

International Best Practice Guidelines

BPG5: Empowering Children and Adults with Cognitive Disabilities to Learn Skills for Powered Mobility: Principles, Evidence, and Recommendations

© 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.

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1. **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.

This working group was established in January 2009 for the purposes of developing Best Practice Guidelines for power mobility for individuals with cognitive disabilities. The target audience for this BPG is clinicians, researchers, administrators of health and community care agencies, consumers and consumer organizations, and technology developers.

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

2. Purpose of this document

To present a position on children and adults with cognitive disabilities and the provision, use and learning/teaching of powered mobility based on current research and practice evidence

To stimulate discussion on this position, identify sources of agreement/disagreement, strategies for implementation, and foci for future research and development

To provide a resource for service provision, programme development, research, and technology development

3. Definitions of Terms

3.1 Cognitive disabilities - International Classification of Functioning, Disability and Health (ICF)

People with cognitive disabilities experience activity restrictions and participation limitations. The body domains related to these problems are the mental functions and the structure of the nervous system (WHO, 2006). These problems cause impairments in learning and applying knowledge, communication, mobility, interpersonal interactions, and relationships. Also environmental factors, such as products and technology and the attitudes of others, can serve to limit this population's activity and participation (Arthanat, Nochajski & Stone, 2004).

3.2 Learning/Empowering - Autonomy and quality of life

Learning powered mobility use is empowering as it provides the user with a certain amount of agency and autonomy, which in turn increases the user's quality of life (Tengland, 2007). The role of the professional is to create an environment, a climate, or a situation that encourages and enables the user to take some responsibility and control in the learning situation (Tengland, 2008). (A professional may support family members and other caregivers in participating in this role as well.) A learning situation that is user friendly, playful and fun, and provides

just the right challenge fosters the users' capabilities to act as agents of their own intentions (Yerxa, 2000).

3.3 Powered mobility skills

When a user is able to drive goal-directedly with responsibility to others and the environment, a certain set of skills has developed. The context where the powered device is to be used sets up the requirement of driving skills. Indoor driving in a sheltered area requires fewer skills than outdoor driving in city traffic.

3.4 Powered wheelchair technology

This technology includes different products designed to promote motorized mobility. It can be standard powered wheelchairs or powered wheelchairs with features to assist the user's driving, or assist the learning of powered mobility use.

4. Issues Related to Powered Mobility Use and People with Cognitive Disabilities

Mobility is an integral part of being active and able to participate in society: it is important to consider this possibility for people with cognitive disabilities.

The skill of goal-directed driving may take a lot of indoor practice to achieve. Mobility independence may mean being autonomously mobile with supervision. Safety reasons often hinder provision of mobility devices to people with cognitive disabilities.

Context influences possibilities to balance benefits and risks, insecurity and safety.

Cultural differences and attitudes as well as different rules regarding provision of assistive technology influence the prospects of this population to get access to powered mobility.

5. Principles of Powered Mobility Provision and Use

The goal of using powered mobility is to assist the user's development, learning, and recovery, and to enhance the user's autonomy and independence, balancing risks and safety issues.

Provision should be guided by the user's needs of learning, empowerment, and engagement in activities and participation.

Service provision is from a user-led perspective and embraces the Social Model of Disability, which means a willingness to transfer power from the provider to the user. This requires the provider to stay open-minded, supportive, and keep up

a positive attitude to a user's potential to develop and learn despite limited abilities.

A developmental learning continuum is encouraged which does not discriminate against users on the grounds of age or cognitive ability.

The learning and driving process is viewed as beneficial in its own right and is not automatically connected to criteria for provision of equipment and technology, and of (rehabilitation) services. The powered mobility device is viewed as a valuable tool for understanding mobility and cognitive processes, for learning new skills, maintaining existing skills, or stimulating latent skills.

The existence of skills defined as 'prerequisite' are viewed as irrelevant, and the learning and driving process will help with development/maintenance/stimulation of capabilities or skills.

6. Survey of Research and Evidence-Based Statements

6.1 Movement and powered mobility

Movement in and of itself is a primary vehicle for learning. Sensory processing; body, spatial, and environmental concepts; and fine and gross motor skills develop through self-initiated movement, as do higher cognitive skills such as predicting and problem solving (Bai & Berthenthal, 1992; Held & Hein, 1963). Several studies have found that lack of self-produced mobility has a significant, negative effect on cognitive, perceptual, and/or motor development (Brinker & Lewis, 1982; Verburg, 1987).

"Mobility is essential for exploratory behavior and so, where possible, aids should be provided so that the child can choose where he goes thereby directing his activity and obtaining perception/proprioception rather than receiving it passively" (Lewis, 1978)

Benefits of powered mobility include: improved visual skills, improved posture (head and trunk control), increased attention, improved motivation and interaction, and an increased desire to communicate.

"The child was more curious and exploratory", "her increased activity and heightened curiosity was dramatic", "his whole understanding of his surroundings has changed; he is getting into everything" (Butler, 1986; Butler, Okamoto & McKay, 1983, 1984).

"A powered wheelchair has the potential to effectively enable human performance and significantly enhance a person's participation in valued life roles", "Many skills previously considered 'prerequisite skills' for powered mobility are actually developmental achievements occurring as a consequence of mobility"

(Hardy, 2004).

“Children grow in their powered mobility skills and this growth has to be viewed in the context of their developmental skills in play, group processes and emotional development”.

“Observations showed that freedom to move and express feelings in a play ‘pretend’ situation can release unresolved issues in how a child begins to understand the realities of their own disability” (Durkin, 2009).

6.2 Assessment and prerequisite skills

If children need to demonstrate prerequisite cognitive and physical skills in order to receive a powered wheelchair, and if these skills are usually developed with mobility, then many children who could benefit from a means of independent mobility may not qualify for a powered wheelchair (Kermoian, 1997 as quoted by Seiberlich).

“Identifying readiness for the learning of a new task within a child cannot be determined through pre-defined criteria and is not a beneficial approach to use with disabled children” (Law, et al., 1998).

“The clinical applications of the criterion-based assessment cannot be generalised to children with severe physical, cognitive and/or sensorimotor limitations” (Guerette, Tefft, Furumasu, & Moy, 1999).

Research indicates that *Cause and Effect* and *Object Permanence* are not significant predictors of powered wheelchair driving performance.

The powered wheelchair is a better *strategy* for teaching cause and effect than is use of a single switch (Nilsson & Nyberg, 1999). Nilsson & Nyberg found that cause- effect from a proportional joystick to affect the motion of a powered wheelchair developed earlier than the understanding of cause-effect learned from single switch control of a toy or apparatus. With individuals who function at any early cognitive developmental level, tools such as a powered wheelchair, which has an effect on all the individual's senses, provides the level of arousal, interest, and motivation for further learning that a computer or toy cannot (Nilsson & Nyberg, 1999).

Even individuals who have profoundly impaired cognition can benefit from a powered mobility aid regardless of their physical, sensory, or learning disabilities.

“As the children participating in the study became more alert and attentive, they became more receptive to external stimulation and interaction.” “As the children developed a use of their arms and hands, even if only in a very limited range, they enhanced their prospects of developing an understanding of very simple causal

relationships". (Nilsson & Nyberg, 2003).

People with profoundly impaired cognition may benefit from sensory, cognitive, and social stimulation offered by powered mobility use and even reach the skill of goal- directed driving.

"The 45 users with profound cognitive disabilities who practised in a joystick-operated powered wheelchair could all, to some extent benefit from powered mobility use." "Eight individuals from pre-school age to middle age reached a level of goal-directed but unskilled driving or higher." (Nilsson, 2007).

"The need remains for a frame of reference that takes into account the many factors that can influence a person's performance in a powered wheelchair, including: elements of the environment; attitudes of others, resources; training; and access to equipment." (Hardy, 2004).

6.3 Learning powered mobility skills

No access to practise, or failure to achieve necessary skills is often the result of external criteria implemented to restrict access to powered mobility (e.g. funding based on medical necessity as defined by policy makers, or if users are unable to use powered mobility devices independently or without supervision), and criteria that prioritize the protection of the safety of others (e.g. for people living in institutions).

Often the goals of the therapist or teacher are at another level than the user – child or adult.

"The children in this study revealed the incongruity of adults' actions and thinking processes in the field of powered mobility provision compared to their own" (Durkin 2009).

Most potential users with multiple and complex disabilities fail because of external (social, cultural, or institutional) expectations or attitudes about powered mobility use.

"Clinicians need to address the children's cognition and ways of learning before they are potentially led astray into believing that provision of powered mobility hardware is the total answer. Provision of hardware is the medical model answer to overcoming the children's problem and clinicians who take this narrow stance are merely carrying through a technical interpretation of the children learning to use a machine to replace their legs for mobility. Powered mobility should be developed with the children, as play, taking into account what the children want to do, with the clinician taking a broader psychological interpretation of meeting the children's overall developmental learning needs" (Durkin, 2006).

This statement counts for people of all ages: children as well as adults. Practising a new skill is based on motivation: thus, to result in development and learning, it has to be experienced as fun and worthwhile.

“Motivation provided joyfulness, belief in possibilities, positive expectations and eagerness to act and respond” “attainment of growth or de-plateauing required motivation, endurance, responsiveness, adaptability and resources with high predictability and usability” (Nilsson, 2007).

As a therapist or teacher it is important to understand the learning process to be able to facilitate progress in an appropriate and optimal way.

“Central to the processes of learning is the ability to understand how children develop important competencies” (Bransford et al, 2000).

“At this point eight stringently separate phases of the process (of growing consciousness of joystick-use) have been distinguished” (Nilsson, 2007).

“Three stages of learning set in context to levels of attention and model of skill acquisition” (Durkin, 2009).

6.4 Cognitive disabilities and the learning process

Learning powered mobility use requires a certain amount of cognitive abilities depending on where the driving is to take place. Cognitive disabilities present differently depending on the background to the disabilities and age. Both children and adults may experience either increasing abilities or decreasing abilities.

Independent of these well-known facts, users have their own learning curve throughout the process of growing consciousness of how the powered mobility device works and how it can be utilized in different environments (Nilsson, 2007).

Some users will reach the typical goal of secure and safe independent mobility. Some users will reach steering level, but need supervision.

Some users who do not reach steering level are empowered by learning agency and tool use, thereby achieving a higher level of independence.

Some users who cannot steer the mobility aid or achieve goal-directed mobility will still benefit and enjoy the experience of self-directed movement.

Some users may develop in unexpectedly positive ways, as it is always difficult to predict how far each user can reach in the learning process.

Some users with a deteriorating condition may keep up their abilities for longer

when practising a learning task involving mobility.

Notably, a powered wheelchair may be considered as a therapeutic tool in its own right, and not just a vehicle to enable movement from one place to the next (Nilsson & Nyberg, 1999).

Almost every user can learn more about powered mobility use than can be predicted beforehand. Thus it is dependent on rules and restrictions, motivation, engagement, and access to predictable and usable resources if people with cognitive disabilities are provided with the opportunity to practise powered mobility use.

7. Position on ‘Independent Mobility’ and Safety Supervision

Typically the goal set for practising powered mobility is to become independently mobile. This is a debatable goal with regard to small children and people with cognitive disabilities. If they are usually supervised on an everyday basis, they should be so when using a powered mobility device. This need for supervision should not cause exclusion from the possibility to be provided with powered mobility. With references to the benefits of mobility – development of a sense of agency and exploratory, goal-oriented, purposeful activity – it is of utmost importance for the user to become the agent of his/her own mobility even if supervised.

Familiar indoor environments may require a different level of safety supervision than outside or unfamiliar environments. Environmental variables such as steps, curbs, or other pedestrian or vehicular traffic will be considerations.

The fact that a user may always need some level of safety supervision does not automatically exempt them from research driven practices that would increase independence and provide access to the environment. A hierarchy model of safety supervision levels from most dependent to independent is as follows:

Hands on, physical contact

Within arm’s reach

Within verbal communication distance

Within line of sight

Periodic checking

Obstacle sensors and safety technology may reduce the level of supervision required, but do not remove the need for supervision. For example, a user driving using track-following technology may require ‘line of sight’ supervision. When

driving off the track they may require 'within arm's reach' supervision.

8. Learning and the Role of Technology

Further research related to learning and the application of technology is needed to understand better the timing and benefits/disadvantages of technology introduction in the learning process or use of technology as a compensatory strategy.

Work carried out by Durkin & Nilsson (in preparation) on their modification and expansion of an assessment tool for powered mobility use identified that the user has to reach a phase in the learning process where the idea of goal-directed driving is born, before any considerations of compensatory equipment should be made. This would mean that the user has developed an understanding of the possibility to steer and is showing intentions to explore beyond what is within arm's reach. Durkin identified in her observations of typically developing children that there was a period of learning in 'how to operate the machine' where the children's attention was totally held and input from another source distracted them (Durkin 2006).

Evidence from use of the CALL Smart Wheelchair with its compensatory features (e.g. collision sensing and track following, etc) has demonstrated that they can help the user to achieve an understanding of goal-directed driving (Odor & Watson, 1994).

Sensor-based technology to protect from collisions may offer opportunities for mobility to users who cannot drive due to physical, sensory, or cognitive disabilities. However, we must consider the possibility that such tools may actually prevent the user developing the skills for powered mobility. For example, technology that prevents the user from bumping into walls and objects could be disallowing the user a key learning experience in how to judge distances, gain awareness of their bodies within the equipment, and receive feedback from the impact felt when hitting hard and soft objects. It is not known if these experiences are part of the learning which needs to be acquired in order to achieve mastery in the task of independent powered mobility (Durkin, 2002).

Typically developed infants can use a joystick to explore and experiment with powered mobility use (Nilsson and Nyberg, 1999). Learning powered mobility use is easiest done with a joystick (Nilsson and Nyberg, 1999) if physical capabilities allow. Consideration and clear clinical reasoning needs to be employed to ensure the user is provided with the most effective tool for accessing the powered wheelchair. For some individuals this may be through the use of joysticks, switches, or combinations of input methods.

8.1 Powered mobility technology

Technology may play various roles in empowering children and adults with cognitive disabilities to learn powered mobility skills. Technology may include: modifications or features added to existing powered wheelchairs, new systems integrated into the controls or functions of the powered wheelchairs, or other systems that are separate from the powered wheelchair. Modified or 'smart' powered wheelchairs and wheelchair simulators are prominent approaches that may augment skills learning or use of power mobility.

Aims for power mobility technology use have been cited to:

encourage and motivate exploration and learning (Harrison, Derwent, Enticknap, Rose, & Attree, 2002; Nilsson & Nyberg, 1999; Nisbet, 2002a; Pithon, Weiss, Richir, & Klinger, 2009)

support skills development and learning (Nisbet, Craig, Odor, & Aitken, 1996; Pithon, et al., 2009)

assess and customize technology to individual needs during learning (Pithon, et al., 2009)

develop skills before driving in real environments with safety hazards (Harrison, et al., 2002; Pithon, et al., 2009; Spaeth, et al., 2008)

improve safety and access to diverse environments (Nisbet, et al., 1996)

assess skills and provide targeted feedback to improve performance (Cooper, et al., 2005)

decrease users' physical effort or struggle while driving (Langner, 2000; Nisbet, et al., 1996)

give more people with cognitive disabilities access to powered mobility (one-for-all) (Nilsson & Eklund, 2006)

enable practice and learning with feedback without the ongoing presence of a clinician (Cooper, et al., 2005)

8.2 Modified or 'smart' powered wheelchairs

Powered wheelchairs can include modifications to the controller to incorporate different input methods, modified control operations, and feedback outputs; sensors (contact or proximity) with control systems that respond in a variety of ways to detected obstacles; and operation modes that offer varying degrees of driver autonomy. In some cases the technology may be applied to the user's existing mobility device.

The CALL Smart Wheelchair was tested with 13 children with severe physical and cognitive disabilities. While benefits ranged greatly between the children, improvements in mobility, exploration, learning, play, communication, socialization, posture, and physical skills were noted (Odor & Watson, 1994). Some of the children went on to use conventional powered wheelchairs while others continued to use the Smart Wheelchair with its augmentative driving features.

CALL Smart Wheelchair and Smart Platform, Smile Rehab Ltd, UK <http://www.smilerehab.com/> and <http://www.callscotland.org.uk/Projects/Smart-Wheelchair/> (Nisbet, et al., 1996; Nisbet, 2002a, 2002b; Odor & Watson, 1994)

C300TS – The learning tool, formerly Entra Tiro, is a one-for-all powered wheelchair developed especially for training with people with different degrees of cognitive disabilities using the Driving to Learn™ method. The method was developed by Nilsson, 2003, 2006, 2007 and refined by Nilsson & Durkin (in preparation). The Driving to Learn project (1993-2006) involved 109 individuals with cognitive disabilities from profound to mild degrees, and 17 typically developed infants 3-12 months old. The outcome showed that individuals with profound degrees of disabilities could also reach steering control even if they needed a high number of sessions over a long period of time (Nilsson, 2007).

C300TS – The learning tool, formerly Entra Tiro, Permobil, Sweden http://www.lisbethnilsson.se/entratiro_eng.htm (Nilsson, 2007; Nilsson & Eklund, 2006; Nilsson & Nyberg, 2003)

Other modified powered wheelchair resources: "Smart Wheelchairs: A literature review (Simpson, 2005)

SCAD (Sensing Collision Avoidance Detector) Assistive Mobility System <http://www.chs.org.uk/what-we-do/research-and-design/scad-system> (Langner, 1996; Langner, 2000)

UD1/UD2 <http://www.udel.edu/udaily/2010/aug/mobility080309.html> (Galloway, Ryu, & Agrawal, 2008; Lynch, Ryu, Agrawal, & Galloway, 2009)

8.3 Powered wheelchair simulators

Powered wheelchair simulators typically include a 2 or 3D virtual reality environment on a display and a user interface, usually a joystick. Increasingly complex simulators may include a powered wheelchair on a motion platform with other multisensory stimuli that may be presented to increase the realism of the simulation.

In a review of the application of virtual reality technology to various areas of motor

rehabilitation, Holden concludes that individuals with disabilities appear to be able to learn in virtual environments and in some cases transfer learning to similar real life situations (Holden, 2005). Evidence that powered wheelchair control skills may be learned and transferred from virtual to real powered wheelchair environments is currently limited.

The use of a computer simulator is better than an alternative of nothing at all but is not a reliable indicator of a child's ability to drive a powered wheelchair (Hasdai, Jessel, & Weiss, 1998).

One study that included adults with different neurological impairments and virtual environments to train users in powered wheelchair maneuverability and route-finding showed mixed, but encouraging, results as some participants showed improvement in the real life tasks (Harrison et al., 2002). The authors recommended several improvements to the controller interface, user movement in the virtual environment, and feedback strategies.

Another study reported two case studies (both participants with cerebral palsy, and severe or moderate motor and learning disabilities) demonstrating the potential of carry over of skills learned in a virtual environment to real life driving tasks including driving straight, turning, and avoiding a static obstacle (Adelola, Cox & Rahman, 2009).

Currently there is very little research that is published to show the feasibility of virtual reality technology in the training of powered wheelchair use (Spaeth, et al., 2008).

Further research and development, for example in mechanical systems, creating more realistic wheelchair behaviour models, and evaluating the ability of virtual reality training to carry over to real world powered wheelchair use (Pithon, et al., 2009) is necessary before it may be recommended for clinical use.

9. Recommendations for Empowering Children and Adults with Cognitive Disabilities to Learn Skills for Powered Mobility

9.1 Goals for practicing powered mobility use

There may be many goals for providing people with cognitive disabilities with opportunities to practise powered mobility use:

To learn the skills needed for independent powered mobility

To learn how to use an adapted powered wheelchair independently

To learn goal-directed steering and do it under supervision

To develop an understanding of tool use

To develop autonomy in play skills and to have fun

To enable children to develop their emotions through movement

To enable children to connect movements with language

To develop a sense for cause and effect relationships

To give an opportunity to interact with the environment and with others.

9.2 Recommendations for empowering learning - 'How to strategies'

The principles for empowering learning are strongly influenced by the research of Durkin and Nilsson. They have both presented dissertations on the topic of people with multiple and complex disabilities learning powered mobility use (Durkin, 2006; Nilsson, 2007). They also worked together in 2009 to fuse and expand their evidence-based knowledge.

9.3 General guidelines

Adopt the role of the 'responsive partner' in learning (Durkin 2009)

Nourish the user's ability to use the powered wheelchair (Nilsson, 2007, 2009; Svensson & Nilsson, 2009)

Assess the user's actual phase of powered mobility use (Nilsson, 2007; Durkin & Nilsson, in preparation)

Provide the user with the just right challenge for their level in the learning process (Yerxa, 2000; Durkin & Nilsson, in preparation)

Practise indoors in a safe and framed environment (not a big exercise room or gymnasium) until the user understands the function of the powered mobility device (Nilsson & Eklund, 2006)

9.4 Specific guidelines

Use dialogue pedagogy, encourage and facilitate the user's own initiatives.

Let the user explore the powered wheelchair and operation of the device at his/her pace. Early in the learning process the user's exploration typically is focused on details of the powered wheelchair and details of its function.

Interchange with manual guidance to show how the powered wheelchair can be

used.

Describe the user's actions and what is happening "grab; hold on; push; pull", "you are going; you stopped".

Allow 'safe' collisions as they provide the user with relational information on how big the powered wheelchair is and when to stop to avoid cruising into things.

Encourage the user's initiative to act, explore, and experiment. Avoid being directive.

Reinforce the user to experience and sustain the enjoyable and motivating movement of the powered wheelchair and facilitate exploration of the environment.

Let the user explore the environment in progressively difficult situations.

Let the navigation be a natural part of the user's exploration of the environment. Encourage exploration by asking questions "where would you like to drive?" "In which direction?" and so on.

Discuss possible dangers and consequences before driving in busy locations and environments "what could happen if..?" "What should you think of..?"

Practise outdoors first when the user is able to drive goal-directed.

Consider energy saving adaptive technologies when the user shows the understanding that the powered wheelchair can be used to reach a desired goal

10. Additional Resources

RESNA Position on the Application of Power Wheelchairs for Pediatric Users

http://www.rstce.pitt.edu/RSTCE_Resources/Resna_position_on_Peds_wheelchair_Users.pdf

Sunny Hill Health Centre – Seating and Mobility http://www.seatingandmobility.ca/pm_evidence.aspx

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