

TRANSITIONING Through Wheelchair Mobility

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FROM EARLY CHILDHOOD THROUGH ADOLESCENCE

WHEELCHAIR SELECTION DURING CHILDHOOD can vary significantly during the child’s adolescent years. Accommodating their needs in childhood often incorporates several variables. This would include their family transportation abilities, and home environments, as well as school and community activities. Matching their needs in adolescence continues to incorporate even more variables. This article will review patients with various diagnoses, including, muscular dystrophy, osteogenesis imperfecta, spina bifida, arthrogryposis, and cerebral palsy. Functional independent mobility relative to the type of equipment selected will be discussed. The medical necessity for the wheelchair component options as the client ages from early childhood through adolescence will be shown to impact the equipment selection as will the patient’s disease progression.

The deterioration of physical skills for the child diagnosed with Duchenne muscular dystrophy affects not only their mobility, but also their psychosocial interaction with their peers. Their awareness of how different they are from their friends begins to be clear. The image that they are “different” sometimes prevents us from initially recommending and thus, acceptance of powered mobility. Reasons why the younger children with Duchenne’s do not want a power wheelchair as their first mobility system, even though they would be more independent and functional, were that they would 1) lose muscle strength and endurance due to lack of use and really lose their ability to walk, and 2) a power wheelchair is more “noticeable” than a manual wheelchair even though they might need someone else’s help getting places.

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The progression of the disease for the patients with Duchenne’s really dictates the transition from manual wheelchair mobility to power wheelchair mobility. Surgical interventions that were common several years ago to continue ambulation when kids were 10 years old included gastrocnemius releases and continued use of hip-knee-ankle-foot orthoses (HKAF0’s). During this time period, the first wheelchair selected was a manual wheelchair – to supplement their ambulation. Secondary to the increase use of steroid therapy, kids are walking longer, until around age 13. Families and children are choosing NOT to have surgery because HKFO’s are not “cool” as a teenager. Seemingly powered mobility is being considered the first choice for mobility because that will get them where they need to go, indoors and outdoors.

Children with spina bifida tend to be between 2 and 3 years of age when they receive their first seating and mobility evaluation. Because upper body strength is functional, and their initial therapy goals are geared toward independence, including transferring into and out of the wheelchair, manual wheelchair mobility is the typical recommendation. Among the types of wheelchair recommended, the Action Comet was often a highly recommended wheelchair. The Action Comet provided 1) low seat to floor heights – important for independent transfers, and 2) front stability – for subjects that use the footboard as a “step” for transfers. No other manual wheelchair provided these two characteristics as well as the Comet provided. Unfortunately, the Comet was taken off the market this year. As our subjects aged into adolescents, their mobility choice remained manual wheelchair mobility. The goal for this age was to have increased efficiency and less weight, but just as stable a base for transfers. The exception to this was when college became part of their future endeavor, thereby bringing powered mobility into the equation. Most of our adolescent patients with spina bifida tended to transition to rigid frame wheelchair due to its lighter weight, maneuverability and aesthetics.

Children with osteogenesis imperfecta were also evaluated for their first seating and mobility system between the ages of 2 and 3. Osteogenesis imperfecta is a genetic disorder characterized by bones that break easily, often from little or no apparent cause. Many times, powered mobility is discussed early on because of their susceptibility to fractures. Power wheelchair mobility not only provides independent mobility, but acts as

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a “barrier” in protecting the user from harm. Often, because of their short limbs and their brittle bones, pushing a manual wheelchair was not possible nor was it effective. Even if they could push a manual wheelchair, the frequent occurrence of broken bones limited the ability for self-propelling. Therefore, to become functionally independent, powered mobility would be the most feasible solution. During adolescents, power seat functions (such as seat elevator and power tilt in space) were considered for enhancing or increasing their functional independent mobility. Children that are not of the severe type of osteogenesis imperfecta, could successfully self propel a manual wheelchair. Similar to our spina bifida population, the first choice in a manual wheelchair was an Action Comet because of its stability and low seat-to-floor height. But more often, powered mobility is the choice for functional independence for this population.

Arthrogryposis, a rare congenital disorder that causes multiple joint contractures and can include muscle weakness and fibrosis, have many subgroups that vary in symptoms. Again, just as in the spina bifida population, wheelchair systems were recommended between the ages of 2 and 3 years. A typical physical characteristic is hand, wrist, elbow and shoulder contractures making manual wheelchair propulsion difficult and labor intensive. Again, for functional independence where ambulation was not a functional goal, and to enhance their cognitive development, powered mobility was recommended. The placement of the joystick is crucial to the safety and success for the child. Custom power seat functions to enhance independence are also discussed. Because of muscle weakness and shoulder and elbow contractures, placing the joystick in the center or midline position, lower than a typically mounted joystick, provided the best placement for success and control in driving a power wheelchair. Because transfers needed to be considered, it was necessary to mount the joystick on either a flip down bracket or a swing away bracket that could be powered through hitting a single switch. As these children grew, many would be able to manage a joystick mounted in the typical location, either on the left or right side of the armrest. But throughout their adolescence, their primary means of mobility remained a power wheelchair.

A cerebral palsy diagnosis implies non-progressive brain damage that does not worsen but carries with it orthopaedic difficulties. In this discussion, children and adolescents who are diagnosed with quadriplegic pattern cerebral palsy that have average or slightly below average cognitive function are being considered. They all have the goal of functional independent mobility. Subjects in this group, because of muscle weakness, tone involvement, and motor planning issues, all transitioned along a similar path. During the initial seating and positioning evaluation, sometimes performed when the child is 18 months of age, it can be unclear and unknown what the child’s mobility potential is. The caregivers are all still focused on ambulation and not thinking about a wheelchair as a functional mobility tool. This is why most times the first mobility system was not geared toward independent mobility. But clearly discussions about mobility are being brought up earlier and earlier in their child’s life.

Therefore, the first mobility system for children with cerebral palsy were usually dependent mobility systems or ones in which the caregiver has full control (such as a KidKart or a tilt in space wheelchair). Over the next two to three years, as therapy goals are more clearly defined and the mobility goals of the child are discussed, focus turns toward independent mobility either in the form of manual or powered mobility.

Once the mobility goals of the patient are more concise, usually about 4 years of age, powered mobility was usually the recommended solution given their tone pattern and inability to consistently or effectively self-propel. Training in this group of subjects was longer than in the other previous group secondary to their motor involvement and sensory involvement, drive interface selection, etc. Power wheelchair training, at times, can last anywhere between months to years. But what really defines when to pursue their own power wheelchair is the motivation and interest and the support of family and therapists.

Other factors that directly impacted the patient’s ability to be functionally independent in mobility were if they had surgical interventions for their tone, or surgery to correct orthopaedic conditions. A baclofen pump would reduce spasticity and enable a patient with high tone to have increased control. This would determine whether they could consider driving with a standard joystick or an alternate drive interface. Most of the time, the head provided the most consistent movements and control and therefore is the preferred method for driving a power wheelchair. As these subjects moved into adolescents, changes in orthopedic conditions as well as spasticity changed their functional abilities to manage driving a power wheelchair. Although these conditions would hinder control, driving still continued while surgical intervention took place. But as they aged, it was clear, that in order to continue functional independent mobility, powered mobility offered the best option.

Transitioning through the world of mobility as a toddler through adolescence retains the same goal, regardless of diagnosis: getting from point A to point B in the most effective and efficient means possible. Similarly, all children with a disability whose primary means of mobility will be power must demonstrate the ability to drive a power wheelchair. The child who is learning to drive must understand that pushing the joystick forward or hitting the switch in the headrest causes the chair to move forward. There may be a level of training that continues into adolescence for many children. But technology has allowed that “continued” learning curve be functional for the caregivers. For users of manual wheelchairs as their primary means of mobility, attention to efficiency and independence is necessary. Asking oneself if the child is reaching his or her mobility potential is crucial to successfully identifying the right mobility system.

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