

RESNA Position on the Application of

Power Wheelchairs for Pediatric Users

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The purpose of this document is to share typical clinical applications as well as provide evidence from the literature supporting the application of power mobility (PM) for young children and to assist practitioners in decision-making and justification.

Functional, independent mobility in children with disabilities has been shown to improve cognitive and perceptual skills, reduce learned helplessness, increase confidence and increase participation with their peers in everyday activities. Provision of powered mobility has resulted in significant improvements in several social components e.g., expressive behavior, cooperation, interacting with family, in the quantity of motor activities, and in the quality of interactive and symbolic play.

Newer therapeutical models focus on task performance, which often requires the use of a power wheelchair for children who otherwise can not perform their daily routine with similar efficiency to their non-disabled peers.

Manual wheelchairs do not provide adequate efficiency for children with fatigue, compromised respiratory capacity, limited coordination, or strength.

A child's ability to drive a motorized wheelchair is not related to chronological age; rather, it is related to cognitive readiness. Age appropriate supervision is natural and may be required for safety and to enhance learning.

Not everyone who is incapable of walking or propelling a manual wheelchair effectively is a candidate for PM. Motivation, understanding of basic cause and effect, spatial relationships and problem solving concepts, attention, and physical ability to activate the access method consistently and purposefully are required to successfully operate a power wheelchair.

It is RESNA's position that age, limited vision or cognition, behavioral issues, the ability to walk or propel a manual wheelchair short distances should not, in and of themselves, be used as discriminatory factors against PM for children. RESNA recommends early utilization of Powered Mobility for the appropriate candidates as medically necessary, to promote psycho-social development, reduce learned helplessness, and to facilitate social and educational integration and independence.

This paper is not intended to replace clinical judgment related to specific client needs.



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I. Philosophical/historical attitudes to PM, and parental acceptance

Historically, only older children were considered candidates for PM, after all other forms of mobility were deemed ineffective. Use of a power wheelchair was often seen as a failure (Wiart, Darrah, 2002). The neuromaturational theory, the dominant traditional practice model of motor development, encouraged intervention strategies that aspired to normalize movement patterns by changing the child, with little regard for altering the task or the environment. The newer therapeutical model referred to as the Dynamic Systems Theory (DST) is the more evidenced based and is regularly accepted. It considers the effect of interactions between person, task, and environment on motor development. DST is a non-hierarchical model in which function drives motor behavior, and allows for parallel interventions. It focuses on function and task accomplishment, as opposed to normalized appearance as defined by our traditional societal perceptions (Wiart, Darrah, 2002).

Parents of children with disabilities and some medical professionals are under the inappropriate assumption that the use of PM will interfere with the development of the skills required for walking, or eliminate the child's desire to walk. They fear that their child will become lazy. However, in reality children often become more interactive, motivated and agile when PM is applied; integration with their environment proves to be motivating, resulting in a more active lifestyle. Research is clear that the use of PM augments the success and motivation toward all methods of mobility (Butler, Okamoto, McKay, 1983), and does not reduce gross motor functions (Bottos, Molcati, 2001). Education of the parent and the care team to these findings is critical to maximizing the overall long term functional mobility outcome.

It is the nature of pediatric medicine that the consumer and the decision maker are two different entities. Yet it is essential to consider the children's own thoughts, attitudes and feelings. As children have not yet developed the social stigma described above, they do not view the PM device as "disabling" in any way. They see it for what it is, a way to augment their goal of efficient, successful exploration and movement within their environment to satisfy their curiosity, experience, participate, socialize, and learn.

II. Physiological demands of mobility

A. Physiological demands of ambulation

There are many energy requirements taxing the system of a neurologically or medically involved child. Their fragile systems often require all available physical resources for breathing, circulation, and digestion. The physiological demands are prioritized over the functional ones. PM provides the medically fragile child the means to conserve energy for survival while maximizing exploration, independence, and mobility.

Many partially ambulatory children with disabilities exhibit a pathological gait pattern (Bennett, et al, 2005) and may require the use of an assistive device or orthotics. Children



with cerebral palsy (CP) performing exercises require 1.5 to 3 times the oxygen per kg of body weight as their typical peers (Campbell, Ball, 1978). In addition, many children with diplegic CP have a crouched gait with increased flexion at the hips and knees; this increases the stance phase of the gait cycle which limits velocity. Children with Spina Bifida have been shown to require 218% more energy to ambulate than their nondisabled peers (Williams et al., 1983). Research also indicates that the gait of a child with a disability often worsens and requires more energy to complete as a child ages (Johnston, et al, 2004; Waters, Hislop, Campbell, 1983). In addition, heat production from the increased metabolic cost requires increases thermoregulation and additional rest is needed to restore normal temperature (Carey, Cromtion, 2005). Weakness alone can functionally limit gait, even when oxygen consumption is not excessive, such as in children with muscular dystrophy (Bowen, Miller, Mackenzie, 1999).

B. Physiological demands of manual wheelchair propulsion

Manual wheelchair propulsion requires upper extremity strength and coordination, hand grip, head and trunk control, endurance and higher oxygen consumption than ambulation in the typical child (Luna-Reyes, et al, 1988.) To use a manual wheelchair, a child needs the ability to tolerate an upright posture and the ability to change position and/or manage pressure. They must be minimally influenced by spasticity and primitive reflex patterns on posture and upper extremity movement. In addition, the child in a manual wheelchair needs to perform mobility tasks in a similar amount of time as their ambulatory peers in a school based setting.

Efficiency of manual wheelchair propulsion in children with disabilities is often hindered by the following issues:

- The typical pediatric manual wheelchair needs to accommodate growth, offer transportation safety, and be equipped with an appropriately supportive and preventive seating system. This, with added school and medical supplies often results in a wheelchair weight in excess of 40-50 pounds, which may be the equivalent or greater than the child's own weight.
- It has been shown in adult literature that wheel placement on the chair can reduce the risk of repetitive strain injuries (Consortium for Spinal Cord Medicine, 2005). Axle placement, however, is often compromised in pediatrics due to safety concerns requiring increased stability of the wheelchair, and the necessity to provide for growth.
- When head and trunk control difficulties are managed by using a tilt frame, the orientation change makes propulsion difficult.
- Reduced strength, fatigue, respiratory and coordination issues which limit pathological ambulation also tend to compromise efficiency of manual wheelchair propulsion (Luna-Reyes, et al, 1988).

The high risk of upper extremity repetitive strain injuries (UE RSI) in manual wheelchair users is well documented with adults (Consortium for Spinal Cord Medicine, 2005). Given that children often push a manual wheelchair equivalent to their own weight and axle location is often compromised, their risk of developing UE RSI is logically higher.



This may place them at risk of reduced ability to transfer, reach and perform Activities of Daily Living tasks (ADLs).

In addition, a true life environment in the classroom or the playground may require negotiation of a variety of terrains, obstacles, and adherence to a schedule or time table. PM provides many children an opportunity for independence and allows the child the energy reserves required for sustaining cognitive attention for learning. In the home setting, play, homework and performance of ADLs also require energy, which is similarly restricted unless efficient mobility is achieved.

C. Physiological demands of power mobility

PM physically requires access to power drive controls. This can be achieved through any body part via controls such as a joystick, switches, head array, touch pad, fiber optics, sip and puff, and voice. These same controls can often be configured for the child to manage his position in space and his pressure management. Endurance is required for the child to sustain control of the access method throughout the day.

D. Mobility and exercise

It is important to emphasize that mobility must be efficient, and is not to be confused with exercise. Children with disabilities, just like their peers, need cardiovascular exercise which may be augmented with therapy. Exercise by definition is tiring, which is the reason the general population does not use their everyday mobility as such. Concerns about weight gain and loss of function must be addressed via other means.

III. Relationship between mobility and child development

A. Intellectual and psycho-social development

Mobility is associated with the acquisition of important cognitive and perceptual skills throughout development, for typically-developing children and for children with mobility limitations. These improvements in cognition and perception are due to the fact that when children move independently they are faced with a complex set of spatial problems such as not colliding with obstacles, not falling off the edge of the stairs, remembering how to get from place to place (Kermoian, 1997; Kermoian, 1997). As a result, young children who do not have self-initiated mobility perform poorly on a wide range of fundamental skills because they are not relevant to their life. Infants who do not have functional mobility, for example, cannot locate hidden objects (lack of object permanence), are not appropriately wary of heights and are more dependent than their peers on vision to control their posture (Bai, Bertenthal, 1992; Campos, Berthental, Kermoian, 1996; Higgins, Campos, Kermoian, 1996; Kermoian, 1997; Kermoian, Campos, 1988).



Older children and young adults with limited mobility perform poorer than their agematched peers who had early access to functional mobility when tested on map reading skills, remembering how to get from one place to another and estimating their ability to negotiate tight spaces (Simms, 1987; Stanton, Wilson, Foreman, 2002). Given the critical role of experience in brain development (Stiles, 2000), it is not surprising that the onset of mobility has been shown to improve brain function (Bell, Fox, 1997).

Mobility also impacts the child's ability to learn and participate fully in the world by dramatically increasing the child's independence (Biringen, et al, 1995; Campos, Kermoian, Zumbahlen, 1992). It helps to avoid learned helplessness, formulate sense of identity, confidence, and reduce apathy and depression (Butler, 1991; McDermott, Akina, 1972; Kohn, 1997). Learned helplessness is a psychological condition in which a person has learned to believe that he is helpless and has no control over his environment. This condition is firmly established in children by four years of age who have not had functional mobility (Butler, 1991). Once learned helplessness is fully developed, the results are long lasting and impair a person's function in the world. Individuals with learned helplessness have passive, dependent behaviors. They lack curiosity and initiative. Academically, they perform poorly. To prevent learned helplessness, mobility must be functional and efficient.

Children with disabilities have also been shown to engage in more solitary and adult play than their age matched peers. When they do play with their peers, they frequently take on lower status roles which can lead to a sense of isolation and a confused sense of identity (Doubt, McColl, 2003; Missiuna, Pollock, 1991; Tamm, Skar, 200). In contrast, children who are given PM become more active and engaged in the world (Butler, 1996). They initiate movement and interaction with others more frequently, are more exploratory, more curious and persistent in the face of frustration. This attitude of independence likely accounts for the reported increase with PM in spontaneous vocalizations, improved sleep habits, disposition, and increased participation in educational programs and ability to interact meaningfully with peers (Deitz, Swinth, White, 2002; Furumasu, Guerette, Tefft, 2004).

B. Vision

As children develop their visual system and the inherent structures that support the visual system, they also develop their ability to move in space. Infants that lack visual ability are affected in their acquisition of postural stability and are found to have significant motor delays (Prechtl, et al, 2001). In turn, independent movement impacts a child's visual development by providing visual experience for cortical development, spatial relationship comprehension, development of depth perception (Nawrot, 2003), and provision of vestibular information. PM for a non-ambulatory child may provide the opportunity to maximize a child's development in all of these domains.

For children with physical motor disabilities, who have low or no vision, alternative solutions and external aids may be used to enable them to independently move in space. High tech solutions (such as sensors with audio feedback) are available, dogs for the



blind, or simple low tech solutions can provide assistance. Examples include the use of bubble wrap for audio feedback and motivation, speed bumps, or yellow tape on the floor.

The trainer should also alter his/her typical model and use additional guidance methods to compensate for the trainee's visual impairments. Examples include using a consistent path, mentioning environmental cues, utilizing abilities such as light perception, providing music or a voice for the student to follow, or tapping on the wall.

IV. Determining readiness

Few assessments are available to help clinicians determine a child's readiness to drive a power wheelchair. These assessments are also not a substitute for clinical judgment. The Pediatric Powered Wheelchair Screening Test (Tefft, Guerette, Furumasu, 1999) can be used to determine cognitive developmental age. To use a power wheelchair functionally, a child must demonstrate the ability to use an access method (i.e. joystick or switches), and show that they have the necessary cognitive, sensorimotor and coping abilities. Cognitive abilities include cause and effect, directional concepts, an understanding of problem-solving and spatial relationships, and judgment. Sensorimotor abilities include perception, processing, motor planning and reaction time. Finally, coping abilities include attention span, motivation and persistence. Clinicians will often attempt power wheelchair trials with a child when they show cause and effect comprehension. This means understanding that activation of the access method is causing movement of the power wheelchair. Research shows that switch consistency is higher when utilizing a power wheelchair as compared to switch toys, as the child experiences additional vestibular and visual stimulation due to the movement of the chair (Nilsson, Nyberg, 1999).

Training is usually required before a child is able to demonstrate readiness. The approach is to use a child's own motivation or curiosity to learn PM skills through play, and not to actually teach driving (Furumasu, Guerette, Tefft, 1996). PM is experienced by spontaneously exploring movement through basic skills and progressively introducing tasks to promote integration of these skills to develop more functional mobility. The amount and type of training will vary with the individual; their needs, deficits, motivations, and learning styles. In general, a child who demonstrates emerging skills and motivation to drive from one location to another, with limited cues and without running into obstacles, is ready for a power wheelchair.

A. Cognition

Unless the child is actually placed in the wheelchair itself, it is difficult for clinicians to determine whether a child has developed the cognitive skills and the temperament to operate a power wheelchair safely. Even with actual power wheelchair trials, a dynamic sensorimotor problem can be difficult to distinguish from a cognitive developmental delay or from temperament issues.



57% of the variance in wheelchair skills amongst young children who used joystick controllers can be contributed to differences in the cognitive domains of spatial relations and problem solving (Furumasu, Guerrette, Tefft, 1996). Problem solving helps the child to determine the most appropriate ways to maneuver the wheelchair in and out of complex, changing environments. Spatial relations help the child understand her own relation to other objects and to navigate through tight places, around stationary objects, or in crowds of moving people.

IQ is not a good determinant of a child's ability to operate a power wheelchair. Children with IQs in the 50's can learn to drive a power wheelchair, if the necessary training time is provided (Bottos, Bolcati, 2001). It is important to realize that the operation of a power wheelchair is not comparable to driving a car, rather to regular human mobility. When typical children learn to walk, they unconsciously develop a movement pattern to move from one point to another. A similar process occurs during power wheelchair driving.

Mobility training might be necessary if a child does not demonstrate all of the required cognitive skills to safely operate a power wheelchair, with or without supervision. To receive a power wheelchair, a child only needs to demonstrate emerging skills in each of these areas, not mastery. Mastery of these skills generally occurs only with actual driving experience, which is not possible to obtain unless a power wheelchair customized for the individual is consistently available.

B. Age

Chronological age is not the best indicator of ability to drive a powered wheelchair. It is the child's cognitive/developmental age which is directly related to driving expectations. Studies with cognitively intact clients have shown children as young as 18-20 months can learn to drive within less then ten hours of training time (Butler, Okamoto, McKay, 1984). Another study carried out with able bodied children showed that infants as young as 3-4 months investigated and manipulated the functions of the joystick and as early as 7-8 months of age had developed an understanding of how the controls could be used to move the chair towards a determined object (Nilsson, Nyberg, 1998). Clinical experience shows that 11-12 month old children have the ability to operate a power wheelchair.

When looking at children driving a powered wheelchair we need to determine what is meant by "driving" and our expectations for these children. Normally developing children start exploring their environment at 3-4 months of age via reaching and rolling. Creeping at 7-9 months of age allows discovery of further distances, with resultant changes in perceptual, cognitive, and socio-emotional behavior. At 12-13 months children typically begin to walk. Therefore utilization of PM at similar ages is also recommended for the appropriate children, to enable them to explore the environment and in turn continue to develop motor and cognitive skills.



When PM is not addressed early enough in a child's development, passiveness often occurs (Butler, Okamoto, McKay, 1983). This effects the child's motivation, which can delay power wheelchair proficiency.

C. Safety

Young children using PM need to be supervised just like their non-disabled peers. Driving a power wheelchair which has force and power behind it can have significant safety implications. Children have a natural curiosity, but not necessarily the understanding of what harm or danger can accompany the task. These concerns, however, should not stop a clinician or parent from allowing and encouraging a child to drive, rather serve as a reminder to pay special attention to safety.

Indoor and outdoor skills and expected safety levels vary by age, cognitive factors, and the environment in which the child is expected to drive. Once a child masters obstacle avoidance and indoors driving, then outside tasks can be approached, such as handling varied terrain, curbs and curb cuts, and moving around in traffic. The prime goal of the trainer is to encourage mobility, provide guidance, and to ensure safety.

The technology of current power wheelchairs can address many of the safety issues and used as learning tools. If a child is not independent and is at risk for injuring themselves or others, stop switches and attendant controls can be used. In addition, progressive programming of the power wheelchair is critical for the chair to operate in conjunction with the client's physical and cognitive abilities and to ensure safety.

Therapists often delay recommending PM until children gain maturity and "outgrow" their behavioral issues. However, this may not be reasonable. We do not limit walking in normally developing children due to impulsive or distractible behavior. Instead, we modify or limit the environments in which the child walks and enhance supervision. Similarly, behavioral issues should not limit children from being candidates for powered wheelchairs. Instead, effective teaching strategies such as Applied Behavioral Analysis (Cooper, Heron, Heward, 2006) combined with environmental modifications, and safety devices should be used during the training sessions.

D. Contraindications

As stated previously, mobility is crucial for all children for a variety of reasons. Unfortunately, some children are not appropriate candidates for PM for the following reasons: limited or no cause and effect skills, limited problem solving, decreased spatial relationships, lack of motivation/initiation, significantly decreased level of alertness, uncorrectable compulsive self or other directed abusive behaviors, and sometimes lack of accessibility (if none of the possible driving environments are accessible or no accessible transportation is available at all). The access method should not be a limiting factor, as many driving methods are available.



V. Additional considerations

Every attempt should be made to enable an accessible environment to allow for PM. Most school environments and school buses are able to accommodate power wheelchairs. Clinicians and providers should work with the family to provide ideas to enhance accessibility in their home environment and vehicle at a reasonable cost.

When prescribing PM to young children, power seat functions, such as tilt, recline, seat elevation, or power standing, also need to be considered. Age of the child is not a limiting factor in the utilization of medically necessary seat functions. Independent operation of these functions is essential whenever possible, and becomes second nature to young children, as they follow their desire to experience movement in space, increase function or enhance comfort, and reduce fatigue or pain.

Summary

It is RESNA's position that early utilization of PM for the appropriate child enhances independence, improves psycho-social development, and enables children to grow to become productive and integrated members of society. Without efficient, independent mobility children may develop learned helplessness, and experience delays in both physical and cognitive domains. Mobility should be effortless and provide the child with the opportunity to attend and fulfill all daily tasks as typically expected from their non-disabled peers. Age, limited vision or cognition, difficulty of accessing controls, parental concerns, or the ability to utilize other means of mobility for very short distances should not, in and of themselves, eliminate the child as a candidate for PM.



Case examples

<u>Julian</u> is an 8 year old boy with the diagnosis of type 2 Spinal Muscular Atrophy. He has just received his second power wheelchair, as he has outgrown his previous one that he used since 3 years of age. He has been using a ventilator for 6 years. He is verbal, and has no mobility or means of changing his position outside of his power wheelchair due to profound muscle weakness. Julian drives his power wheelchair within his home, school and in the community. He has a caregiver with him at all times due to his medical needs.

Julian has significant weakness and very limited active movement. He uses a fiber optic switch at his index finger to control forward and reverse. He moves his head slightly to the left to use a proximity switch built into the headrest to control left movement of the wheelchair. As he has slight medial movement of his left leg, he uses a mechanical switch by his knee for right directional control. Another fiber optic switch is activated as Mode switch by his thumb. This allows him to switch between forward and reverse, activate his power tilt, change his speed, and to send a switch signal to an Electronic Aid to Daily Living (EADL) system to control devices in the home environment such as the television and power door opener.

The new power wheelchair allows Julian to independently navigate his environment, explore and interact with his environment, participate and interact with others for learning and socialization, control his position in space to manage comfort and reduce pressure and control devices in the environment for increased independence. Julian views himself as an independent and capable person.

<u>Jason</u> has a complete spinal cord injury at the C4 level, following transverse myelitis at 9 months of age. He crawled prior to his injury. After his illness, he was provided with a manual tilt in space wheelchair, in which he was completely dependent. At 2 1/2 years of age Jason moved to an accessible house. At the time, he was shy and did not engage other children. He was evaluated for a powered wheelchair using a head array for access. Within 3 weeks of operating a school owned powered wheelchair, Jason drove independently within his home. It is hypothesized that because Jason had experienced movement before prior to his accident, he was able to learn to drive with a head array in a short period of time. Once he received his power chair, Jason became much more outgoing. He began making interacting with his peers and now has many best friends.

<u>Kate</u> is a 5 ½ year old female with type 2 Spinal Muscular Atrophy with global weakness & poor head control. Initiation for PM began at 21 months of age and she received it at 2 ½ years of age. She drives the wheelchair using a mini joystick with her right hand. She uses it to experience her environment, bumping the footplate into a rocking chair to watch how it rocks, appearing to be running into a pine tree when really she just wants to touch it to experience the feel of the tree. At school when she was in a dependent mobility base, she had to be placed in a seat with a floor base due to another child climbing on her and her chair. It was observed that classmates treated her somewhat as a "baby". Next year when she was in her powered chair again, classmates treated her more



as one of their peers. She feels that it is punishment when she is not allowed to drive her chair.

Jorge is an 11 year old male with a diagnosis of cerebral palsy, seizure disorder, tracheostomy and s/p multiple lower extremity orthopedic surgeries. He also has cognitive delays and cortical vision impairments. He uses head posturing to use his peripheral fields to visually focus and he has impaired depth perception. In the past, he has been using a tilt-in-space manual wheelchair and has been dependent for mobility. Two years ago his school therapists reconfigured the large wheels to enable him to reach and propel himself limited distances on level surfaces. After 3 weeks of mobility in this manner, he demonstrated an improvement with his ability to self- propel within a noncrowded familiar environment, improved initiation to move himself to other people to communicate, and improved use of his functional vision. His behavior improved as well. Because he needs to transport multiple medical devices and he has poor postural control (particularly when self-propelling), he then was given the opportunity to trial a power wheelchair for a 3-week period. He demonstrated a significant improvement in his ability to maneuver the power wheelchair over this time period, and was then able to independently maneuver himself within familiar environments from classroom to classroom within his school with distant supervision. His school personnel reports that he is using his vision much more effectively and his overall compliance and motivation for other functional tasks has increased significantly since using a power wheelchair. A power wheelchair is being ordered for him for home use.

<u>Maggie</u> is a 3 year old female with Cerebral Palsy. By three years of age it was clear and acceptable for her parents that she needs to augment her mobility as ambulation is not an efficient option. She did not have enough strength, coordination and endurance to propel a manual wheelchair. Upon her first trial with the power wheelchair, Maggie was able to drive around with a joystick purposefully and in all directions within 20 minutes. Her first trip indoors was to the water fountain, where she was able to elevate herself and get a drink. Next she wanted to go outside. Upon exiting the building, she immediately took off on the grass, yelling "I'm free! Mom, I'm free".



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