Providing power and mobility to toddlers around the world

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Conflict of Interest

• All four presenters report no conflict of interest.
  • Elisabet and Jackie funded by research money to attend.
  • Roslyn funded by her employer to attend.
  • Ginny funded by a local manufacturer to attend but is not employed by that company.
Photographs and Videos

**NB.**

The *photographs and videos* have been removed from this copy of our presentation to protect the children/families.

Permission has been given explicitly to the presenters for use during this presentation and by the presenters only.
Outline

• Who benefits from power mobility?
• What are the benefits of using power mobility at a young age?
• What is the child and family perspective on power mobility?
• Experiences and practice around the world
Objectives

• Describe at least four benefits for children using power mobility in the preschool years.

• Describe at least three different groups of children who can benefit from early introduction of power mobility.

• Compare and contrast the challenges and approaches used to support introduction of power mobility in at least three different countries and clinical settings.
References


Who needs power?

- Children who will never walk
- Children with inefficient mobility
- Children who need mobility assistance in early childhood
- Children who lose mobility

Children who will never walk

- Cerebral Palsy
  GMFCS IV and V
- SMA type I and II
- Limb deficiencies
- Arthrogryposis
- Spinal Cord Injury
- Osteogenesis Imperfecta types II, III and VIII
Children with inefficient mobility
(who ambulate or use a manual mobility device)

- Cerebral Palsy
  - GMFCS III and IV
- Spinal Cord Injury C6/7
- Meningomyelocele
  - thoracic level
- Osteogenesis Imperfecta
  - type IV-VII
Children who need mobility assistance in early childhood

- Arthrogryposis
- Meningomyelocele lumbar level
- Osteogenesis Imperfecta
- Down Syndrome
- Arthritis or other medical conditions affecting mobility at times
Children who lose the ability to walk, or to walk efficiently

- Neuromuscular diseases e.g. Duchenne muscular dystrophy, Limb girdle dystrophy, SMA III
- Acquired brain injury
- Spinal Cord Injury
Transferable Message

- 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.
Children can begin learning to maneuver 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.

Level II
- Jones et al., 2012

Level V
- Butler et al., 1983 and 1984
- Everard, 1984
- Jones et al., 2003
- Dunaway et al., 2012
Positive impact on development

Level II – RCT Jones et al., 2012

- Increased receptive language
- Increased overall development
- Increased functional mobility
- Decreased need for caregiver assistance
- No negative impact on motor development

28 children (GMFCS IV or V) 14.8 to 30 months
ICF and Power Mobility

Health Condition

Body Structure and Functioning (motor impairment)

Activity (mobility limitation)

Participation (participation restriction)

Environmental Factors

Personal Factors

(WHO, 2001)
Body Structure and Function

- **Cognition**
  - Level II - Jones et al., 2012
  - Level V - Lynch et al., 2009

- **Receptive language**
  - Level II - Jones et al., 2012
  - Level V - Lynch et al., 2009

- **Alertness and motivation**
  - Nilsson & Nyberg, 2003

- **Sleep/wake cycle**
  - Level IV - Tefft et al., 2011
Child and Family Experience

- Power mobility experience promotes developmental change and independent mobility
  - Psychological, emotional and behavioural development
  - Independence and freedom
  - Power mobility skills continuum of development
  - Self-initiated communication and motor development

- Berry et al 1996; Durkin 2009; Evans et al 2007; Gudgeon & Kirk 2013; May & Rugg 2010; Nilsson et al 2003; Wiart et al. 2004
Transferable Message

- For children with minimal mobility experience, a power mobility device can promote overall development as well as functional mobility
Activity

• Independence
  Level IV - Bottos et al., 2001
  Level V - Douglas & Ryan, 1987

• Self-initiated movement
  Level III - Butler, 1986
  Level IV - Deitz et al., 2002

• Cause-effect
  Qualitative -
    Nilsson & Nyberg, 2003
    McGarry et al 2012
Transferable Message

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

- There is no evidence that using power mobility at a young age impedes development of ambulation or other motor skills

Level II - Jones et al., 2012  Level IV - Bottos et al., 2001
Child and Family Experience

- Power mobility enhances social relationships and engagement in meaningful life experiences
  - Enhances ability to play
  - Enhances peer relationships
  - Increases participation

• Berry et al 1996; Evans et al 2007; Gudgeon & Kirk 2013; Huang et al 2009; May & Rugg 2010; Wiart et al 2004
Participation

• Social and play skills
  • Level IV - Tefft et al., 2011
    Guerette et al., 2013
  • Level V - Ragonesi et al., 2010
    Ragonesi et al., 2011

• Personal-social and communication
  • Level V - Jones et al., 2003

• Peer relationships
  • Level V - Everard, 1984
Transferable Message

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

Qualitative - Wiart et al., 2004
Transferable Messages

- Mobility experience in a power mobility device may support development of self-initiated behaviour and learning.

- Many children with severe intellectual and/or sensory impairments can learn to use a power mobility device competently with appropriate practice and environmental support.
Environmental factors (physical, social, attitudinal)

- Parent views Bottos et al., 2001
- Therapist views Wiart & Darrah, 2002
- More ‘normal’ peer relationships Everard, 1984
- Public acceptance Tefft et al., 2011
- Attitude change from “isn’t that a shame” to “isn’t she clever” Everard, 1984
Child and family experience

• Power mobility access and use is influenced by factors in the physical, social and attitudinal environment
  – Environmental and transportation barriers/facilitators
  – PWC features
  – Other’s attitudes
  – Service delivery

• Berry et al 1996; Durkin 2009; Evans et al 2007; Frank et al 2010; Gudgeon & Kirk 2013; Huang et al 2009; Skar 2002; Wiart et al 2004
Transferable Message

- Successful development of power mobility skills may depend at least as much on practise time and quality of learning support within the child’s environment as the child’s motor, cognitive or sensory abilities

Level IV - Bottos et al., 2001
Level V - Nilsson et al., 2010
Qualitative - Nilsson et al., 2011
Can or Does?

• Environmental factors
  – Physical, social, attitudes
  – Influence of parents

• Personal factors
  – Choice, motivation, acceptance

• Body functions

(Holsbeeke 2009)
Wheelchairs in Children with CP

Wheelchair indoors 29%

- No wheelchair: 324
- Manual: 172
- Man + Pow: 47
- Powered: 9

Wheelchair outdoors 41%

- No wheelchair: 391
- Manual: 130
- Man + Pow: 33
- Powered: 2

Rodby-Bousquet 2010
Use of Wheelchairs

• In every 4 children who use a wheelchair, 3 use a manual wheelchair and 1 uses a power wheelchair.

• Of those who use manual wheelchairs, only 1 in 7 children can self-propel;

• Whilst of those children who use power wheelchairs, 6 in 7 can self drive (Rodby-Bousquet 2010).
Difference

• Powered wheelchair increases independent mobility

• Manual wheelchair facilitates care
Instability

- 89% unstable in MWC
- 61% unstable in PWC
- 41% difficulties propelling due to instability (CP 8-18 yrs)

- Instability affects arm function

(Lacoste 2009)
• Instability Restricts Function

• Stability Improves Function
Stability and Attention

Interaction Between Executive Attention and Postural Control in Dual-Task Conditions

“Children with spastic CP are significantly more unstable compared with typically developing children, in the dual-task condition”

Reilly 2008
Manual Ability  MACS III-V

- 80% dyskinetic CP
- 41% ataxic
- 39% spastic bilateral CP
Power Wheelchairs

• Require more space
• Heavier (transports, cars, stairs)
• Require training
• Security
• More expensive
ASSESSMENT TOOLS
WHAT SHALL WE MEASURE?

So many things we can measure.
Need to know what we are measuring and why.
Select the appropriate tools.

Before child able to operate/drive their wheelchair they must be seated stably.
# Posture and Postural Ability Scale

<table>
<thead>
<tr>
<th>Quality, frontal (score 1=yes, 0=no)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Head midline</td>
</tr>
<tr>
<td>Trunk symmetrical</td>
</tr>
<tr>
<td>Pelvis neutral</td>
</tr>
<tr>
<td>Legs separated and straight relative to pelvis</td>
</tr>
<tr>
<td>Arms resting by side</td>
</tr>
<tr>
<td>Weight evenly distributed</td>
</tr>
<tr>
<td><strong>Total score</strong></td>
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Posture and Postural Ability Scale

1. Unplaceable in an aligned posture
2. Placeable with support
3. Able to maintain position but cannot move
4. Able to initiate flexion/extension of trunk
5. Able to transfer weight laterally
6. Able to move out of position
7. Able to move into and out of position
Current Wheelchair Skills Outcome Measures

- Wheelchair Skills Test version 4.2.3 (WST)
- Powered Mobility Program (PMP)
- Functioning Everyday with a Wheelchair (FEW)
- Functional Mobility Assessment Questionnaire (FMA)
- Assessment Learning Powered Mobility (ALP)
- Electrically Powered Indoor/Outdoor Chair assessment (EPIOC)
Wheelchair Skills Test (WST) version 4.2.3

- Evaluates how safe and effective the wch user is in clinic/home
- 3 skills levels – basic, community, advanced
- Gives information on what skills the wch user has difficulty performing.
- Gives a treatment focus;
- Identifies level of safety in the community
Wheelchair Skills Test contd.

• Version for manual; power wheelchair users; caregivers; scooters.
• Wheelchair user version – 32 items
• Capacity score obtained 0-2 (pass, pass with difficulty, fail, not possible, testing error)
• Then has a training programme (WSP) available with AV demonstrations
Functioning Everyday with a Wheelchair (FEW)

(Mills, Holm & Schmeler 2007)

- www.few.pitt.edu
- Questionnaire format

- 10 items
  - Stability, durability, dependability
  - Comfort needs
  - Health needs
  - Operate
  - Reach
  - Transfers
  - Personal care
  - Indoor mobility
  - Outdoor mobility
  - Transportation
Functional Mobility Assessment (FMA) Questionnaire

(Kumar A et al, 2012)

• Similar to FEW – same items
• Self-report of individual’s ability to complete functional activities when in their wheelchair (eg. Reaching, transferring objects, personal/public transport, comfort,).
• Measures difficulty and independence, as well as frequency & ease of participation.
• Likert scale for scoring – (1-7)
• Comments also recorded
• Use with all types of mobility devices
Powered Mobility Program (PMP)  
(Furumasu et al, 1996)

• Grades the amount of assistance (0-5 from task not attempted to age appropriate supervision)

• Measures skills for
  • functional mobility
  • directional control
  • speed control
  • negotiating a ramp
  • negotiating a sidewalk
  • community mobility
Assessment of Learning Powered mobility use (ALP)

(Durkin & Nilsson 2010)

• Really exciting tool that can be used in assessment and treatment;
• And with children with a wide range of abilities/disabilities.
# Assessment Tool

- **ALP** – Assessment of Learning Powered Mobility

## The ALP-instrument – Assessment of Learning Powered mobility use, version 2.0

<table>
<thead>
<tr>
<th>Attention</th>
<th>Activity &amp; Movement</th>
<th>Understanding of tool use</th>
<th>Expressions &amp; Emotions</th>
<th>Interaction &amp; Communication</th>
<th>STAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Two-channeled attention</td>
<td>Sequences of chains of acts</td>
<td>Idea of Competent Use is Born</td>
<td>Eager</td>
<td>Reciprocated interaction</td>
<td>Explore</td>
</tr>
<tr>
<td>Active, concentrated</td>
<td>Intentional more eager or violent movements</td>
<td>Conscious of the ability to cause many</td>
<td>Smile</td>
<td>Directs attention by pointing to convey a message</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Exploring the machine</td>
<td>different effects, motion in different</td>
<td>Serious</td>
<td>that requires the playmate to respond</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Experimenting with steering by</td>
<td>directions. Searching the steering</td>
<td></td>
<td>Triadic Interaction</td>
<td></td>
</tr>
<tr>
<td></td>
<td>composing effects in different patterns.</td>
<td>pattern.</td>
<td></td>
<td>Interaction with a person on a third part – a</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Experimenting to find the pattern of the</td>
<td>Understands the use of electronic</td>
<td></td>
<td>person, an object or something else in the</td>
<td></td>
</tr>
<tr>
<td></td>
<td>tool.</td>
<td>mobility guidance systems</td>
<td></td>
<td>environment</td>
<td></td>
</tr>
</tbody>
</table>

5 Sophisticated beginner

- **Difficult transition – focus on**
EPIOC – N.Ireland

- Each Trust has an approved route.

- Belfast HSCT test contains 25 categories – based on obstacles and manoeuvres the user must face along the training and test route.

- Each factor has a risk factor of low, medium, or high.

- Pass/Fail test

- Scored /500 points

- Assessor is certified EPIOC trainer/ tester
• This tiny robot is ringed with sensors that can determine the obstacle-free roaming space, and will either allow infants to bump obstacles or will take control from the infant and drive around the obstacle itself.

Turtle Trainer

- Mark I. Bresler
- Assistive Technology Specialist
- Langhorne, PA 19047
- (215) 750-4112
- mbresler@woods.org

No longer available....
LISA KENYON, MICHIGAN

- Power Mobility Training Tool (PMTT)
- Car Seat (no seating adjustments...)


- A large base to place current seating system on (like Bresler’s Turtle Trainer)
Christy Byers, PT
CCS Buena Park, California
Enabling devices scooter $650

- Zero tolerance for poor positioning
- Demand stability
- How do you know if this can be successful without consistent posture?
Wizzy Bug - $2,500 deposit in UK

http://www.designability.org.uk/product/wizzybug/
Adapt a toy car

- GoBabyGo (UDelware and Cole Galloway)
- About $300
- You void the manufacturers warranty
- Single switch only – no real way to steer
- No speed adjustment (rough start and stop)
- You need skills to build and modify
- Hard to adjust seating and switch placement for multiple users
- Great for one family
Lil' Rider Space Rover Ride On Battery Operated Car $70-100

- Drive with ears
- Has parent remote
- Has laterals, but may need to enhance seating
- 70lb weight limit
- Seat to Go from Firefly (Leckey) fits in!
OTHER CARS?

A big car with lots of room for seating, high weight capacity, a foot pedal and parent remote!
Beg, Borrow, Steal

- Find a used adult or pediatric chair
- Add seating
- Add stable appropriate switches
Other Options...

• Remember to consider all other mobility options too, for example, power walkers/gait trainers.
Summary

- Most power mobility research evidence is descriptive only 1 level II and 1 level III study.
- Expert consensus capable of generating Level III evidence (Johnston & Dijkers 2012).
- Power mobility can be reasonably supported as an appropriate and effective intervention for children who lack efficient independent mobility.
- It should be considered for all children lacking independent mobility from around 12 months.
- Power mobility experience is beneficial for children who will never become independent drivers and for children who only need mobility assistance in early childhood.
IDEA 2004 requires IEP teams to consider the assistive technology needs of all children with disabilities. (20 U.S.C. 1414(d)(3)(B)(v))

The IEP team makes decisions about assistive technology devices and services based on the child’s unique needs so that he/she can be more confident and independent. The law requires schools to use assistive technology devices and services "to maximize accessibility for children with disabilities." (20 U.S.C. 1400(c)(5)(H))

If the IEP team determines that a child needs assistive technology devices and services, the school district is responsible for providing these and cannot use lack of availability or cost as an excuse.
IDEA defines an 'assistive technology device' as any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of a child with a disability. (20 U.S.C. 1401(1))

IDEA defines an 'assistive technology service' as any service that directly assists a child with a disability in the selection, acquisition, or use of an assistive technology device. Such term includes - (A) the evaluation, (B) purchasing, leasing, or otherwise providing for the acquisition of assistive technology devices, (C) selecting, designing, fitting, customizing, adapting, applying, maintaining, repairing, or replacing, (D) coordinating and using other therapies, interventions, or services with assistive technology devices, (E) training or technical assistance for such child, or (F) training or technical assistance for professionals (20 U.S.C. 1401(2))
THE LAW THAT GETS DME FUNDED BY MEDICAID

- When Medicaid says it’s not a covered benefit, you can still get it paid for...
- EPSDT
- [http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-and-Periodic-Screening-Diagnostic-and-Treatment.html](http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-and-Periodic-Screening-Diagnostic-and-Treatment.html)
UNITED HEALTHCARE AND KAISER

- Apply for their grant if power is not a covered benefit
APPEALS

- Get help from the manufacturer of the device
- Go through the intake process with your state’s disability attorney
- File a complaint with your state’s insurance commissioner — establish nationally the need....
- Call me
Comments and Questions

Want handouts? Email ginny@paleg.com
References

References continued