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**Evaluation of the health disparities and health access issues for cognitively impaired individuals with physical disabilities who require Physical and/or Occupational Therapy.**

**Abstract:** People with developmental disabilities face many issues when trying to attain quality access to healthcare and an improvement in their overall quality of life. As the debate continues on the importance of establishing a healthcare system which will benefit and meet the healthcare needs of all Americans, more complex issues has become increasingly apparent. The issues related to, the dynamics and definitions of quality healthcare have swiftly emerged, provoking some nationwide uncertainty and difficult questions that will require thoughtful responses and hopefully prompt resolution as individuals with disabilities demand a higher standard of care. Questions such as how to best apply overall quality healthcare services to those inflicted with chronic diseases, how to best serve an increasingly aging population with disabling conditions and what methods of treatment and public service are truly most advantageous for this population are of growing concern. As chronic disease surveillance increases, the transparency and blatancy of more problematic conditions will move toward the forefront of a list of health issues that will need to be addressed in the 21st century. Developmental disabilities and their associated secondary conditions are some of the primary issues that will have to be tackled as the discussion ensues concerning the best ways to serve this ever growing population. As the idea of quality of life is thoroughly analyzed and the definitions of quality of life are debated, public
health practitioners, will have to speak to how to better prepare the community, private and public facilities with physical and occupational therapists who are trained and informed on the intricacies they will face when treating a slowly deteriorating physical, mental and aging population. The developmentally disabled in conjunction with their caregivers must be prepared to face greater challenges when finding people that are adequately outfitted to deal with a number of conditions that place further limitations on their care. These preliminary efforts will need the combined public efforts to help change attitudes in the ways that the community views and reacts to these individuals.

“Disability is typically defined in terms of an underlying physical health condition or impairment of body structure or organ systems. It is often expressed, however; in additional limitations of physical or psychological function and restricted performance of essential activities and skills (Simeonsson and Leskinen, *Issues in Disability and Health* 51).” Prescribing various treatment services for children with these limiting cognitive and physical impairments is complex and on theory should include the active participation and collaboration of a number of individuals or developmental teams who would be involved in the overall development, treatment and quality of life for that individual. Due to the prevalence of chronic diseases there has been a new focus on chronic, persistent health issues in the past 25 years. Today “Approximately 13 million people in the United States are developmentally disabled and/or intellectually challenged (Seidel-Bittke 32).” Chronic Diseases, specifically emotional and behaviorally related conditions, as well as conditions related to the work place, environment, and genetic inheritance has steadily moved up on the list of priorities, taking a more prominent seat in America’s battle with disease competing with attentions that were placed on of acute infectious diseases during the development of antibiotic usage in the United States in the 1940’s
Developmental disabilities or cognitive impairments usually identifiable at a young age, affects the developmental functions of children into adulthood. “Chronic illnesses often begin early in life, long before overt symptoms appear and before medical attention is directed toward them. As a result, chronic illnesses have an opportunity to become firmly implanted before their actual symptoms call attention to their presence (Torrens, Introduction to Health Services 7”).

Perhaps equally important are several kinds of chronic illnesses that have historically received very little attention and, in many instances, were not even considered “illnesses”. The chronic mental illnesses, for example are now only beginning to receive the attention that they deserve. These illnesses pose an enormous challenge for the health care system of the future (Torrens, Introduction to Health Services 7).

Cognitive disabilities often accompany many physical disabilities which makes the rehabilitation process for physical and occupational therapists somewhat more multifaceted; contributing to the theories behind the usefulness of developmental teams who must work in tandem to ensure that individuals receive the proper treatments through valued assessments and collaborative expertise from experts with diverse therapeutic backgrounds. The range of cognitive impairments which can impact the quality of life for many physically impaired children is broad.

The spectrum of motor impairments affecting functions in children and adolescents is wide and compromises many congenital and acquired conditions, primarily involving the neurological and musculoskeletal systems, including but not limited to cerebral palsy, traumatic brain injury, myelomeningocele, spinal cord injury, neuromuscular disease, juvenile rheumatoid arthritis, arthrogryposis and limb deficiencies.”… “Many children with impairments attributable to these conditions will have some degree of disability that may limit their participation in age appropriate activities at home, school, and in the community and should benefit from Physical, Occupational, and/or speech-language therapy services (Michaud 1836).
Diagnosing and creating programs to help treat these impairments while an individual is young becomes important in prescribing effective treatment programs. For example, Pediatricians will often become the first persons to diagnose cognitive disabilities in children. It is important that pediatricians and family health practitioners are able to provide an informed, initial consultation to concerned parents to promote their early involvement and education on the positive ways to best treat their disabled children. It becomes of increasing importance and of a time sensitive nature to diagnose their children early hence the definition of developmentally disabled and/or intellectually challenged which suggests that these disabilities “which manifests itself before the person reaches the age of 22, is likely to continue indefinitely and results in substantial limitations in three or more of the following areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, or economic self-sufficiency (Seidel-Bittke 32)”. Potentially becoming the initial clinician to diagnose and suggest therapies in a disabled individual’s treatment is a huge responsibility. Physicians must learn to better utilize the health services available and communicate with other medical professionals to ensure that the best line of treatment is obtained. Pediatricians, in their effort to act on and address issues related to treatment for the individual, will often recommend additional therapy services to children to help improve their quality of life. Enhanced daily life function can be obtained by requesting the assistance of occupational therapists to teach children basic daily skills which include personal hygiene, swallowing techniques and grooming. Pediatricians may also request the assistance of physical therapists whose goals is to focus on the functionality, mobility and adaptability equipment that is developed specifically to meet that individual’s needs. Children often diagnosed with dual disabilities, have traditionally been left to be managed by the state’s provided programs due to the difficulties in patient care management that the family is able to
provide. The importance of family involvement in the progress of individuals with disabilities is critical.

Prescribing therapy services for children with motor disabilities clearly cannot be based entirely on sound scientific evidence. As the knowledge base is expanded related to the effectiveness of the therapy interventions, evidence-based practice described as using the best available evidence, along with clinical judgment, and taking into consideration the priorities and values of the individual patient and family in a shared decision-making process, as outlined by the Institute of Medicine, is advised (qtd Michaud 1837).

Family involvement can not be undermined in the overall development and rehabilitation of their children.

The Scope of Disability

When developing programs which involve the family, pediatrician and therapy teams to treat individuals with the decreased capacity you must consider the evaluation and analysis of several conditions which contribute to the rehabilitation process. An understanding of these conditions will enable teams to communicate and identify problems that they may encounter making the treatment process somewhat more complex but achievable.

When defining disability conditions, three criteria play a huge role in the way those persons with cognitive disabilities are assessed and treated to include the following:

1. “…the concept of person-environmental interactions overtime” or age and developmental stage. “Interactions with the environment by a child with a primary health condition such as cerebral palsy will differ from those of an adult or elderly person with the same condition. (Kokkonen, Issues in Disability & Health 53)

2. “A person’s behavior style and personality characteristics are clear factors that will influence a person’s engagement with the environment. Behaviors and the way
people are able to interact with their environment influences their treatment (Kokkonen, *Issues in Disability & Health* 53).

3. “…final criterion for defining secondary considerations is the premise that they are preventable. This criterion provides a basis for distinguishing between physical, social or psychological conditions for which the impairment is a necessary but not sufficient cause (Kokkonen, *Issues in Disability & Health* 53).”

For instance because a person may be cognitively disabled, they may not be able to express to their healthcare provider when a particular technique, or treatment is comfortable. As a result of a primary condition, additional physical deterioration may have been caused by the primary condition itself or by the degree of therapy services provided.

A transactional model of development best explains why the environmental argument is valid. The transactional model explains that the existing environment and the interactions of the individual work in tandem and impact one another over time (*Simeonsson and Leskinen, Issues in Disability and Health* 58). The existing environment and what that environment provides the individual contributes some therapeutic advantages (see Appendix A). To better emphasize the behavioral aspect of the environment and patient interactive theory, it has been demonstrated that interventions and therapy services must be integrated and made a part of a patient’s continuous pattern of activities to better support and elucidate how rehabilitation can incorporated into the individual’s environment. The term “natural environments” defines a place where any child and their families can gravitate regardless of their disability status. “Research has demonstrated that young children with disabilities benefit from participating in groups of young children without disabilities, as well as in home and community activities orchestrated by their families (*Bruder and Dunst* 27)
To better explain how this impacts the individual we must better understand the premise for which this is built.

Physical, occupational and speech therapy services are necessary when addressing and treating the capabilities and progress of individuals. According to Johnstone KS and Perrin JCS in *Sports for the Handicapped Child* 331-350, provisions of a home exercise program with instruction of family members and caregivers in therapeutic exercises and age appropriate activities to meet the child’s goals is generally indicated. “Aquatic therapy, hippotherapy, and participation in karate, gymnastics and dance classes in integrated or special classes also can be considered to meet the child’s therapeutic goals. Parent and caregivers education by all therapists is critical in effective partnerships with families for implementation of therapy programs (Michaud 1837). Many times the stress of individual problems associated with the disability itself takes a toll on family relationships and commitment to the patient.

As with the support system that is required of all patients involved in traditional therapy programs …

**(Person-Environment Interaction)**

**FARM DAY  Case #1 September 29, 2007**

In keeping with the principle described by Michaud’s article the state of North Carolina has instituted an activity called FARM DAY at Murdoch Center a state supported facility which serves as the primary residence for Mentally Retarded Developmentally Disabled (MR/DD) children and adults. FARM Day was originally developed as a mechanism to help families to become more involved with their mentally retarded developmentally disabled family members. Often Murdoch Center serves as the permanent residence for these individuals from a very young age, who are evaluated and placed in this facility by state and are agreed to be somewhat of a
challenge for the families to manage alone. The programs that are instituted become part of the rehabilitation process to ensure that the quality of life for these individuals is as similar to that of fully functioning individuals that it can be. Money that is raised during the FARM DAY is used to help buy miscellaneous items for the residents at Murdoch Center. As more normal individuals benefit from the interaction and support from various groups so do MR/DD individuals with varying competencies and experiences in this community. The social aspect of rehabilitation services is proven to be just as valuable a therapeutic method as the physical and occupational therapy. FARM DAY also allows the community to become involved in the effort to understand the services that the state provides. FARM DAY is held on the campus at Murdoch Center usually on a Saturday in early fall. Each division within Murdoch Center establishes a stand where they sell food items such as tacos, hot fudge cake, hamburgers and hot dogs. While I was on campus I noticed that a band was hired to play the banjo for the enjoyment of the residents, their families and the staff at Murdoch. Music and the ability to maintain the attention of the residents helps to increase individual’s auditory skills and mobile coordination. Dancers were hired to clog and several games were set up as entertainers. The games serve as entertainment but also can increase hand, eye coordination. The residents win prizes for their attempts at completing the tasks and it becomes fun for everyone (See Appendix B). The center also hires an outside farm facility to bring in horses for the residents to ride. As described in Michaud’s article hippotherapy involves rehabilitation through the controlled movement of the horse. According to the American Hippo Therapy Association this technique was developed and recognized in 460 BC for individuals with various physical impairments

“Specially trained physical, occupational and speech therapists use this medical treatment for clients who have movement dysfunction. Historically, the therapeutic benefits of the horse were recognized as early as 460 BC. The use of the horse as therapy evolved throughout Europe, the United States and Canada.”

The hippotherapy technique is used to increase neurofunction and responses in patients through coordinative activities involving the horse.

The benefits of horseback riding are as numerous as the types of disabilities and conditions served. Research shows that students who participate in therapeutic riding can experience physical, emotional and mental rewards. Because horseback riding gently and rhythmically moves the rider's body in a manner similar to a human gait, riders with physical disabilities often show improvement in flexibility, balance and muscle strength (http://www.americanequestrian.com/therapy.htm).

In various settings other than FARM DAY, this technique has been successfully incorporated into the daily activities of persons seeking to improve upon their neurological and sensory processing.

Observations  October 4, 2007

Case #2 (Behavior Style and Personality Characteristics)

Some of the rehabilitation services that the Physical and Occupational Therapists at Murdoch provide are identical to the general therapeutic services that most therapists provide but with one caveat; the combined difficulty of cognitive and physical disorders which often creates a delay in the time and effectiveness in the treatment and rehabilitation of that individual. One significant factor that prolongs the ability of the individual to obtain adequate care at rates comparable to those who only suffer from the physical disability, is their willingness and ability
to fully cooperate, understand the instructions, requirements and usefulness of the services provided to them by their therapists. As is the case of *Susan a 77 year old Mentally Retarded Developmentally Disabled female resident at Murdoch Center. Susan is a mentally retarded individual who has been treated at Murdoch Center for the majority of her life. Susan has been treated by the physical therapists at Murdoch Center related to her mobility issues that have increased as she has aged. Her ability to understand verbal communication is minimal although she is able to express her dislikes through more corporeal means. During my visit to Murdoch, a new walker/rollator was being prepared for Susan in an attempt to encourage her to walk. Upon introducing the walker/rollator to Susan she became a bit agitated when the therapist suggested that she use the new device. Susan has become acclimated and somewhat attached to the use of a wheelchair and the convenience of being transported via this device. Sometimes the proposal and accompanying therapeutic treatment may be interpreted as frustrating to Susan as she has been treated for her chronic illnesses for a number of years by the faculty at Murdoch. Murdoch’s physical therapists had issues with trying to encourage Susan to cooperate with their attempts to determine if she would effectively use the device that was designed for her. Although Susan will probably be incapable using all of the features that come with the rollator, due to her mental capability, she can utilize the basic operating functions to aid in her transport. In addition to Susan’s communicative issues that must be treated through Murdoch’s Speech Pathology services, Murdoch must add her disabilities associated with aging to the list of chronic diseases and secondary conditions which she has attained as a result of her illness which will be discussed later.
Observations  October 4, 2007

Case #3 (Prevention: Secondary Conditions)

My third observation was that of a female patient approximately in her fifties with limited communication skills. Her cognitive skills upon initial interaction with her is undetermined as she seemed to respond to basic commands and was extremely cooperative when the occupational therapists began to work to take measurements to better develop her adaptive equipment. She was unable to speak but obviously had some limited comprehensive and mobile ability. This individual whom I will refer to her as *Kim is involved in a vocational work program where she performs light duties (paper folding) where she earns a small wage on Friday’s as part of the program developed by the state. Kim is being measured for a new chair due to her spinal curvature which has increasingly become worse over time. The reason for Kim’s curved spine is due to some results of aging, but also potentially due to some genetic problem that had not been diagnosed early on. Perhaps the treatments which include the chair adjustments were intended to make Kim more comfortable while completing tasks. Because Kim is somewhat verbally deficient she can not express the root of any initial pain and thus many of the areas which required medical focus were overlooked. Genetic problems which should be diagnosed at an early age may not have been an area of interest at the time Kim was a child and many problems were diagnosed incorrectly or progresses beyond correction.

Barriers to Healthcare

The ability of the state to locate experienced staff that has the necessary training to perform rehabilitation services while also addressing specific cognitive disabilities is a challenge. This is
a health disparity that has become increasingly apparent in both state and privately funded facilities. Attempting to locate and maintain medical resources for the treatment of this specific and unique disabled population can become quite frustrating. Attitudes of some care givers in private settings are dampened by continual underpayment, long hours and strenuous conditions. Health care access to medical facilities is complicated when attempting to transport the cognitively and physically disabled to those few clinicians who have access to adaptive equipment designed to meet the intricate needs of this population. Often the public is unaware of the methods needed to locate trained medical professionals or must go through extreme and aggressive searches to locate specialists who are willing to or have the equipment to treat either the physically or cognitively disabled. Barriers to healthcare access appear in various places when attempting to treat this population. Unlike regular physical or occupational therapy services, it is common for the cognitively disabled to be restrained when medical services are offered in an effort to secure the protection of that individual and the medical provider. Transfers will often require the work of several staff members to carry them from their wheelchairs to medical chairs to receive the appropriate treatments (Seidel-Bittke 34). In an interview conducted at Murdoch Center on September 7, 2007, Cathy Kluttz-Hile described some of the issues individuals with disabilities face because of the dynamics associated with cognitive and physical disability. “Caregivers often become burned out when treating this population due to some of the unrealistic expectations in patient care progression. ‘Large gains’ in patient care are often not immediate. Compared with the usual documented progress often seen in standard physical therapy programs, those working with the cognitively disabled must be prepared to address chronic issues and look to improve conditions rather than resolve them.” Lack of available staff resources willing to commit to these issues is a recurrent problem at state
supported facilities such as Murdoch Center, where the goal is to teach independent living. The focus and goals of the Physical Therapist/Occupational Therapist may be to help improve and address the issues which weaken a person’s ability to ascertain an improved Quality of Life. The issues related to chronic diseases versus those of acute illnesses means that the ways in which the patient is treated must vary, and will require trained personnel who are able to tailor their treatment to fit those differences. Chronic diseases are not those diseases that in a more traditional therapeutic setting are curable. Often identifiable early in life chronic diseases will remain with the individual throughout the course of a person’s life and must be treated and adjusted according to a patient’s life stages. When addressing the issues of disability, these and other factors must be considered which affect an individual’s quality of life. Chronic disease such as mental illness, aging and secondary conditions will increase the difficulty in obtaining treatment because of the complexity in issues and combined treatments. Secondary conditions are considered those issues which manifest itself as a result of a primary condition. A secondary condition may appear as a physical, social or psychological limitation. The barriers continue to mount as individuals grow into adulthood and more hands-on management becomes necessary and increasingly difficult with age.

The rapid aging of the United States population makes it a certainty that a majority will live for at least eighty years, increasing the probability that they will need long-term care to help them handle the multiple physical and mental challenges of becoming very old. These types of needs must now receive much more attention from the organized health care system.

Similarly, a person’s behavior style also influences the way in which treatments are received. As when dealing with individuals with various types of cognitive and physical disabilities you must also take into account the various personality types that are involved during the treatment. The
argument for continuous long-term family and therapist involvement is strengthened as patients become more familiar with their therapists and the therapists learn specific ways to work around potential barriers.

“Part C of the individuals with Disabilities Education Act (IDEA) amendment of 1997 requires a service coordinator to be assigned to each family eligible for early intervention. This person would help families to find those persons who are trained in the treatment of children with disabilities. This service worked in conjunction with training programs geared toward students, faculty and organizations would be effective in addressing and helping to ensure that these individuals were provided with all the possible avenues for attaining quality of care for their family members.

Another focus area mentioned (Bruder and Dunst 26) is the development of an Individualized Family Service Plan (IFSP). In many areas in Public Health a plan is used as a guide to help document the preliminary steps necessary to accomplish much needed tasks within a specific public health division or department. Typically the IFSP is used in conjunction with a meeting where the welfare and precise needs of the child are discussed with the family. Early intervention services are generally assessed for children aged 3 years and younger. These children if assessed, diagnosed and placed appropriately at an early age, can sometimes have a more favorable prognosis. Although many of these services are prepared for and implemented by state supported agencies and children are often placed in institutions after being reviewed by committees who evaluate their mental capabilities, there is an argument which supports additional interaction with children who do not have extensive cognitive and physical disabilities. The difficulties occur in the education of the public to understand the ordeals that
the cognitively disabled must endure. As many disabled individuals must find a way to bridge the gaps which exist in the quality of care and their access to that quality, there also must be a shared responsibility by the community as a whole to better understand the challenges that exist. In an attempt to provide better services to mental health professionals, private industry has taken on more responsibility in providing services to individuals with disabilities. “In 1963, President John F. Kennedy passed a law to de-populate institutions for the developmentally disabled Seidel-Bittke 33).” The emergence of the group home has taken a step in the direction of providing improved quality services to individuals. Group homes are typically chosen by families who want another option other than traditional state supported services that provide access to more personable privatized care for their family members. Group homes have been an aspect that has been fought historically by many communities through zoning laws to keep the disabled from moving into specific neighborhoods which ultimately discriminated against disabled citizens. In Michigan, federally funded dollars were originally funneled into the Medicaid system through the Intermediate Care Facility for the Mentally Retarded (ICF/MR) in the early 1970’s which provided a basis and incentive for further community development (Parish 224). The new incentives did result in the development of additional group homes, but also incentivized the states to revamp and reconstruct state agencies that currently existed and fund the construction of state supported, community based facilities (Parrish 224). Although group homes are perceived to add more value to the lives of individuals offering community focused programs that better serve individuals with disabilities, many of the size restrictions implemented by the ICF/MR resulted in a reduction in the number of individuals that could be placed. The cost savings however were huge when compared to state institutions within states such as Michigan. “In legislative testimony, the Arc president argued: The individuals who
could go into these homes} are presently at Plymouth Center where the cost is roughly $194.00 per day. A fair estimate of the cost of a community program would be a per diem of $80.00 per day. The difference between per diems is: $114.00 per day. Multiplied by 150 clients, this is $17,000 extra cost for each day these individuals remain at Plymouth, or over half-a-million dollars per month (qtd. in Parish 224).” One special project developed in London emphasized the importance of community support and preparedness to assist disabled populations. Their objective was “…to enable people with high support needs to be more fully included and have a valued role in their community (Riley 23).” Group homes have emerged on the basis of a good premise but generally serve a particular type of disabled individual. Many group homes will only serve primarily functional individuals who require very little maintenance and supervised care. Many group homes advertes their ability to reintroduce the developmentally disabled into the community through community work programs and activities. Like the IFSP plans developed for the MRDD patients involved in state programs, private group homes have initiated case managers who are assigned to assist each individual with their personal development goals by working with the individual’s family, friends and community providers. The assumption is that a certain level of cognitive ability is necessary in order for the individual to be able to contribute and make small decisions about their personal development and welfare. The ability to make those decisions is critical to your inclusion in and approval status in many group homes. Monitoring is provided to ensure that individuals are meeting their goals. Funding and the ability to provide adequate funding is crucial to the survival of any private of state program. What is interesting about some programs are supplemental funding sources for many non-profits. For many group homes funding sources include such agencies as The State of North Carolina, The N.C Council on Developmental Disabilities and The Department of Housing and Urban
Development. Erin Waanders an Occupational Therapist at Murdoch Center has observed some of the more obvious reasons and benefits to using a state supported agency versus that of the group home. “Group homes tend to favor residents that are more mobile. Many times group homes are not equipped with the appropriate amount of oversight and safety necessary to manage large numbers of patients. As patients age we have seen an increased number of individuals whose families originally chose to place their family members in community based facilities returned to the state due to the complexity of their conditions.”
Personnel Preparation

Personnel preparation becomes an issue when dealing with adequate services that can be ascertained by developmentally impaired individuals seeking improvement in their quality of life. Many students involved in early intervention programs which included occupational therapy, physical therapy, psychology, social work, special education and speech language pathology had disciplinary heads who felt that their specific programs lacked the significant job preparatory skills necessary for working professionals in that field (Bruder and Dunst 25). This survey performed in 449 programs to include 237 undergraduate and 212 master’s programs also found that the level of training was varied across the aforementioned disciplines thus concluding that no standardized curriculum existed or universal assessment and knowledge based model present to address chronic diseases pertaining to the mentally ill (Bruder and Dunst 25).

Changes to the curriculum in early intervention programs which groom students to take on professional opportunities in fields that serve the developmentally disabled unfortunately also have many barriers when attempting to change educational programs. Barriers to progress may include organizational or bureaucratic problems, the current curriculum or student and faculty resistance to change and/or their comfort level with alternative less familiar methodology.
Interaction of Concepts

World Health Organization 1999

Health Condition
(disorder/disease)

Body Function & Structure

Activities
(activity limitation)

Participation

Environmental Factors

Personal Factors

Appendix A
FARM DAY AT MURDOCH CENTER

2007

Cathy Kluttz-Hile my Preceptor (on the left) at Farm Day September 29, 2007.
Horses grazing before providing a bit of Hippo therapy!