

Best Practice Guidelines

BPG7: Clinical practice considerations for the use and introduction of powered mobility with children

© 4th International Interdisciplinary Conference on Posture and Wheeled Mobility

Use of this document

As a code of practice, this Best Practice Guideline (BPG) takes the form of guidance and recommendations. It should not be quoted as if it were a specification, and particular care should be taken to ensure that claims of compliance are not misleading.

Contractual and legal considerations

This publication does not purport to include all the necessary provisions of a contract. Users are responsible for its correct application.

Background

This Best Practice Guideline (BPG) document is one of a series of documents prepared in advance for discussion at the 4th International Interdisciplinary Conference on Posture and Wheeled Mobility, held in Glasgow in 2010.

An international group of therapists reviewed the RESNA position paper on The Application of Power Wheelchairs for Pediatric Users (2009) (which is still available on <http://www.resna.org/dotAsset/18249.pdf>) and came up with recommendations which were presented at the conference.

The original committee was made up of the following:

Josephine Durkin, OT, PhD, UK (Group Leader)

Anne Harris, OT, UK

Roslyn Livingstone, OT, Canada

Lisbeth Nilsson, OT, PhD, Sweden

Ginny Paleg, PT, USA

Roslyn Livingstone and Ginny Paleg went on to conduct an international consensus on best practice for paediatric powered mobility with a broader team which had

the additions of

Jacqueline Casey, OT, UK

Stephanie Chapman, OT, UK

Debra Field, OT, Canada

Jan Furumasu, ATP, USA

James Galloway, Professor, USA

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Maria Jones, PT, PhD, USA

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Tylie Stokes, OT, UK

This has resulted in a new set of Guidelines which have been published as part of an article: Livingstone R & Paleg G (2014) Practice considerations for the introduction and use of power mobility for children. *Dev Med Child Neurol* **56**: 210-221, which is available in final form at: <http://onlinelibrary.wiley.com/doi/10.1111/dmcn.12245/pdf>

The aim is that the Guidelines be updated from time to time, and comments collected here will be taken into account.

Introduction

The onset of crawling has a broad effect on children's overall development(1,2). Using a power mobility device has been shown to trigger emotional and visual-perceptual development in a similar manner(3). Children typically take

independent steps and freely explore their environment by 12-15 months of age, whereas children with physical disabilities may have limited opportunities to learn about the properties and principles of their own bodies in space. Lack of purposeful movement and a limited ability to affect the environment can result in passive, dependent behaviour (4). Power mobility allows children with physical disabilities to move around more effectively and efficiently in their environment. Children may also use other mobility aids, such as walkers and manual wheelchairs, but these are only considered functional mobility aids if the child is able to keep up and participate with their peers.

This paper aims to combine research evidence with clinical experience and has been structured around nine bolded, transferable messages (5). Evidence has been rated using American Academy of Cerebral Palsy and Developmental Medicine (AACPDM) guidelines (6) (Appendix 1), and International Classification of Functioning Disability and Health (ICF) terminology (7) is used throughout. 'Power mobility skills' describes the development of skill from the exploratory behavior of the novice through learning to control the functions of the power mobility device, to competent or proficient use in daily life. 'Competent' means ability to avoid obstacles and manoeuvre in a safe environment whereas 'proficient' means able to use judgment and focus on the activity rather than on controlling the device (8).

The field of rehabilitation is undergoing a paradigm shift from considering power mobility as a final option, reserved for older children once all other forms of mobility have been tried and found ineffective, to a therapeutic modality that can be used to support development, exploration, and participation for a wide range of infants and children with disabilities (9). Children and families may use a variety of mobility solutions depending on the environment or activity (10). While not all children will become competent or proficient power wheelchair users, clinicians should consider power mobility as an accepted intervention for all children who do not have the ability to move and explore independently. The aim of this intervention is to address the secondary effects of lack of mobility on areas of development such as socialization, cognition, visual-perception, and language.

Children's use of power mobility should be commensurate with age-appropriate and developmental expectations. An infant using a power mobility device should be in a safe environment or have adult supervision and assistance. Older children with cognitive or sensory limitations may need adult supervision or assistance in the community (as they would if able to walk) but may learn to use a power wheelchair to meet their independent mobility needs.

General considerations for all children when introducing power mobility:

1. Identify the child's postural abilities and needs for support when using the proposed device. Remember that the child will likely need more support when in a mobile system than when in a stationary seat. Postural supports should enhance the child's abilities to use their hands (or other body parts)

to activate the power mobility device (11,12).

2. Identify any limitations within the child's visual, perceptual or sensory system. Visual, perceptual or sensory limitations do not preclude consideration of power mobility, but may require an alternative approach to training, compensatory strategies and/or technology (13).
3. Consider the child's developmental level. Children functioning at around a two-year-old cognitive level may start by driving the power mobility device in circles (14), but quickly move on to attempt to drive purposefully to a toy or person and are expected to become proficient drivers in time. Some children with more complex physical, cognitive, or sensory limitations move relatively quickly from the exploratory behaviours of the novice to attempting to move to develop competent driving skills (15). Some children functioning at very early developmental levels may never move beyond the exploratory behaviours of the novice, but power mobility experience can stimulate overall development in areas such as initiation, head and hand control, visual attention, and child- directed exploration that are also important outcomes (16). Knowing the child's developmental level guides clinicians as to the most appropriate device, approach, or expectations for power mobility.

Which Children Need Power Mobility?

Four different groups of children can benefit from power mobility (17):

1. Children who will never walk
2. Children with inefficient mobility
3. Children who lose the ability to walk or to walk efficiently
4. Children who need mobility assistance in early childhood.

1. Children who will never walk and need functional mobility

Children in this group have a poor prognosis for functional mobility without use of power mobility. The group includes, but is not limited to, children with the following diagnoses: cerebral palsy (CP), Gross Motor Function Classification System (18) (GMFCS) levels IV and V; spinal muscular atrophy (SMA) types I and II, or congenital muscular dystrophy; multiple limb deficiencies or severe arthrogryposis; congenital high-level spinal cord lesions; and osteogenesis imperfecta (OI) types II, III, and VIII.

With access to a specialized power mobility device, it is possible for infants with disabilities to have augmented mobility experiences as early as 8 months of age. Evidence: Level V. (19,20).

This research challenges the lower age limit for considering power mobility. In order to limit the impact of physical disability on overall development, clinicians should consider augmenting independent mobility opportunities around the same

age as children typically begin to crawl. In these case reports, the specialized power mobility device was fitted with a supportive infant seat and could be remotely controlled by an adult to ensure safety.

Children can begin learning to manoeuvre a power mobility device below 14 months of age and those able to use a joystick have demonstrated competent control as young as 18 to 24 months. Evidence: Level II: (15) Level V. (14,21-24).

The majority of power mobility research addresses the age of successful use with most studies having focused on children using joysticks. Children who are unable to use a joystick efficiently may benefit from an assessment to identify a more appropriate access method. Children who use alternate access methods (that are more cognitively challenging than a joystick) or who have additional visual, perceptual, cognitive, or communication disabilities may require a longer time to learn power mobility skills or may require more specialized training.

For children with minimal mobility experience, a power mobility device can promote overall development as well as functional mobility. Power mobility experience appears to have a broad impact on development. The supporting evidence is divided into different domains for ease of understanding, but it should be recognized that these areas are interwoven and all emerge from and have intellectual underpinnings.

Cognition: Evidence: Level V. (20)

Receptive language: Evidence: Level II:(15) Level V. (20)

Social and play skills: Evidence: Level IV:(25,26) Level V. (27)

Independence: Evidence: Level IV. (28)

Cause-effect: Evidence: Level V. (16)

Self-initiated movement: Evidence: Level III: (29) Level IV:(30) Qualitative.(31,32)

Case example: Lisa

Lisa is a 2-year-old girl with congenital muscular dystrophy. Her joystick was modified to increase sensitivity and positioned in midline to allow her to use both hands. She became competent in power mobility skills within 6 hours and her parents felt confident that she would be able to use a power wheelchair in their home and community with age-appropriate supervision. A paediatric, ISO standard-compliant (33) power wheelchair with tilt was ordered to allow the family to transport the device in a wheelchair-accessible vehicle.

2. Children who have inefficient mobility

Children in this group have limited ability to walk or wheel a manual wheelchair, but need more effective mobility through use of power mobility for energy conservation and efficiency. This group includes, but is not limited to, children with the following diagnoses: CP (GMFCS levels III and IV, and some adolescents at level II); C6 or C7 spinal cord injuries (SCI); thoracic meningomyelocele; and OI, types IV-VII. Children with arthritis or medical conditions may also have inefficient mobility at times.

In children with a disability, walking ability peaks well before adolescence (34) and gait often worsens and requires more energy as these children age (35). Very small numbers of children with CP are able to propel manual wheelchairs efficiently (36) and power mobility may enhance participation at school, outdoors, and in the community (37). To achieve efficient mobility and meaningful participation, a child must be able to maintain the same speed (without undue effort) and access the same activities and environments as their peers.

For children with inefficient mobility, power mobility may enhance independence and facilitate participation in family, school, and community life.

Evidence: Level V (38). Qualitative (39,40). Children need an efficient means of mobility to move around the classroom and playground and to keep up with friends in the community. Using a power wheelchair can help save energy for learning and play with others. Adolescents need safe and efficient mobility choices and some, who can walk or use a manual wheelchair, also use power mobility to enhance participation in school and community life. The need for exercise should be addressed at other times and by other more effective means.

There is no evidence that using power mobility at a young age impedes development of ambulation or other motor skills. Evidence: Level II (15); Level IV (28); Level V (41). Power mobility does not appear to affect motor development negatively, and it has been suggested that children may be more motivated to use their motor skills and participate in therapy once they have experienced the independence that power mobility can provide.

Case example: Chase

Chase is a 12-year-old boy with thoracic-level meningomyelocele. He has been an efficient manual wheelchair user for a number of years and plays wheelchair basketball and sledge hockey. However, his kypho-scoliosis has progressed rapidly and Chase is experiencing chest pain when seated in an upright position for long periods.

Chase is on a waitlist for spinal instrumentation surgery and, following this, will not

be allowed to wheel for at least six months. A power wheelchair with tilt has been prescribed for use at school and outdoors, while he continues to use his manual wheelchair in the home. Following surgery, Chase will be a full time power wheelchair user for at least 6 months and long term may use power mobility outdoors and in the community to enhance participation with peers.

3. Children who lose the ability to walk, or to walk efficiently

These children may have a prognosis for increasing disability or have lost the ability to walk due to illness or injury. This group includes, but is not limited to, children with the following diagnoses: neuromuscular diseases, e.g., Duchenne muscular dystrophy, limb girdle dystrophy, type III SMA, Friedreich's ataxia; acquired brain injury (ABI), and SCI. These children have already experienced independent mobility at a young age, and therefore power mobility is used to maintain participation in family, school, and community life.

With progressive neuromuscular diseases, children can usually operate a standard joystick initially (42), and learn power mobility skills quickly (24). Children with ABI often have more complex learning needs (43). Children with high-level SCI are usually unable to access a standard joystick (44). Access options typically involve movements of the head or face, and include chin joystick, mouth switches, or joystick, sip and puff, or proximity head array. An assessment by a clinician specialised in alternate access methods for power mobility may be helpful.

Clients with muscular dystrophy gradually lose ability to use a standard joystick, but can regain independence through alternative driving methods (42). It is important to select a power wheelchair that will meet the client's needs for speed and outdoor performance, and electronics that can accommodate changing needs as well as integrating power seating functions, medical equipment (e.g. ventilator, suction, G-tube pumps), electronic aids to daily living, and computer access (45).

Case example: Nikki

Nikki was diagnosed with limb girdle dystrophy at 8 years of age. Although she was able to walk independently and to wheel a manual wheelchair, her muscle disease progressed rapidly and an indoor/outdoor power wheelchair with tilt-in-space and expandable electronics was recommended. The funder declined the expandable electronics and reluctantly agreed to include tilt.

Three years later, Nikki is completely wheelchair-dependent. She has a rapidly progressive scoliosis and uses contoured seating. She constantly uses her tilt system to change position and increase comfort. Recline and lateral tilt options are being considered to address respiratory and pain issues. Nikki is also having difficulty exerting enough pressure to operate the standard joystick. The funder will now have to pay for an expensive upgrade to the electronics in order to accommodate the provision of a more sensitive joystick and integration of seating

functions through the drive interface.

4. Children who require mobility assistance in early childhood

Children need efficient, effortless, functional mobility early in childhood, even if they will later use other means of mobility. This group includes, but is not limited to, children with the following diagnoses: arthrogryposis (surgical intervention may allow walking at older ages); lumbar-level spina bifida (ambulation and efficient manual wheelchair use may be achieved in later childhood); OI (interventions such as intra- medullary rodding may allow walking at older ages); and CP (GMFCS Level III).

Children with conditions that limit early functional mobility may benefit from power mobility to promote independence and support overall development.

Evidence: Level V. (20)

Case example: Maya

Maya is a 3-year-old girl with type IV OI. She has had intra-medullary rodding of her femurs, and professionals in her specialized clinic anticipated that she would stand and walk by this age. However she has not progressed beyond independent sitting due to frequent upper limb fractures. Maya learned to steer a power wheelchair within a few minutes' practice and a paediatric ISO standard compliant (33) power wheelchair with seat elevator was prescribed to give her a means of effortless, independent mobility, and increased access to activities in her environment. Maya's joystick was modified to allow it to be easily transferred from left to right side due to her frequent fractures, and a custom foot box was provided for protection while she develops proficiency.

Learning Power Mobility Skills

Children begin power mobility by exploring movement and learning to control direction. Gradually, they start to develop functional mobility skills. Competence in using the chair in daily life emerges first, but proficiency occurs only over time and with experience (8). Readiness assessments such as the Pediatric Power Wheelchair Screening Test have been used to identify children who will quickly and easily learn to use a joystick-operated power wheelchair. This screening is not appropriate for children with multiple and complex disabilities who may use switches or other access methods (46). Instead of focusing on readiness skills, or passing a 'driving test,' clinicians should consider augmenting mobility at an early age for children who are unlikely to walk, in order to promote overall development and help lessen the secondary effects of immobility.

Mobility experience in a power mobility device may support development

of self-initiated behaviour and learning. Evidence: Level V:(32,47) Qualitative. (31,48)

For children with delayed cognitive and physical development, use of a power mobility device may facilitate overall learning. Movement of the device provides immediate feedback, as well as vestibular and visual stimulation, when the child activates the joystick or switch. Some of these children may never develop competent use of a power mobility device, but still benefit from the independent mobility experience.

Many children with severe intellectual and/or sensory impairments can learn to use a power mobility device competently with appropriate practice and environmental support. Evidence: Level IV (28); Level V (32); Qualitative (31,48). These children may need extensive experience and training to be successful (48). Some children will always require adult supervision to ensure safety, but a power mobility device can allow spontaneous exploration in a safe environment which will promote overall development (32). For young children, learning power mobility skills is not like an adolescent with typical mobility learning to drive a car, but is similar to a child learning to walk or to use a tricycle (49). The adult needs to be a 'responsive partner' and to help elicit children's learning through play rather than interfering with their concentration by talking and directing (9). The amount and type of training will vary with the individual, their needs, deficits, motivations, and learning styles. Even those with severe visual impairment can use power mobility with adaptations, such as use of a cane or a specialized wheelchair with sensors (31).

Case example: Oliver

Oliver has dyskinetic CP (GMFCS level V). He is non-verbal, and cognitive testing is unreliable; however, he makes choices through eye gaze. Oliver has some independent mobility in a supportive gait trainer, but this can only be used indoors on smooth surfaces.

At age 6, Oliver's ability to target switches with his hands was erratic and effortful. He was loaned an old power wheelchair with a proportional head control to develop the initial skill of learning to keep his head up to activate the chair and dropping his head to stop. After 6 months of training, he tried different types of head control devices and was most successful with small mechanical switches. One was positioned behind his head with right and left turn switches by his cheeks.

After 5 years, Oliver is a proficient driver. His switches were recently changed to a proximity style and are arranged close to the back of his head. He is able to drive through doorways and in crowded corridors, showing good judgment and safety awareness. His family has a wheelchair accessible van and a new, more powerful power wheelchair has been ordered in preparation for high school.

Supporting Power Mobility Skills

Initially, parents may view power mobility negatively, but once their children have power mobility experience, most describe positive feelings related to seeing their child experiencing independence and control (28,39). Families describe power mobility as leading to increased integration and participation by their children with other children, but note that appropriate training and support are major factors in successful use (50). Aspects of the physical, social, and cultural environment can have a great influence on power mobility use, as well as personal factors such as motivation, goals, and priorities.

At this time, power wheelchairs are often large and difficult to transport. This can be a major barrier for families incorporating one into a child's life. The development of less expensive and more child- and family-friendly options, such as ride-on toy cars, may help to reduce this barrier (51). Standard power wheelchairs do not appear to facilitate reach and interaction with toys (26). Development of inexpensive, lightweight, child- and family-friendly power mobility devices to facilitate participation in home and preschool environments is needed.

To enhance power wheelchair use without contributing to problems of posture and pain, supportive seating, powered seating functions and adequate suspension are important features to consider (40). For children with progressive or severe and complex disabilities, power wheelchairs should be ordered with electronics capable of accommodating alternate access technologies, integration of powered seating functions, and control of other assistive technologies such as communication, computer, or electronic aids to daily living through the drive controls (45). These features are often needed to promote optimal participation and independence through the power wheelchair.

Clinicians may have difficulty accessing power mobility devices for extended trial and training for children who do not immediately demonstrate ability to manoeuvre and control the device safely (52). Developing relationships with wheelchair providers in order to borrow power wheelchairs for longer periods may help address this barrier. Power mobility experience can also be provided with powered toys, cars, standers, recycled, or shared wheelchairs during therapy sessions.

Successful development of power mobility skills may depend at least as much on practice time and quality of learning support within the child's environment as the child's motor, cognitive, or sensory abilities. Evidence: Level IV (28); Level V (53); Qualitative (31). To learn any new skill, all children need extensive practice.

Identifying where the child is in the learning process, providing a suitable environment (including an appropriately programmed power mobility device) and learning strategies is critical to success (47). Children who are given more time and experience using a power mobility device, and who are supported in their

learning by those around them, are more likely to be successful in developing power mobility skills.

Conclusion

Use of power mobility enhances independence and overall development in young children who do not walk (15,25,26,28). In children who have inefficient mobility or lose the ability to walk, power mobility enhances activity and participation (39,40). Without efficient, independent mobility, young children are at risk of developing passive, dependent behaviour (29) and older children are at risk of decreased participation and isolation. Mobility should be effortless and allow children and adolescents the opportunity to participate fully in age-appropriate and meaningful activities (10). All children who lack efficient independent mobility should be considered for power mobility and not excluded on the basis of age, limited vision, early developmental level, physical access limitations, or the ability to use other means of mobility for short distances.

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Appendix 1: American Academy of Cerebral Palsy & Developmental Medicine - Levels of Evidence December 2008 (5)

Appendix 2: Evidence Table for Studies Reviewed

To view appendices, please refer to the BPG 7 document [here](#)

