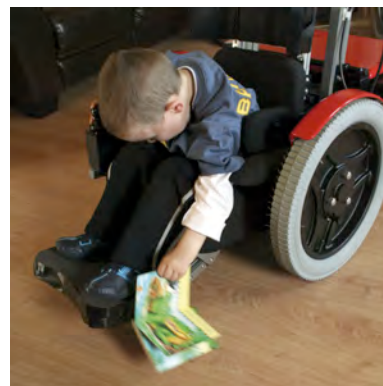


Effective Mobility for Children with Motor Disabilities

What? Why? When? How?



Contents

Paradigm Shift in Rehabilitation3	Model of Disablement.....14
Traditional Philosophy	Disability Movement.....16
Emerging Philosophy	Civil Rights Laws.....17
Effective Mobility: What?5	Availability of Powered Devices.....18
Effective Mobility: Why?5	Effective Mobility: When?18
Outcomes: Traditional Approach.....5	Theory of Child Development.....19
Walking: At What Cost?	Importance of Self-Produced
The Reality of Walking	Locomotion.....20
Outcomes: Restricted Locomotion.....7	Neuroscience: Developing Mind
Theories of Motor Development	and Brain.....21
and Motor Learning.....8	Hi Tech Tots.....22
Classifications of Motor Conditions.....10	Wheelchair Toddlers
Gross Motor Functional	Effective Mobility: How?24
Classification System	Assistive Technology.....24
Classification: Prescribing	Outcomes: Powered Mobility
Wheeled Mobility Devices	Conclusions: Powered Mobility
Classification: Potential for	Augmentative Mobility.....29
Independent Walking	Service Animals.....30
Model of Service Delivery.....14	Principles of Management30

Charlene Butler, EdD



GLOBAL HELP
HEALTH EDUCATION USING LOW-COST PUBLICATIONS

Author: Charlene Butler, EdD

Charlene is a special educator with a unique background of training and experience in education, child psychology, physical therapy, medicine, assistive technology and research. She pioneered the use of powered mobility by very young children with motor impairments. Her primary clinical and research interest has been in use of assistive technology to promote the overall development and achievement of independence of children with cerebral palsy and other motor impairments.

She was a teacher in a model program for children with motor disabilities for 25 years where she worked in close collaboration with therapists, nurses and a variety of physicians. She was a health educator for the Birth Defects Clinic at Seattle Children's Hospital, and as a consultant to teachers and families about the complex needs of these children.

Charlene has extensive international experience. She networked innovative ideas for the care of disabled children in 13 Mediterranean, African, and Southeast Asian countries as a Fellow of the International Exchange of Experts and



Information of the World Rehabilitation Fund. She led delegations on childhood disability to China and India for the People to People Ambassador Program. She served on several editorial boards for journals published in the US and India.

She is a Past President of the American Academy for Cerebral Palsy and Developmental Medicine where she led that Academy's effort to develop and establish a methodology suitable for systematically reviewing interventions for cerebral palsy and other complex developmental disabilities.

Special Acknowledgement

The author wants to especially thank her colleagues, Johanna Darrah, PhD, PT, and Lesley Wiart, PhD, PT of the University of Alberta, Canada, for their contribution to the ideas expressed in this publication.

Effective Mobility for Children with Motor Disabilities

What? Why? When? How?

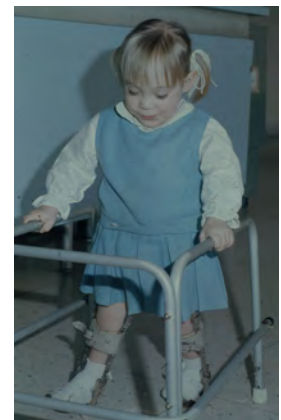
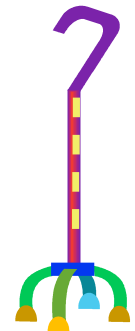
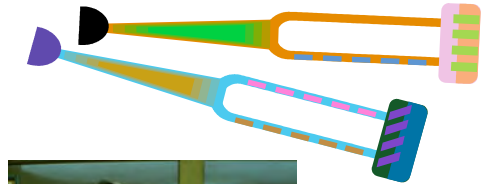
Paradigm Shift in Treatment and Management

No one would disagree that effective mobility is an obvious and compelling need of all people. Yet, it has not previously been a priority of our management of people who have a childhood motor disability such as cerebral palsy, myelomeningocele, muscular atrophy and dystrophy, arthropgryposis, osteogenesis imperfecta, phocomelia, polio, juvenile rheumatoid arthritis, or an injury-related motor impairment.

Organized efforts to help children with motor disabilities began just after World War II with the polio epidemic and soon began to include children with other motor disabilities. What we now regard as the traditional rehabilitation approach evolved during those first 35 years of treatment.

Traditional Philosophy

Traditionally, these childhood motor disabilities were fundamentally understood as an impairment of motor development and function. The core concept in rehabilitation for these children was normalization of movement. The primary goal of rehabilitation was the acquisition, use, and maintenance of normal movement patterns with walking as the most widely and highly valued achievement. Even when the prognosis for walking was poor or limited, primary, if not exclusive, attention was given to therapy, casting, bracing,



Last Resort

surgery, and ambulatory aids, in the hope of eventually achieving some form of walking. Life for the child and family revolved around these interventions. Walkers, crutches, canes, walking frames, and orthotics were acceptable aids because they were “walking” aids. Whatever level or quality of walking the child achieved was to be used in all situations. There was a belief that if the child did not use it (i.e. walking), he or she would “lose it”. Moreover, it was expected that this achieved walking would be maintained throughout adult life.

Wheelchairs were acceptable only when all other efforts and techniques to produce ambulation had failed. In other words, wheelchairs were viewed as the last resort—rather than as an aid to locomotion. Moreover, a wheelchair was thought to be inappropriate for any person at any age who could walk at all, regardless of how much of a struggle it was to walk or how long it took to get somewhere. These concepts had become widely accepted--even entrenched--by the late 1970’s and

framed the traditional philosophy of pediatric rehabilitation.

However, a paradigm shift is underway that is changing the emphasis from walking to effective mobility for these children. Thomas Kuhn first used the term, paradigm shift, in his book “The Structure of Scientific Revolutions” to describe a basic change in assumptions within a ruling theory of science. A paradigm shift is a radical change in thinking from an accepted point of view to a new one, necessitated when new scientific discoveries produce anomalies in the current conceptual view.

Emerging Philosophy

The paradigm of pediatric rehabilitation has been shifting from normalization of movement to normalization of overall child development and independence. The goal of rehabilitation is becoming the achievement of meaningful function and participation in age-appropriate activities and occupations throughout life. Meeting this goal

Paradigm Shift

Traditional Paradigm

From motor disability



From normalization of motor development and movement



From achievement and maintenance of walking



From remediating impairment



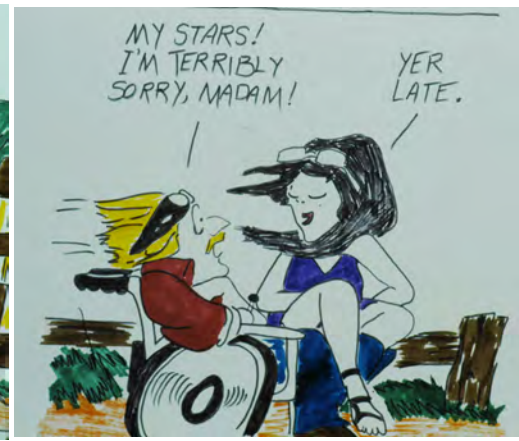
Emerging Paradigm

developmental disability

normalization of overall development and independence

achievement and maintenance of mobility

bypassing impairment



depends directly on being able to meet the required mobility demands.

Effective Mobility: What?

Effective mobility is locomotion that is functional, timely and energy-efficient. In other words, it is moving easily and independently from one place to another. It may include a variety of wheeled and ambulatory aids that augment whatever movement a person may have.

Effective Mobility: Why?

Two conditions need to be present for a paradigm shift to occur. First, evolving practice and research fails to support the traditional thinking. Second, there needs to be a critical mass of people who begin to question the traditional assumptions. This is what is happening in our thinking about mobility for children with childhood motor disabilities.

There have been several advances in knowledge from the fields of healthcare, education and psychology as well as in the society at large that are responsible for the

paradigm shift from “walking” to “mobility”.

First, our clinical experience and scientific studies demonstrated that the traditional approach had yielded disappointing outcomes.

Outcomes of Traditional Approach

Walking: At What Cost?

By the 1980's, studies of energy expenditure and efficiency had demonstrated that there are significant physiologic penalties imposed by abnormal gait. Replicated evidence led to acceptance of the following realities for children and adults.

- 1) When prolonged exercise is performed at greater than 50% of an individual's maximal aerobic capacity, available oxygen is insufficient to meet the energy demands of the muscles, and the individual cannot sustain activity without exhaustion.
- 2) People, with and without motor disabilities, walk at a speed that is most efficient in terms of energy expenditure. To maintain this comfortable level of energy expenditure in free walking, motor disabled persons move more slowly.

- 3) The more abnormal the gait pattern, the greater the energy expenditure and the slower the speed.
- 4) Walking with crutches, braces, parapodia, or walkers greatly increases energy cost and slows speed, regardless of the type of motor impairment or age.
- 5) Any ambulation aid that increases effort is likely to be abandoned.
- 6) Wheelchairs allow individuals to travel at a speed comparable to that of unimpaired walkers with equivalent energy expenditure.

The magnitude of the physiologic penalty of abnormal gait is significant. For example, research has shown that walking in children with myelomeningocele to be twice as strenuous as propelling a wheelchair. Children with thoracic and upper lumbar lesion levels who walked without aids worked at maximal aerobic capacity. The ones who walked without orthotic devices or upper extremity aids, had the highest energy expenditure. Their speed of free walking was much slower (average of 26 meters per minute) than that the speed of unimpaired walkers (range of 69-73 meters per minute). Rapid onset of fatigue occurs with this level of exertion. Children with lower lumbar levels required 85% of maximal aerobic capacity to walk compared with 30% maximal aerobic capacity used by unimpaired children.

Similarly, research comparing children with no motor disability and children with cerebral palsy found that those with spastic diplegia had three to six times higher energy expenditure even at slower than normal walking speeds. Even the children with hemiplegia who had higher energy costs.

Results from other cerebral palsy research may explain why teenagers want—and need—to walk less and use a wheelchair. The rate of energy expenditure at self-selected walking speed in unimpaired people decreases with age while their aerobic and physical working capacities increase. The opposite happens in people with spastic diplegia: their rate of energy expenditure increases while aerobic and physical working capacities decrease. Children, youth, and adults who walk with an abnormal gait and who complain of fatigue or difficulty in keeping up are not lazy. They are experiencing an extreme physical exertion.

When walking requires near-maximal aerobic capacity, classroom performance may also suffer from exercise-induced fatigue. This risk increases as growth accelerates, school campuses are large, and students move between classes frequently during the day. A small but robust study demonstrated that adolescent students with myelomeningocele who walked with crutches or a walker between classes at school had mean heart rates that exceeded 60% to 75% of maximal heart rate following walking, and they showed significant decline in visual-motor performance test measures. By contrast, both heart rate and visual-motor performance improved when these study participants used wheelchairs to get around their school.

Children with neuromotor disabilities such as cerebral palsy and myelomeningocele are already at risk for poor academic achievement because, in addition to their motor impairment, they have visual-perceptual problems, poor hand function, learning disabilities, and/or

attention deficit disorders. High energy consumption compromises them further.

Some people began to argue that the high cost of the traditional approach was not justified. Moreover, it made many young people think they were "lazy" or "failures" when they eventually "retreated" to wheelchairs. In 1997, Dr. Eugene Bleck, noted pediatric orthopedic surgeon, wrote in *Orthopedic Management of Cerebral Palsy*, that "These data indicate how impractical is it to encourage (or force) disabled children to walk long distances with assistive devices. They need to avoid undue fatigue in order to accomplish other tasks of daily living as as school work, learning, social life and community integration."

The Reality of Walking

A review of walking in individuals with cerebral palsy by Bottos in 2003 showed that indoor-only ambulators that relied heavily on walking aids had often stopped walking in teenage years because of the extraordinary time and fatigue associated with walking. By about age 25, community ambulators who relied on walking aids had lost ambulatory capacity due to "physiological burn-out syndrome". This occurs when an individual's physiological system, constantly stressed and working to the maximum, becomes overburdened. By about 45, even mildly motor impaired individuals with cerebral palsy, who had become independent walkers on their own as children, experienced debilitating pain from joint deterioration. A 2009 working conference supported by the American Academy for Cerebral Palsy and Developmental Medicine found that severe pain, chronic fatigue and a premature decline in mobility and

Reality of Walking (Cerebral Palsy)

Never achieved by some

Loss or deterioration in many

Teenage years: extraordinary energy cost

Mid-20s: physiological burn-out syndrome

Mid-40s: painful joint deterioration



function are the major challenges in the care of adults with cerebral palsy.

Outcomes of Restricted Locomotion

Motor-impaired youngsters who lack the necessary movements to engage and act upon their environment miss learning opportunities. But even more important, their inability to influence their environment (i.e, to affect or alter it through their own actions) can lead to a condition called "learned



helplessness” in which children give up trying to control their own world.

Repeated failure in exploring and mastering situations can lead to a self-perception of incompetence and passive resignation that extinguishes further attempts. Studies have indicated that a sense of helplessness (or incompetence) becomes well-established in a child by four years of age. Moreover, motor-impaired children have an ongoing risk for progressive delays in perceptual, spatial, and social development.

Severely restricted locomotion is associated with long-term, negative effects on psychological development, even in non-disabled children whose mobility was restricted during early childhood for medical or other reasons. The most frequent outcome of restricted locomotion was a pattern of passive, dependent behavior—specifically a lack of curiosity and initiative that persisted into later life. These are personality traits that are associated with poor academic achievement and social interaction.



Theories of Motor Development and Motor Learning

For many years, neuromaturation theory had held that motor development and learning occurred through pre-programmed brain maturation. Use of normal patterns was believed to produce normal movement whereas use of abnormal patterns was expected to lead to more severe abnormal movement and postures. The implications for treatment were the following:

- 1) Reducing the child’s motor impairments would automatically improve the child’s functional motor skills.

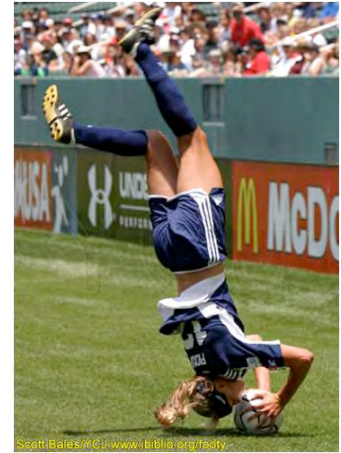


- 2) Walking was “the” movement solution of choice for every child and every situation.
- 3) Only normal patterns of movement were acceptable.

As neuroscience failed to support this theory, new theory arose that better explains what has been observed.

Currently, dynamic systems theory and motor learning theory both emphasize that motor performance is influenced by the interaction of a person’s abilities, the functional task they want to achieve and the environment in which they are moving. The implications for treatment that arise from these are quite different.

- 1) Intervention should attempt to change each or all of these three elements, i.e., the child’s ability/impairment, the functional task, and the environment.
- 2) There are a variety of appropriate ways to achieve successful completion of a functional and meaningful task, which also applies to typical movement. An example is this adapted “throw in” by a soccer player to get more power behind the ball.
- 3) Optimal motor performance may be achieved by movement patterns that were previously considered abnormal. For example, W-sitting was rigorously not permitted for children with cerebral palsy in the past. Now it is being suggested that W-sitting may be an innovative and efficient movement solution for these children.
- 4) Optimal motor performance may be achieved with mobility devices, even powered ones.
- 5) One size does not fit all, that is to say, walking is not the only movement solution for all children at all times. There should be different movement options for different children and for different environments whether impaired or not.



In rehabilitation, children are helped to discover their most functional movement patterns and to develop an system of movement options from which they may choose, depending on the task and environment.

Classifications of Motor Conditions

Traditionally, classification of a motor disability has been based on the type or degree of motor impairment. For example, cerebral palsy is classified by the different types of abnormal movements that may be seen (e.g., spasticity or athetosis) and by the distribution of these abnormal movements throughout the body (e.g., quadriplegia or hemiplegia). Experience and research have shown such a classification to be neither a good predictor of walking ability in cerebral palsy, nor to be useful in providing guidance about what interventions to pursue.

Functional classification systems that are more appropriate for rehabilitation purpose have appeared for management of cerebral palsy. One categorizes children by their gross motor abilities and the other by prognosis for achieving and maintaining independent walking.

Gross Motor Function Classification System (GMFCS)

Palisano, Rosenbaum and others at the *CanChild* Centre for Childhood Disability Research developed this five-level classification system based on self-initiated movement with particular emphasis on sitting, transfers and mobility. The focus is on determining which level best represents the child's or youth's present abilities and limitations. The level of motor function is determined by functional limitations

and the need for hand-held mobility devices (i.e., walkers, crutches and canes) or wheeled mobility, and to a lesser extent, the quality of movement. It reflects ordinary performance, not best performance, and does not judge potential for improvement.

Levels of GMFCS
Level I. Walks without limitations
Level II. Walks with limitations
Level III. Walks using a hand-held mobility device
Level IV. Self-mobility with limitations, may use powered mobility
Level V. Transported in manual wheelchair

Distinction Between Level I and II -

Compared with children and youth in Level I, children and youth in Level II have limitations walking long distances and balancing; may need a hand-held mobility device when first learning to walk; may use wheeled mobility when traveling long distances outdoors and in the community; require the use of a railing to walk up and down stairs; and are not as capable of running and jumping.

Distinction Between Level II and III -

Children and youth in Level II are capable of walking without a hand-held mobility device after age 4 (although they may choose to use one at times). Children and youth in Level III need a hand-held mobility device to walk indoors and use wheeled mobility outdoors and in the community.

Distinction Between Level III and IV - Children and youth in Level III sit on their own or require, at most, limited external support to sit, are more independent in standing transfers, and walk with a hand-held mobility device. Children and youth in Level IV function in sitting (usually supported) but self-mobility is limited. They are more likely to be transported in a manual wheelchair or use powered mobility.

Distinction Between Level IV and V - Children and youth in Level V have severe limitations in head and trunk control and require extensive assisted technology and physical assistance. Self-mobility is achieved only if the child/youth can use a powered wheelchair.

The GMFCS is widely used in clinical practice and research to measure the effectiveness of interventions on motor function.

Classification by Potential for Mobility Independence

Bottos proposed a functional classification system intended to guide clinical management of children with cerebral palsy. This classification contains four categories that differentiate children by prognosis for mobility independence--a prognosis that can be made in early childhood. For each category, the key rehabilitation concerns are identified. These concerns are the problems that will likely develop over time and cause further limitation for the child or family. Intervention strategies to reduce or avert those expected problems are recommended for each category.

Children whose prognosis is for complete dependence on caregivers - There are two key rehabilitation concerns for this group with severe physical and mental impairments. One is that the relationship between the child and caregiver will

Prognosis for Independent Mobility	Rehab Concerns	Intervention Strategies
Dependent on caregivers	<ul style="list-style-type: none"> •Symbiotic relationship •Deformity 	<ul style="list-style-type: none"> •Assistive devices and equipment •Variety of caregivers •Normal life rhythm •Prevent deformities
Independence achieved only through powered mobility	<ul style="list-style-type: none"> •Functional mobility •Functional sitting, transfers, standing •Deformity 	<ul style="list-style-type: none"> •PT to develop balance, prevent deformities •Assistive devices •Early provision of powered mobility
Mixed independence (walking + wheeled mobility, manual and/or powered)	<ul style="list-style-type: none"> •Limited mobility •Physiological burnout •Deformity 	<ul style="list-style-type: none"> •PT to age 8 for walking •Walking aids and orthoses •Possible ortho surgery •Wheeled devices, possibly powered •PT to prevent deformities
Independent walking	<ul style="list-style-type: none"> •Pain, possibly limiting function in adulthood 	<ul style="list-style-type: none"> •Periodic PT in adulthood for balance and gait, monitor musculoskeletal status/deformity •Assistive devices over ages 40-45

become increasingly symbiotic and unhealthy. Often it is the mother who assumes care of the child. This child, then adolescent and finally adult, may be cared for, fed and so on, on the mother's lap, or in close proximity to the mother. The youngster may increasingly refuse physical separation making management ever more difficult. The second rehabilitation concern is the high risk of physical deformities. Deformities may make it impossible for one person to physically manage the child alone, especially as weight and height increases with age. When the child is predominantly held by someone, the prevention of deformity is made very difficult or impossible. Use of assistive devices and equipment, such as suitable chairs and supports is an intervention strategy that can help prevent deformity and reduce symbiosis. For example, use of a customized chair for feeding or toileting will provide head and trunk support and symmetrical posture. When using these chairs, the child can begin to experience the separation of self, physically and psychologically, from the mother. Similarly, early integration into preschool is important—not for academic achievement but to reduce symbiosis and participate in a normal occupation of childhood. The child will experience physical separation in leaving home in the morning, saying goodbye to his or her parents, and returning to them in the afternoon. While at school, the child will become accustomed to a variety of caregivers. While these interventions cannot free the child from caregiver dependence, it does reduce dependency on one unique caregiver and, hence, contributes to an overall improvement in the quality of life of the family.

Children whose prognosis is that independent mobility will only be achieved through the use of wheeled devices for locomotion, most likely powered ones -The key rehabilitation concerns for this group are lack of functional mobility as

well as functional sitting, transferring and standing, and for development of deformities. Intervention focus should, therefore, be on early provision of adequate assistive devices and equipment, including powered devices. Physical therapy should be focused on developing balance and stamina for sitting, standing and transferring as well as the prevention of deformities.

Children whose prognosis is mixed independence - They have the possibility of independent walking indoors, but it will not be functional outdoors. The rehabilitation concerns are that only limited walking will be achieved and that physiological burnout will eventually occur with deterioration of walking. Intervention for this group should be multifaceted. They should have intensive and prolonged physical therapy along with the use of appropriate orthoses, and possibly eventual orthopedic surgery, to promote independent walking. However, interventions to promote walking in children with cerebral palsy should be limited to the early childhood years because we now know that the probability of a child walking after age 7-8 is remote, at least in spastic types. Prevention of deformities should be a part of the therapeutic program at all ages. Until, and even if, walking is achieved, assistive mobility devices should be provided and used. These may be manually propelled or powered devices, or both. The purpose of using mobility devices is to widen motor independence, to reduce excessive energy expenditure, to avoid early physiological burnout with the consequent loss of independent walking in teenage years, and to reduce risk of eventual joint deterioration and pain.

Children whose prognosis is to become independent walkers on their own - The primary rehabilitation concern is for joint deterioration and debilitating pain in adulthood. Intervention should, therefore, focus on strategies to improve balance and gait as walking develops, prevent deformities, and to monitor musculoskeletal evolution over the years. Assistive devices may play an important role even in the case of these relatively mild forms of cerebral palsy. Using wheeled devices may be used as a preventative measure in people over the ages of 40-45 to reduce joint deterioration and , thus, preserve the capacity of independent walking for as long as possible. If and when walking deteriorates, mobility devices will increase an individual's overall functional independence.

Classification for Early Powered Mobility

Hayes proposed a four-part classification to identify children with representative diagnoses who will need powered devices, in early childhood if they are to have effective mobility.

Children who will never walk - They will have no opportunity for independent locomotion without wheeled devices, most likely powered devices.

Children with inefficient walking - They will walk but be unable to do so at a reasonable rate of speed with acceptable endurance for all activities so will need multiple modes of mobility. They may walk with aids, use a manual wheelchair, and a powered device, depending on the circumstances.

Children who will eventually walk - They will require non-ambulatory mobility during much of childhood. They will need an efficient mobility device during early childhood development and until functional walking becomes possible. Because these children have insufficient

muscle power or fragile bones, powered devices will be needed. **Children with permanent loss of independent walking** - They will need a wheelchair or other device to restore self-produced mobility. While some children may be able to wheel a manual wheelchair, most will need powered devices for functional mobility.

Children Who	Representative Diagnoses
Will never walk	Severe cerebral palsy with spastic quadriplegia or athetosis, spinal muscular atrophy types I and II, multiple limb deficiency, spinal cord injury
Have inefficient mobility	Ataxia, spastic diplegia and milder forms of quadriplegia and athetoid cerebral palsy, myelomeningocele, and juvenile rheumatoid arthritis
Will eventually ambulate	Spastic diplegia cerebral palsy or arthrogryposis in which eventual surgical corrections may make walking possible; osteogenesis imperfecta requiring protection during childhood
Have lost mobility	Neurological sequelae from trauma and infectious disease, progressive disorders such as Duchenne muscular dystrophy

Model of Service Delivery



Expert-centered
care



Family-centered
care



Model of Service Delivery

Traditionally, we worked in a service delivery system in which experts dictated which interventions children would get and when and how those interventions would be provided. This was directly influenced by the medical interests and specialties of the healthcare professionals involved.

About 1980, a shift from expert-centered care to client-centered care began to occur. In pediatric rehabilitation, this approach is called family-centered care. Family-centered care is based on the concept of family empowerment. Basic tenets are that the family knows the child best, the family is the constant in the child's life, and that families can function well given adequate social support and resources. Therefore, in family-centered care, healthcare professionals collaborate with families to identify the needs and abilities of the child in the context of the family, provide information to families on available treatment options, and work in partnership with families to implement intervention strategies.

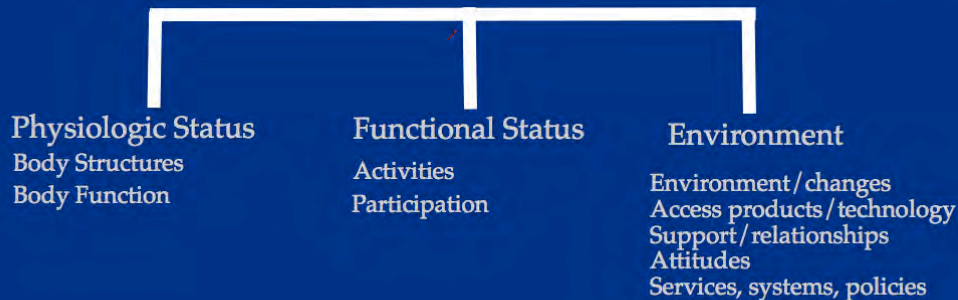
The emergence of family-centered care changed the extent of families' involvement in the definition and implementation of services for children. Empowerment of families to make decisions about and provide care for their child became a main goal of rehabilitation.

Model of Disablement

A model of disablement provides the framework for describing, measuring, and managing disability. Before 1980, a medical model guided rehabilitation. This model described and managed disability as an impairment of body

International Classification of Functioning, Health and Disability

Framework for description, measurement and management of disability



structures and functions. Successful rehabilitation was determined by measuring for changes in muscle tone, muscle mass, bone density, joint range of motion, and so on.

In 1980, however, the World Health Organization (WHO) advanced a biopsychosocial model of health status and disability that grew out of the work of adults with disabilities, healthcare clinicians and researchers and policy-makers from around the world. The International Classification of Functioning, Health and Disability (ICF) provided a new framework to discuss and classify the contribution of a person's physiological status, their functional abilities, and the environment on their health status or disability. The International Classification of Functioning, Health and Disability (ICF) recognizes three components in which disablement occurs. One is impairment in body structures and functions, which was the only component in the medical

model of disablement under which we had previously worked. Another component, activity and participation, is a component in which people function in everyday life and are most likely to experience their disability as they live their lives. A third component is environmental factors, which also have a significant impact on disability: (1) the natural environment and human-made changes to it, (2) access to products and technology, (3) support and relationships, (4) attitudes, and (5) services, systems, policies and laws.

Successful rehabilitation is also determined by measuring for changes in meaningful function such as effective locomotion, playing a game, or accomplishing activities of daily living. Successful rehabilitation is also determined by measuring for changes in the environmental factors such as parental attitudes about walking, accessibility to technology, or access to housing and transportation.

The ICF reminds us that disability is a product of influences from all three areas and that a cause and effect relationship cannot be assumed. A person can have an impairment but not have restricted function, and environmental factors can 'cause' a disability.

After 25 years of use and revisions, the International Classification of Functioning, Health, and Disability has now been formally adopted by more than 90 nations of the world. It provides a common language to discuss all the factors that contribute to a person's health status.

The Disability Movement

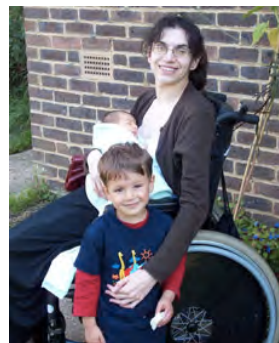
A social-political movement led by individuals with disabilities, which is now active throughout the world, also challenged the traditional restorative model of rehabilitation. Persons with disabilities rejected the idea of 'normalcy' that was implicit in traditional rehabilitation in favor of "differently-abled". They championed the right to be proud of their individual differences and to be fully accepted and participating members of society.

They made us realize that barriers to functioning were not simply because of an impairment in a person. It is often the architectural barriers, societal attitudes, legal restrictions and lack of civil rights within a community that limit activities and participation of disabled people in society, together with lack of access to adequate technology.

Our perception of what is possible changed dramatically as people with disabilities broke out of the societal perceptions that had severely limited their lives, and as their stories of being "differently-abled" found their

way in the popular press. We learned about people with motor disabilities that drove vehicles, skied, sailed, went scuba and sky diving, hiked, climbed mountains, traveled, played basketball, had successful careers, lived independently, married, had and raised children. Specially designed equipment made it possible, but more fundamentally we, as rehabilitation specialists, came to see that it is not important how you drive a car, or farm your land, or play in the snow, or explore the beach--but that you do it.

Today there are many "how-to" books, Internet websites and chat rooms, organizations, and specialized commercially-available equipment that promote participation in many aspects





of life previously believed to be inappropriate or impossible for persons with disabilities. We even began to see how beautiful “differently-abled” can be.

Civil Rights Laws

This disability movement led to the passage of laws to protect people with disabilities from discrimination. In the United States, Canada and the European Union, there are already a number of laws that insure access to education, employment, government services, public and private buildings, voting, transportation including air carriers, and housing.

In 2006 the United Nations General Assembly ratified the UN Convention of the Rights of Persons with Disabilities, which urges recognition of the civil rights of disabled people throughout the world. It defines disability as long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others. This document contains the following principles of rights for people with disabilities: reasonable accommodation for their





disability, accessibility, no discrimination, and right to education, health, participation and voting.

By mid-2010, 87 countries had signed this document.

Availability of Powered Mobility Devices

The availability and quality of assistive technology, in general, and powered mobility devices, in particular, has increased dramatically and expanded in scope in recent years. These make it possible for many youth and adults to participate in a wide variety of outdoor activities and sports. Once assistive devices were available only to those who had capable parents, family members or friends who could acquire parts to construct a device or who had access to a specialized rehabilitation center. For example, this powered device was made by a clever father with a large tree log for the driver and passenger seats, a joy stick from a computer, a car battery, and a base he constructed, and wheels from a cart.



Mobility devices have also become commercially available for children at younger and younger ages. Some pediatric wheelchair designs accommodate the needs of children—for them to grow, move in standing as well as sitting, to access different levels of their environment and to play outside on muddy or uneven terrain.

Effective Mobility: When?

The advances in science and society discussed have led to the paradigm shift in rehabilitation away from achievement and maintenance of normal walking as the gold standard form of mobility. We have moved



toward valuing effective mobility, however it may be achieved.

When should effective mobility be considered? There are four developments in science and technology that inform us about its timing in a child's life. One is the evolution of a unified theory of child development.

Theory of Child Development

Advances in developmental psychology have changed our understanding about the various domains of child development. The several domains of development (motor, cognitive, language, emotional, and social) were initially thought to be separate lines of development that proceed independently of one another as children grow up. The several domains of development were initially treated as separate lines of development proceeding independently of one another. It became apparent, however, that one developmental acquisition produces experiences that bring about a host of of new developmental changes in the same and different domains. These lines intertwine such that any delay or restriction in one domain of development negatively impacts development in all other domains as well.

Motor development is of key importance, however. It is through their motor skills that very young children learn about things and people in their world...and that they can cause things to happen. They become initiators and active participants rather than passive recipients of experience. When motor skills are restricted, then all areas of the child's experience and development are at risk—unless we



Motor Development





can intervene in ways to keep this from happening. Through their motor interactions, young children learn about things and people in their world. They also learn that they can cause things to happen. They become initiators and active participants rather than passive recipients of experience. This, in turn, promotes development of their attention, motivation, and intelligence. If motor skills do not develop normally, then all areas of the child's experience and development become restricted.

Importance of Self-Produced Locomotion

Within the motor domain, the skill of self-controlled locomotion is especially important. Theoretically, locomotion has long been linked to new capacities to cope with stressors, new levels of self awareness, the emergence of a sense of competence and of a sense of initiative.

Now, research about the appearance of locomotion in unimpaired development has demonstrated that locomotion plays a central role in the development of visual spatial cognitive competencies. It also induces or accelerates exploratory behaviors, emotional expression, attentional resources for problem solving, a change from being a passive to an active participant in social interactions, and the growth of new structures in the brain.

However, the only two studies, which investigated locomotor impairment in youngsters and the visual spatial cognitive skill of object permanence with manual search for a

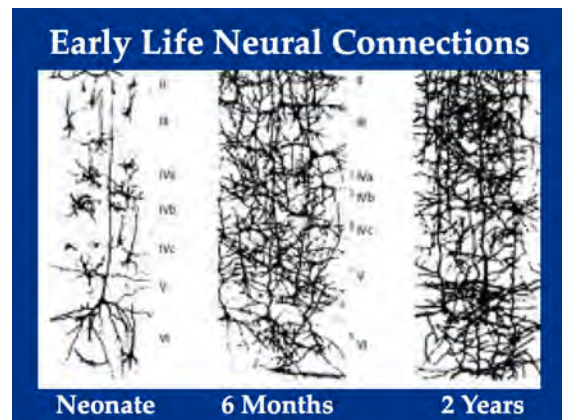
hidden object, had differing results. Both studies were small and more conclusive research is needed to identify whether there may be pathways other than locomotion that induce this important skill.

Neuroscience: Developing Mind and Brain

The advent of brain imaging is another development that informs us about timing of effective mobility.

The core concepts about developing mind and brain are these.

- 1) Early experiences shape brain architecture. They cause proliferation of neural connections followed by pruning and formation of more complex circuits in the first few years of life.
- 2) Brains are built on this foundation of early experiences and there are critical periods for experiences to have their most positive and powerful effects.
- 3) The physical activity in the brain created by experience is not only powerful in changing brain architecture, but it also changes the chemistry that encodes the genes in brain cells. Experiences, positive or negative, leave a chemical signature on the genes, which may be temporary or permanent.
- 4) Although the window for brain and behavior change remains open throughout life, these brain circuits become increasingly difficult to alter over time. It is easier and more effective to influence a baby's developing brain architecture by ensuring positive conditions for healthy development than it is to rewire parts of its circuitry in later years.





5) Neurons in children who experienced chronic and extreme poverty, neglect, abuse or severe maternal depression display underdeveloped neural connections or weaker brain architecture. This research has not explored deprivation effects from chronic and severe locomotor restriction yet, but one might expect the brain architecture, in these cases, to also display underdeveloped or different brains.

High Tech Tots



Assistive technology such as powered mobility devices, augmentative communication systems, environmental controls, robotic arms and hands, and specialized computer access have enabled children of all ages with motor disabilities to participate in many age-appropriate activities. In research and clinical settings, children as young as three months have interacted with computers. Twelve-month-old children have driven powered mobility devices to get around and used myoelectric hands to play. Two-year-olds have talked using sophisticated voice output systems.



Even for children with little or no hand control, a multitude of alternatives for computer access, battery operated toys, environmental controls (e.g., lights, TV) and wheelchair control is now available. There are alternative keyboards, mouse emulators, mouse-driven keyboards, software with word prediction capabilities, touch screens, screen enlargers, voice recognition software, and eye-controlled input for computer use. The rapidly developing virtual technologies and robotic

technologies will offer still more opportunities for experience and control for very young severely disabled children.

Wheelchair Toddlers

Ruth Everard is the original wheelchair toddler. Born with severe spinal muscular atrophy, Ruth could nevertheless locomote independently from the age of 21 months, accessing different heights while either standing or sitting, and could play outside in uneven terrain. The unique powered device built by her father made this possible. Her language, social-emotional and cognitive development followed a normal path. She attended normal schools and participated in all activities of children her age. Ruth traveled with a same-age female friend and companion to the United States before starting college. Now 31 years old, Ruth has graduated Oxford University and qualified as a solicitor in London, where she lives independently.

There is a small but growing body of research demonstrating that children of toddler age can drive powered devices independently and safely after learning in a relatively short time when given ample opportunity to practice. There are 14 research studies, which were published between 1983 and 2009, with 141 children who had varying types orthopedic and neuromuscular disorders that severely limited their locomotion. They ranged in age from 7 months to 7 years of age although most were 3 years old or less.

What we know now makes it clear and imperative that provision of effective mobility not wait. It cannot



RED FLAG

Mobility Cannot Wait

wait until a child eventually achieves some form of walking later in childhood or until it is accepted by the parents and healthcare professionals that walking will not happen or that it is not sufficiently effective. Moreover, it does not have to await a child getting older.

Effective Mobility: How?

Assistive Technology

“How” young disabled children can achieve effective mobility depends largely on the use of assistive technology.

Assistive technology is the study, development and application of devices, machines and techniques for assisting human function or bypassing physical limitations. For many children, powered mobility will be necessary.

There is compelling logic, theory and clinical experience to suggest that a rehabilitation approach based on assistive technologies will address important issues in the management of motor disabilities from early childhood onward. But is there evidence that it will empower and enable the overall development of young children and allow them to



achieve independence and maintain it as adults?

Research Outcomes of Powered Mobility

The advent of powered devices for very young children has allowed us to explore whether alternative forms of locomotion induces or accelerates development, as does walking and crawling.

This author reviewed studies of powered mobility that have included young children. There were 34 studies published in English-language, healthcare journals through August, 2010.

The main body of this evidence addressed questions about “learning to drive” and about effects of the use of powered mobility. Fifteen studies conducted in the US, Sweden, Canada, and Italy explored the following questions:

1. At what age can children acquire and safely use powered mobility?
2. Does powered mobility reduce a child’s efforts to walk?
3. Does powered mobility promote development in other domains?

Breed and Ibler, in 1982, were first to report that children could achieve powered mobility. They described a case series of 27 children with cerebral palsy, including one as young as 4 years old, who had learned to drive a motorized wheelchair.

In 1983, two publications demonstrated that even very young children could achieve powered mobility and do so rapidly. Zazula and Foulds reported on a baby boy, born with no legs, who had been given a powered cart when he was 11 months of age. At 18 months old, he was independently mobile at home and in his community. The same year, Everard described a 22-month-old girl with spinal muscular atrophy who

achieved functional and skillful driving within 6 weeks of being given access to a powered wheelchair made by her father.

In 1984, two more studies were published. Butler, et al reported a case series of very young children with various motor disabilities (aged 20 to 37 months) that had achieved driving competency based on 7 driving skills. Twelve of 13 of these children had learned at home with surprisingly little practice time spread over a relatively few days and with only parental supervision. They then used this powered mobility to participate in age-appropriate activities and drove safely while playing and exploring.

Also that year, Paulsson and Christoffersen reported on a case series of 12 disabled children, 2½ to 5 years old, who had become independently mobile using motorized carts. These investigators were specifically interested in the psychological and intellectual effects of independent mobility and found positive effects of this powered mobility to be increased self-confidence and curiosity and positive effects on family life. Despite fears that powered mobility would negatively impact potential for walking, motor development instead increased.

The effects of powered mobility on self-initiated behaviors investigated by Butler were reported in 1986. Six children who were 23-38 months old had achieved independent mobility with a powered wheelchair in 3 weeks or less. Self-initiated communication, interaction with objects and spatial exploration increased as soon as each child acquired independent locomotion. It stimulated the children’s attempts to move about on their own.

In 1987, Douglas and Ryan published the first report of a severely

impaired preschooler who had to control operation of the wheelchair using a mouth operated joystick. He had some problems learning to drive, but once he became independently mobile, his emotional, intellectual, and behavioral development improved notably.

A decade passed with no further publications. Research activity picked up again in 1998. Chiulli et al described adapted ride-on powered toys given to a 3-year-old with cerebral palsy and a 4-year-old, post polio. Independent mobility provided by this equipment gave each child a boost of self-esteem and independence.

In 2001, Bottos and his colleagues reported their investigation of the effects of powered mobility on independence in 29 children with cerebral palsy who were 3-8 years old. Level of independence improved significantly after provision of powered wheelchairs. However, measures of motor impairment, IQ, and quality of life did not show change. Almost all parents said they were skeptical about powered mobility before the study began, but afterward changed their minds.

Bottos' follow-up of those 29 children four years later showed that 72% of them were still using their powered wheelchair for locomotion independence at home, at school and/or in the community. Parents of the 28% who were not cited technical problems as the reason.

In 2002, Wright-Ott and her colleagues described significant changes in young children during a mobility camp at which they used a variety of powered mobility devices that allowed them to actively and independently explore their environment. The investigators reported increased vocalizations, increased arm and hand movements, greater motivation to explore, improvements in sleep, and happier dispositions in these children.

That same year, Deitz et al reported higher frequencies of self-initiated movements, changes in initiation of contact with others, greater participation in educational programs, and increased ability to interact meaningfully with peers when the children used powered mobility. When their wheelchairs were removed, these improved behaviors reverted back to baseline levels.



In 2003, Jones et al reported on powered mobility in a 20-month-old girl with spinal muscular atrophy. She drove safely after 6 weeks. Developmental gains were measured in all domains. Before intervention, she had been developing at a slower rate than occurs in normal children while, after intervention, her developmental rate doubled that of normal children. Her mother also described significantly increased independence.

Jones also reported a randomized controlled trial in 2005 in which 12 disabled children, ages 15-30 months, were matched and then assigned to the experimental condition (i.e., access to powered mobility) or the control group. Results of the measures showed that the experimental group had significantly greater improvement in receptive language, social skills and self-care/ caregiver assistance than the control group.

Finally, in 2009 Lynch et al reported a 7 month-old child with spina bifida. During a 5-month training period, the infant improved in all driving variables. The infant's Bayley III cognition and language scores also

increased at a rate greater than his chronological age.

The body of evidence contains four studies that addresses the question, "How do children and their families perceive powered mobility?" In 1996, Berry et al published the perceptions of 36 mothers of their children (5-23 years old). Children who had been completely dependent on their caregivers gained independent movement, although environmental barriers limited their use. The mothers described freedom for their child and themselves as well as increased participation in games with peers. Many described the power chairs as their child's "legs".

In 2004, Wiart et al investigated the question with five mothers and found they had initially seen powered mobility as a last-resort option. However, with powered mobility, they observed significant changes in their children including increased personal control, independence, and opportunities to participate in age appropriate meaningful acts. Furthermore, the increased independence positively affected others' attitudes toward their children



and allowed them to develop more legitimate relationships with peers.

In 1989, Kibele interviewed 5 adults with cerebral palsy who reported that their worst memories of their therapy experiences as children were their ongoing inability to achieve walking and the repeated feeling of failure this gave them. Alternatively, their best memories were using mobility devices which gave them feelings of success.

In 2002, Skar interviewed 8 children between the ages of 6-11 who used wheelchairs and walking aids. The younger children perceived these assistive technologies as a natural part of themselves.

Another 7 studies involving about 300 more children in the US, Canada and England have pursued other lines of research inquiry:

- 1) Can we predict successful powered mobility?
- 2) Are there benefits of powered mobility training even for children with profound cognitive limitations?
- 3) What is the current status of referral and provision of powered mobility for young children?

While these studies are not directly pertinent to this discussion, they do contain important statements.

In a 2002 study, Nisbet concluded "Not to allow children the opportunity to engage in the same childhood occupations as his or her peers by unnecessarily limiting the child's mobility goes against the occupational and enabling focus of the profession of occupational therapy... It may also be suggested that not to permit a disabled child equal opportunities for mobility on a par with his or her peers is to engage in discrimination".

Similarly in 2003, Staincliff found found discrimination at work in the

referral and eligibility policy related to powered wheelchairs for children under 5 in England and stated that "National Health Service provision of powered wheelchairs for children needs to be reviewed in light of clinical evidence and children's rights." Perhaps these comments signify the beginning of a yet another shift in perspective: from assistive technologies being regarded as an intervention option to assistive technologies being regarded as children's rights' issue.

Conclusions From Powered Mobility

The evidence from powered mobility is still limited by the numbers of studies that have been done, the number of participants the studies have involved, the types of outcomes the investigators have measured and the strength of the studies. Though the body of evidence is neither extensive nor robust, all the evidence suggests that powered mobility had positive developmental effects for all the domains of development as well as increasing independence and reducing caregiver burden--with no evidence to the contrary. The strongest evidence, in terms of research design, and therefore, the confidence we can have about it, is for psychosocial and language outcomes and for caregiver burden. These are Level II on a scale in which is Level I represents the strongest evidence to Level V, the weakest. Less strong is the evidence for positive effects in the motor domain (Level III, IV, V), specifically for arm-hand function, self-initiated movement and spatial exploration. There is Level V evidence that powered mobility stimulated rather than extinguished attempts at ambulation. There is also Level V

evidence of improvements in sleep, and happier dispositions.

Augmentative Mobility

It is not simply a matter of giving a child a walking aid, a wheelchair or powered device, however. We need to think in terms of developing comprehensive, functional mobility systems that augment or add to whatever movement a person has. This is, in fact, the situation for almost all people. Few people use walking for all their movement from one place to another. Most people augment their walking with mobility devices such as cars, bicycles, motorcycles, scooters, skates and skateboards, carts and wagons. They use these devices to go from one place to another more quickly and to arrive without being fatigued. They also use these devices because different types of locomotion can be fun and exhilarating. Similarly, people with locomotor impairments need comprehensive, functional systems of mobility for all their activities. For example, this 10-year-old uses a walker inside her home and sometimes in her school classroom. She has had tendon releases to give her better foot position for standing and walking, and she works with a physical therapist to improve her balance and strength. She uses a powered wheelchair to keep up with friends on the school campus and in her community. Although she does not have effective mobility with a manual wheelchair, she has one because it can be transported in the family car providing at least some self-controlled mobility upon arrival. Other elements of her system may eventually include a specialized device for sports or outdoor activities





or that allow her to stand while moving as well as a car she can drive.

Service Animals

Animal power is also an underutilized but important aid to augment mobility. There is a long and successful history of guide dogs, also known as seeing-eye dogs, providing independent mobility for people with visual impairments. Dogs are now being trained to help people with motor impairments. These are variously called mobility dogs, mobility assistance dogs, companion dogs, therapy dogs, service dogs, and dogs for independence. These dogs assist their owners in a variety of ways from pulling them in a cart or wheelchair to fetching things for them. Dogs have the added benefits of providing a loving relationship for the child and often make it easy to connect with other people. Now monkeys are also being trained as helping hands for persons with motor disabilities.



Children could ride on horses or donkeys on saddles or in special seats. These animals could pull a child in a wagon or cart. Monkeys are common in many countries and could be trained as helping hands.



Principles of Management

These principles of management are based on the emerging new rehabilitation philosophy of optimizing function and participation that has grown out of 60 years of intervention for children with motor disabilities.



1. We cannot cure these disorders, but we can improve the quality of life for the child and the family. Recognizing the limitations of our treatments is important in developing a rehabilitation

plan that balances time for treatment and healthy living with the particular medical condition.

2. Recognize the potential of childhood motor disability to become a developmental disability. Development of intellectual, social-emotional, and language domains depend on the presence of motor skills, and these domains will develop abnormally or be restricted if motor skills or substitute means of movement are not present.

3. Motor skills induce or accelerate appearance of skills in other domains of development. From the time of diagnosis, every effort should be made to explore movement options that allow a child with a motor impairment to do and experience what other children their age are doing and experiencing. To promote overall development, be guided by the motor skills needed at each age and provide alternatives until such time that the child acquires motor skills that are functional and efficient.

4. Augment whatever motor skills are present. Be realistic about the child's capacity to develop or improve motor skills. Balance time spent developing motor skills, preventing deformity, and developing alternative means of movement.

5. Do not wait. Provide movement alternatives from infancy onward. Having other means of movement will not prevent a child from developing his or her motor skills to the fullest extent possible.

6. Movement must be functional, timely and energy-efficient. Manual wheelchairs allow individuals who can push them easily to travel at a speed comparable to that of unimpaired walkers with equivalent energy expenditure. When manual wheelchairs





are not functional, powered devices can provide functional mobility.

7. Develop comprehensive systems of movement. Recognize the motor disability is likely to change and deteriorate as people grow and age. Abnormal movements and fixed contractures cause altered loading of joint cartilage, disturbed growth and bony deformity. These further limit function and mobility, and eventually cause degenerative arthritis and pain. Understanding this sequence is important in planning management and preventing adverse motor outcome.

8. The overall goal is to enable and empower individuals with disabilities to participate as fully and independently as possible in every activity and occupation of life. Realization of more independent and productive life opportunities depends directly on the individual's ability to meet the mobility and communication demands. When prognosis for functional, independent walking or talking is limited, then intervention must provide alternative means to achieve independent mobility and communication.

9. Value and promote the concept of being "differently-abled". This means doing things in a different way—doing them by means of normal and abnormal patterns of movement, compensatory movements, non-technical aids, assistive technologies, animals and robots.

10. There are a variety of ways to achieve successful completion of a functional and meaningful task. In addition to changing the motor circumstances of the child, modify the environment of the activity or the task itself.

11. Empower families to make decisions about and care for the child,

but avoid overwhelming them. Protect the health and well being of the marriage and the family. Help the family and support groups through information, perspective, support and friendship. Recognize that all treatments have a cost in time, money, and energy to the child and the family.

12. Steer the family away from interventions that are unproven or unrealistic, likely to drain their resources, and that may lead to disappointment for them and the child. The history of medical management includes many treatments that were either harmful or ineffective. Extensive bracing, misguided operations, and exhaustive therapies are examples of treatments once in vogue and later abandoned as evidence failed to support their effectiveness.

13. When a family insists on trying an unproven intervention, help them to proceed scientifically. Help them determine the specific outcomes the proponents of the treatment say will occur and in what time frame. Help the family evaluate these expected outcomes against the costs (time, money, energy) and any risks of the treatment. Help them understand that even if it is possible to some underlying motor impairment of muscle, nerve, or bone, this will be important only if it significantly increases the child's function. For example, a decrease in spastic muscle tone will not automatically give the child a higher level of function. Finally, help the family set up a way they can gather objective evidence about whether, and the extent to which, the treatment is proving effective for their child—including some way to measure whether the child is also more functional and independent. Encourage the family to stop an intervention that

is not making a significant difference in the life of the child or family.

References

- Adults with Cerebral Palsy, DMCN Supplement 4, October 2009, Vol. 51
- 1998 Yan JH, Thomas JR, Downing JH. Locomotion improves children's spatial search: a meta-analytic review. *Percept Mot Skills*. 87 (1):67-82.
- Berry E, McLaurin S Sparling W. (1996) Parent/caregiver perspectives on the use of power wheelchairs. *Pediatric Physical Therapy* 8:146-50.
- Bertenthal B, Campos J (1984) Self-produced locomotion: an organizer of emotional, cognitive and social development in infancy. In Barrett K, R Emde R Harmon. *Continuities and Discontinuities in Development* New York: Plenum.
- Bleck EE. (1987) Clinics in Developmental Medicine Nos 99-100: Orthopedic Management in Cerebral Palsy. Philadelphia, JB Lippincott
- Bottos M, Bolcati C, Sciuto L, Ruggeri C Feliciangeli A. (2001) Powered wheelchairs and independence in young children with tetraplegia. *Developmental Medicine and Child Neurolog*
- Bottos M, Feliciangeli A, Sciuto L, Gericke C Vianello A. (2001) Functional status of adults with cerebral palsy and implications for treatment of children. *Developmental Medicine and Child Neurology* 43:516-28.
- Bottos M, Groppi A, Bolcati C, Bragliano V Sciuto L. (2003) Powered wheelchairs and independence in young children with tetraplegia II: four years later. In *European Academy for Childhood Disability* edited. Oslo: MacKeith Press. p. 19-20.
- Bottos M Gericke C. (2003) Ambulatory capacity in cerebral palsy: Prognostic criteria and consequences for intervention. *Developmental Medicine and Child Neurology* 45:786-90.
- Breed A, Ibler I. (1982) The motorized wheelchair: New freedom, new responsibility and new problems. *Developmental Medicine and Child Neurology* 24:366-71.
- Butler C, Okamoto G McKay T. (1983) Powered mobility for very young disabled children. *Developmental Medicine and Child Neurology* 25:472-4.
- Butler C, Okamoto G McKay T. (1984) Motorized wheelchair driving by disabled children. *Archives of Physical Medicine and Rehabilitation* 65:95-7.

Butler C. (1986) Effects of powered mobility on self-initiated behaviors of very young children with locomotor disability. *Developmental Medicine and Child Neurology* 28:325-32.

Butler C. (1988) High tech tots: Technology for mobility, manipulation, communication, and learning in early childhood. *Infants and Young Children* 1:66-73.

Butler C. (1991) Augmentative mobility: Why do it? In K Jaffe. *Pediatric Rehabilitation, Physical Medicine and Rehabilitation Clinics of North America* p.

Butler C. (1997) Wheelchair toddlers. In Butler C, J Furumasu. *Pediatric Powered Mobility: Developmental Perspectives, Technical Issues, Clinical Approaches* Arlington, VA: Rehabilitation Engineering and Assistive Technology Society of North America. p.

Chiulli C, Corradi-Scalise D Donatelli-Schultheiss L. (1998) Powered mobility aids as vehicles in independent locomotion for young children. *Physical Therapy* 68:997-9.

Clearfield MW. (2004) The role of crawling and walking experience in infant spatial memory. *J Exp Chd Psych* 89(3): 214-41

Clearfield MW, Osborne CN, Mullen M. (2008) Learning by looking: infants' social looking behavior across the transition from crawling to walking. *J Exp Chd Psych* 100(4): 307

Deitz J, Swinth Y White O. (2002) Powered mobility and preschoolers with complex developmental delays. *American Journal of Occupational Therapy* 56:86-96.

Douglas J Ryan M. (1987) A preschool severely disabled boy and his powered wheelchair: A case study. *Child: Care, Health and Development* 13:303-9.

Duffy CM, Hill AE, Cosgrave AP, et al. (1996) Energy consumption in children with spina bifida and cerebral palsy: a comparative study. *Dev Med Child Neurol.* 38:238 -243.

Everard L. (1983) The wheelchair toddler. *Contact* 38:19-21.

Furumasu J, Guerette P Tefft D. (1996) The development of a powered wheelchair mobility program for young children. *Technology and Disability* 5:125-9.

Gustafson G. (1984) Effects of the ability to locomote on infants' social and exploratory behaviors: An experimental study. *Developmental Psychology* 20:397-405.

Hansen L. (2008) Evidence and Outcomes for Power Mobility Intervention with Young Children. *Casemakers* 4(1) (electronic publication of Center for Advanced Study of Excellence in Early Childhood Family and Support Practices)

Hays R. (1987) Childhood motor disabilities: clinical overview and scope of the problem. In K Jaffe. *Childhood Powered Mobility: Developmental, Technical and Clinical Perspectives* Washington DC: Rehabilitation Engineering and Assistive Technology Society of North America.

Jennings K, Connors R Stegman C. (1988) Does a physical handicap alter the development of mastery motivation during the preschool years? *Journal of the American Academy of Child and Adolescent Psychiatry* 27:312-7.

Johnston TE, Moore SE, Quinn LT, Smith BT. (2004) Energy cost of walking in children with cerebral palsy: relation to the Gross Motor Function Classification System, *DMCN* 46: 34-38

Jones M, McEwen I Hansen L. (2003) Use of power mobility for a young child with spinal muscular atrophy. *Physical Therapy* 83:253-64.

Jones M. (2005) Effects of power mobility on the development of young children with severe motor disabilities. Doctoral Dissertation thesis, University of Oklahoma.

Kermoian R. (1998) Locomotor experience facilitates psychological functioning: Implications for assistive mobility for young children. In D Gray, I Quatrano M Lieberman. *Designing and Using Assistive Technology: The Human Perspective* Baltimore, MD: Brookes Press. p. 251-68.

Lynch A., Ryu, J.C., Agrawal, S., Galloway, J.C., "Power mobility training for an infant with spina bifida", *Pediatric Physical Therapy*, Vol. 24, No. 4, 2009, 362-368.

Nicholson J Bonsall M. (2002) Powered mobility for children under five years of age in England. *British Journal of Occupational Therapy* 68:291-3.

Nilsson L Nyberg PJ. (2003) Driving to learn: A new concept for training children with profound cognitive disabilities in a powered wheelchair. *American Journal of Occupational Therapy* 57:229-33.

Norman JF, Bossman S, Gardner P, Moen C. (2004) Comparison of the energy expenditure index and oxygen consumption index during self-paced walking in children with spastic diplegia cerebral palsy and children without physical disabilities. *Pediatric PT* 16:206-211.

Palisano L Rosenbaum P Walter S Russell D Galuppi B. (1997) Gross Motor Function Classification System. *Developmental Medicine and Child Neurology* 39: 214-223.

Paulsson K Christoffersen M. (1984) Psychological aspects of technical aids: how does independent mobility affect the

psychological and intellectual development of children with physical disabilities? In Second Annual Conference on Rehabilitation Engineering edited: RESNA. p. 282-6.

Rose J, Gamble JG, Medeiros J, et al. (1989) Energy cost of walking in normal children and in those with cerebral palsy: comparison of heart rate and oxygen uptake. *J Pediatr Orthop.* 1989;9:276 -279.

Rose J, Gamble JG, Burgos A, et al. (1990) Energy expenditure index of walking for normal children and for children with cerebral palsy. *Dev Med Child Neurol.* 1990;32:333-340.

Rosenbloom L. (1975) The consequences of impaired movement--a hypothesis and review. In K Holt. *Movement and Child Development: Clinics in Developmental Medicine Philadelphia: Lippincott.*

Skar L. (2002) Disabled children's perceptions of technical aids, assistance and peers in play situations. *Scandinavian Journal of Caring Sciences*

Staincliffe S. (2003) Wheelchair services and providers: Discriminating against disabled children? *International Journal of Therapy and Rehabilitation* 10:151-2, 4-9.

Telzrow R, Campos J, Shepard A. (1987) Spatial understanding in infants with motor handicaps. In K Jaffe. *Childhood Powered Mobility: Developmental, Technical and Clinical Perspectives Washington DC: Rehabilitation Engineering and Assistive Technology Society of North America.*

Van den Hecke A, Malghem C, Renders A, Detrembleur C, Palumbo S, Lejeune TM. (2007) Mechanical work, energetic cost, and gait efficiency in children with cerebral palsy. *J Pediatr Orthop.* 27(6):643-7.

Verberg G. (1987) Predictors of successful powered mobility control. In Verberg G, K Jaffe. *Childhood Powered Mobility: Developmental, Technical and Clinical Perspectives Washington, DC: RESNA Press.* p. 70-104.

Wiat L Darrah J. (2002) Changing philosophical perspectives on the management of children with physical disabilities--their effect on the use of powered mobility. *Disability and Rehabilitation* 24:492-8.

Wiat L, Darrah J, Cook A, Hollis V May L. (2003) Evaluation of powered mobility use in home and community environments. *Physical and Occupational Therapy in Pediatrics* 23:59-75.

Wiat L, Darrah J, Hollis V, Cook A May L. (2004) Mother's perceptions of their children's use of powered mobility. *Physical and Occupational Therapy in Pediatrics* 24:3-21.

Wright-Ott C, Escobar R Leslie S. (2002) Encouraging exploration. *Rehabilitation Management* 15:30-5.

Zazula J Foulds R. (1983) Mobility device for a child with phocomelia. *Archives of Physical Medicine and Rehabilitation* 64:137-9.

Internet Photo Credits



Summary

Multiple medical and societal advances are responsible for a fundamental shift in management of children with motor impairments--from the search for normalization of movement to the achievement of meaningful function and participation in age-appropriate activities and occupations throughout life. Meeting this goal depends directly on being able to meet the required mobility demands. Assistive technology, especially powered mobility, makes it possible for even very young and severely involved children to have the motor skills that promote all other areas of child development.

This HELP publication provides knowledge about the advances in the field regarding mobility options for children to help clinicians evaluate their own approach in light of this new information.

Copyright © 2009 Global HELP all rights reserved



GLOBAL HELP
HEALTH EDUCATION USING LOW-COST PUBLICATIONS

www.global-help.org

ISBN 978-1-60189-103-7



9 781601 891037