expensive treatment, inaccessible facilities, difficulty in finding dentists who will take care of persons with special needs, a fear of treatment, and reluctance to use available services due to unsatisfactory previous experiences.

We have observed that little is known about the incidence and experience of adults with cerebral palsy with stomach and intestinal problems. However, there are concerns that appear directly related to these problems. They include concerns about poor nutrition that are related to an inability to maintain a balanced diet, and have control over the quality and quantity of food intake. Other significant issues among some adults include having difficulties in feeding oneself, shopping for food, and having someone available who can help determine nutritional needs. These problems are often directly related to the individual's overall health status and ability to sustain him or herself.

We have observed that both women and men with cerebral palsy have significant health concerns, that health care providers are often not equipped to help them, and that in many instances the problems they experience are misdiagnosed or not properly treated. Many adults find that health care insurance for persons with a disability is extremely difficult to obtain and that even when they have insurance most clinics or physician offices are inaccessible or do not respond to them adequately because the providers are lacking in knowledge about cerebral palsy.

We have observed that many adults with cerebral palsy experience distress and frustration in making themselves understood because of speech difficulties. These difficulties may contribute to negative reactions from listeners and a lack of willingness to make the effort to carry on a conversation. These difficulties may also affect general attitudes expressed about adults with cerebral palsy and may lead to the general impression that people with cerebral palsy are of low intelligence or interpersonally incompetent.

We have observed that adults with cerebral palsy experience problems that reflect the normal aging process, as well as those unique to a life spent living with a disability. With the onset of middle age, many adults with cerebral palsy report changes in functional abilities that they did not anticipate. Since they had been led to believe that cerebral palsy is a non-progressive disorder, most are not prepared for the fact that as they age they can no longer do easily what they could do previously. These unexpected changes and impediments pose a new threat to their independence and may become more of a problem when these losses interfere with their day-to-day social functioning, interpersonal relationships, employment, parenting, and other common demands.

We have observed substantial stressors related to work and the transitions imposed by advancing age. Older age transitions, such as retirement, have provoked a variety of concerns for adults with cerebral palsy. These include concerns about loss of health care benefits, loss of income, and loss of contact with friends developed in the work place. They include problems associated with locating accessible housing and possible difficulties in maintaining such housing with increasing age. They also include a high incidence of physical, verbal and sexual abuse linked to the vulnerability of some adults with cerebral palsy, who because of either their physical condition or emotional fragility are particularly susceptible to unwarranted exploitation or mistreatment. These stressors, heightened by the interaction of disability and age, in turn may lead to psychological problems, such as depression and increased anxiety.

We have observed that many adults with cerebral palsy express a fear about growing old because they associate growing old with "pathological aging." Among these fears is loss of mobility and personal competence and independence. That fear is present even though they have come to terms with their disability. The possibility of future loss of function is upsetting their expectations that their lives had stabilized. Also, we see a fear that with advanced age, they will lose the significant people in their lives leading to the loss of those very people upon who they depend for assistance and support. These fears are further heightened by a lack of viable role models of "successful agers" among older adults with cerebral palsy.

What can be done?

Our report raises a variety of clinical or research needs. We see the need for an increased availability of and accessibility to health care resources. We see the need for a network of providers who are trained and knowledgeable in the problems of aging and cerebral palsy. We see the need for more substantial information so adults with cerebral palsy can become informed consumers of health and social services. We see the need for an expanded emphasis on research in medical issues pertaining to the aging of adults with cerebral palsy.

We feel that health care providers and health care resources need to be made much more available and accessible. Information about these resources should have widespread dissemination. As our governments wrestle with examining the health care system, the needs of adults with lifelong disabilities should be given the utmost consideration since many have been and continue to be disadvantaged by existing health care practices and policies. Reshaped or augmented health care practices need to take into consideration both lifelong care related to a disability and the special considerations of aging-related health needs. There should be equity in both the financial availability and accessibility of health services. There should be no physical or financial barriers to the use of health care facilities.

There also should be increased sensitivity by health care systems to the special needs of adults with cerebral palsy. The various health care professions need to have practice guidelines that help the provision of clinical services. Most importantly, there is a need for knowledgeable and responsive health care providers to accommodate informed consumers and, more importantly, create informed consumers from among their services' users.

There is a great need for more information. Our medical, social and psychological literature is devoid of any significant work on the aging of persons with cerebral palsy. There is no body of information that can be given out to provide the answers to the questions posed daily. Adults with cerebral palsy generally have no one to turn to for answers about their physical and emotional needs as they experience growing older. There is a great need, not only for information for adults with cerebral palsy, but also for providers who need training and need to become more knowledgeable about the problems of aging and cerebral palsy. Many providers currently hesitate to treat persons with cerebral palsy because they are perplexed by a combination of cerebral palsy issues and age-related changes. We need to develop venues for the exchange of information on specific topics (such as conferences, workshops, and written materials).

People with cerebral palsy need to advocate for themselves. We need to ensure that adults with cerebral palsy have the appropriate information and adequate assistance to help them get proper medical care, plan for the future, and become informed consumers of health and social services. Many adults with cerebral palsy are well aware of the difficulties encountered in finding doctors and other medical providers who can treat symptoms associated with cerebral palsy as well as treat problems not related to their disability. Assurance should be given that they should and must be assertive in taking what steps are necessary to assure that they receive adequate medical and support services.

Local systems for the dissemination of information and exchange of self-help information and supports need to be put in place via "1-800" or other no- or low-cost local lines or easily accessible computer networks. These systems, facilitated perhaps by cerebral palsy agencies, independent living centers, local wellness clinics, and the like, should be managed and maintained by adults who would most benefit from them.

We need to see more effort within the research community to examine medical and social issues related to aging and cerebral palsy. We need to explore whether age-related changes and age-related diseases occur with the same frequency as in the general population. We need to investigate under what conditions the presence of cerebral palsy is a contributing factor to changes in function, and we need to find out what treatment and assistive technologies can slow down these changes. We need to determine effective strategies that can delay the onset of aging-related or secondary conditions. And most importantly, we need to develop a sound strategy for health promotion and wellness education that is based on research and sound practice.



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