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INTRODUCTION

FROM THE CLINICAL EDITOR

Welcome to the first FOCUS: Pediatric Power & Early Intervention, a DIRECTIONS publication. NRRTS is always looking for new ways to "raise the bar," and Executive Director Weesie Walker, ATP/SMS, conceived the idea of FOCUS.

Too many children are not considered for power mobility soon enough … or at all. Too many children may receive a power mobility device, yet barriers preclude optimal use – lack of parental acceptance, accessibility or mobility training.

Please share this valuable information with seating and mobility team members – suppliers, clinicians, parents and more. This issue is packed with comprehensive and up-to-date content that can inform the pediatric power mobility service delivery process from product design to evaluation, funding and mobility training.

Thanks for taking the time to serve our youngest clients.

Michelle L. Lange, OTR/L, ABDA, ATP/SMS

FROM THE EXECUTIVE DIRECTOR

"The power of mobility is the power of ability."
-Quote from a parent during CRT Awareness Day

This FOCUS is dedicated to all the Complex Rehab Technology (CRT) professionals who are providing early intervention services and technology. Nothing is more rewarding that enabling independent mobility for children with disabilities. Numerous studies show far-reaching benefits beyond functional goals such as social development and language skills. The articles, case studies and clinical perspectives contained here demonstrate the effort put forth by the seating and mobility team to provide the best outcomes.

The return on this investment is immeasurable. And that is what CRT is all about.

Weesie Walker, ATP/SMS

FROM THE PRESIDENT

There is a quote from Henry Kessler, MD, that hangs on the wall at the Kessler Institute in New Jersey that contains the line "extraordinary people doing ordinary things." There is nothing more extraordinary than watching the face of a child move in their world, on their own for the first time, using their first power mobility device. Somewhat more fun than extraordinary is watching the faces of that child's parents when they realize nothing will be the same again.

All of us at NRRTS hope you find this FOCUS a great read and powerful resource.

Gerry Dickerson, ATP, CRTS®
President, NRRTS

FROM THE EDITOR-IN-CHIEF

FOCUS is a new publication for NRRTS. We're pleased to add FOCUS to our DIRECTIONS family and hope you enjoy this issue as much as we've enjoyed producing it.

Amy Odom, BS

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THE TIME IS NOW: SUPPORTING POWER MOBILITY USE IN YOUNG CHILDREN WHO HAVE MOBILITY LIMITATIONS

Written by: **LISA K. KENYON, PT, DPT, PHD, PCS**

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OVERVIEW

For young children who have mobility limitations, using a powered mobility device offers more than just a way to move from point A to point B: It provides the self-initiated mobility their typically developing peers are already experiencing – allowing these children the opportunity to reap the developmental benefits of independent mobility. But just how does self-initiated mobility influence development in typically developing children? How about in children who have mobility limitations? When should we start considering a powered mobility device for children who have mobility limitations? What can we do to optimally support use of powered mobility devices? This article addresses these questions and more by exploring the developmental implications of powered mobility device use in young children and providing an evidence-based overview of power mobility assessment and intervention/training techniques.

INTRODUCTION

THE INFLUENCE OF SELF-INITIATED MOBILITY IN TYPICAL DEVELOPMENT

The onset of self-initiated mobility, e.g., rolling, scooting, crawling, initiates a cascade of developmental changes and transforms the relationship between a developing young child and their environment.[1, 2] No longer is the independently mobile young child dependent on others to passively move them from place to place. Moreover, their expanding self-initiated mobility provides them with a plethora of novel experiences and opportunities that contribute to their problem-solving abilities, spatial awareness, visual skills, memory, social/emotional processes and overall development.[1,2] Research strongly suggests self-initiated mobility, and the sensory information, knowledge and exploration gained through such mobility, provide the basis for intelligence in the young child and indeed lays the foundation for cognition as an adult.[3, 4]

Typically developing older infants and toddlers are often highly mobile. Adolph et al.[5] found children ages 12-19 months averaged 2,367.6 steps/hour and traveled 701.2 meters/hour. This means in one hour, the young children in Adolph's study walked, on average, the length of 7.7 American football fields (701.2 meters).[5] If this is what they accomplished in an hour, imagine how much walking practice these young children accumulated throughout the course of a single day! Even if we assume they were free to move for just six hours a day, these young children would be walking, on average, approximately 14,000 steps over the length of 46 football fields.[5] Just think of the number of learning opportunities, sensory experiences, and chances to use and develop problem-solving skills that accompany this amount of independent mobility! When viewed in this manner, it is easy to see how typically developing young children benefit from self-initiated mobility.

THE INFLUENCE OF MOBILITY LIMITATIONS IN EARLY CHILDHOOD

Children with mobility limitations are often unable to roll, scoot, crawl or walk within the same time frames as their typically developing peers. As such,

THE ONSET OF SELF-INITIATED MOBILITY, E.G., ROLLING, SCOOTING, CRAWLING, INITIATES A CASCADE OF DEVELOPMENTAL CHANGES AND TRANSFORMS THE RELATIONSHIP BETWEEN A DEVELOPING YOUNG CHILD AND THEIR ENVIRONMENT.

they are unable to reap the inherent developmental benefits of self-initiated mobility,[6, 7] putting them at risk for secondary impairments in multiple areas of development including cognition, communication, and social skills.[1, 2] Passive mobility, such as being carried by an adult or pushed in a stroller, does not provide the same experiences and opportunities as self-initiated mobility.[2] On the contrary, on-going passive mobility may lead to the development of passive, dependent behaviors and learned helplessness, wherein a child feels they have no control over themselves or the social and physical events in their world.[7, 8] Children who develop learned helplessness may exhibit poor task mastery (especially when tasks are perceived to be challenging), limitations in executive function and difficulties with problem solving.[8] However, children with mobility limitations who are able to experience self-initiated mobility through use of a powered mobility device are more likely to develop independent behaviors and exhibit an “I can do it” attitude.[9, 10]

ON TIME MOBILITY

It is clear powered mobility devices can play an important role in the development of children who have mobility limitations. But when is the best time to introduce mobility devices, including powered mobility devices? A new concept by Sabet et al.,[11] known as ON Time mobility, recognizes in typically developing children, self-initiated mobility starts at approximately 6-8 months of age. As such, ON Time mobility calls for introducing mobility devices to children who have mobility limitations within time frames that mimic typical development.[11] According to the ON Time mobility framework, waiting until a child with mobility limitations is 1, 2, or 3 years old (or older) to introduce a powered mobility device is not “early” power mobility, but rather “late.”[11] As we work to educate families, other stakeholders and indeed society on the importance of ON Time mobility, it is important to recognize powered mobility device use must be initiated in collaboration with a child’s family when they are ready and should not be forced upon families.

MOBILITY AS A HUMAN RIGHT

Mobility devices enable people who have mobility limitations by providing them opportunities to achieve mobility, benefit from human rights and live with dignity.[12] The 2006 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)[12] states people with disabilities are autonomous individuals with the human right to actively participate in society. Article 20 of the UNCRPD[12] further asserts nations have the responsibility to provide the greatest possible level of independence for all people who have mobility limitations by ensuring them access to mobility devices as soon as possible. Article 7 of the UNCRPD[12] specifically declares nations must take all necessary measures to ensure children with disabilities enjoy all of the human rights and fundamental freedoms afforded to children who are typically developing. When viewed through the lens of these international proclamations, providing infants and toddlers who have mobility limitations with opportunities to use power mobility can be recognized as a human right.

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FIGURE 1 A 17-month-old girl with cerebral palsy, cerebral visual impairment, and a seizure disorder using our Play & Mobility Device, an alternative powered mobility device consisting of a motorized platform and a car seat, designed and built at Grand Valley State University.

FIGURE 2 A 12-month-old girl with cerebral palsy, who is expected to eventually walk but who needs mobility assistance during early childhood, using the Explorer Mini.

FIGURE 3 A toddler with developmental delays using a modified ride-on toy car. She was expected to eventually walk independently, but needed mobility assistance during early childhood.

THE TIME IS NOW ...
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As such, four groups of young children who can benefit from powered mobility device use have been identified:[13]

1. Those who will never walk;
2. Those who have inefficient mobility;
3. Those who have lost the ability to walk or to walk efficiently; and
4. Those who will eventually walk but who need mobility assistance during early childhood.

When providing powered mobility devices, it is also important to remember all children, regardless of their mobility status, need age or developmentally appropriate adult supervision. Figures 1-4 depict young children with various conditions using different types of powered mobility devices.

POWER MOBILITY LEARNER GROUPS

Children who are learning to use a powered mobility device advance through a continuum represented by three different power mobility learner groups: exploratory, operational and functional.[14] The learning focus and learner characteristics for each of these learner groups is provided in Table 1. While recognizing not all children are able to progress into higher learner groups, all children start as exploratory power mobility learners.[14] While some children rapidly progress into the functional power mobility learner group and others may remain in the exploratory or operational power mobility learner groups for prolonged periods of time, children in all three learner groups can benefit from powered mobility intervention and use.[14] Although young children are often thought of as exploratory or operational power mobility learners, some young children are functional power mobility learners who are learning to integrate powered mobility device use into their daily lives. Scan the QR code located at the end of the article to view videos with examples of young children in various power mobility learner groups using different types of powered mobility devices.

As shown in Table 1, the goals and desired outcomes of power mobility use differ for each of the power mobility learner groups. These differences can be used to assist clinicians in tailoring power mobility assessment and intervention/training techniques for young children.[14-16] As such, this article will use these power mobility learner groups as a way to help organize and direct evidence-based power mobility assessment and intervention/training techniques.

FIGURE 4 A 2-year-old girl with a neuromuscular condition using a pediatric power wheelchair.

> CHILDREN IN ALL THREE LEARNER GROUPS CAN BENEFIT FROM POWERED MOBILITY INTERVENTION AND USE

Learning Focus and Learner Characteristics	
Exploratory Power Mobility Learners	*Learning Focus: Development of cause and effect skills, i.e., understanding they are moving the power mobility device through activation of the access method (a joystick, switch, etc.).* Learner Characteristics: • All children start in this learner group. • Requires frequent assistance and extremely close supervision. • Requires extensive practice to attain basic beginning power mobility skills. • May benefit from power mobility training even if they never become independent community drivers. *Children who have visual, intellectual or hearing impairments are often in this learner group.*
Operational Power Mobility Learners	*Learning Focus: Activating the access method in specific ways that control and maneuver the power mobility device.* Learner Characteristics: • Understands cause and effect (i.e., they are moving the power mobility device through use of the access method). • Has not yet mastered directional control of the power mobility device. • Requires intermittent assistance and close supervision. • Requires extensive practice to master maneuvering the power mobility device.
Functional Power Mobility Learners	*Learning focus: Integration of power mobility use into daily life routines.* Learner Characteristics: • Immediately understands that activating the access method causes movement of the device. • Quickly understands and masters directional control of the power mobility device. • Requires age-appropriate supervision. • Often meets the "qualifications" for an individually prescribed power wheelchair.

TABLE 1 Learning Focus and Learner Characteristics of Each Power Mobility Learner Group.

Note: Some children progress quickly and rapidly enter the functional power mobility learner group, while others may remain in the exploratory or operational power mobility learner groups. Not all children are able to progress into higher learner groups.

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INTRODUCING POWER MOBILITY WITH YOUNG CHILDREN

Before introducing a young child and their family to powered mobility device use, it is important to discuss expectations. Many families underestimate how complex learning to drive a powered mobility device is and mistakenly believe once their child is placed in the device, they will magically know how to use and drive it perfectly. In reality, a powered mobility device is a complex, multi-part tool involving coordination of three individual tools: a part of the body (a hand, head, foot, etc.), an access/driving method (switch(es), joystick, etc.), and the motorized device itself.[17] Learning and developing a conscious awareness of how to engage and coordinate these three tools together is a process that, for many young children, takes time.[17]

In the exploratory power mobility learner group, all children must first learn to control actions of their body and develop a foundational understanding of the function of the access method before being able to consciously activate and use the access method to operate the device.[18] As children start to progress into the operational power mobility learner group, they must learn to accurately control and sequence their body actions on the access method and refine their controlled operation of the powered mobility device within space and time.[18] Finally, as children progress into the functional power mobility learner group, they must learn functional navigation and integrated use of the powered mobility device within varied physical and social environments.[18] The trajectory and ending point each child follows during this learning process differs based on their individual abilities, preferred learning pace, motivation and available support.

> IN REALITY, A POWERED MOBILITY DEVICE IS A COMPLEX, MULTIPART TOOL INVOLVING COORDINATION OF THREE INDIVIDUAL TOOLS: A PART OF THE BODY (A HAND, HEAD, FOOT, ETC.), AN ACCESS/DRIVING METHOD (SWITCH(ES), JOYSTICK, ETC.), AND THE MOTORIZED DEVICE ITSELF.

Safety is a non-negotiable requirement for powered mobility device use. The need to ensure a child's safety in terms of medical stability (e.g., a stable airway) and environmental factors is paramount and should not be underestimated. The child also must be awake, alert and agree to engage in the activity, in whatever way they are able to express their agreement/disagreement. Only then should the child be introduced to the powered mobility device in a manner and pace that supports the child's specific needs and preferences for approaching new situations. The child must feel safe and secure, emotionally and physically, and be allowed to explore the device before being placed into it. Once the child is ready and has been placed into the powered mobility device, they should be encouraged and allowed to explore the device and the access method in their own way. Some children might like to mouth or lick the joystick or bang on the switch. Such actions are completely typical and allow the child time to adjust to the new situation and overcome any uncertainties or anxieties. Scan the QR code located at the end of the article to view videos that provide an example of introducing a young child to powered mobility device use.

SELECT POWER MOBILITY ASSESSMENT TOOLS FOR YOUNG CHILDREN

Field and Livingstone[14] identified two main types of power mobility implementation packages: task-based and processed-based. Both types often combine assessment and intervention procedures in a single "package" such that assessment directly guides intervention.[14, 18] Task-based packages, such as the Wheelchair Skills Program (WSP)[19] (consisting of 29 skills) and the Powered Mobility Program (PMP)[20] (consisting of 34 skills), are focused on a child's completion of power mobility tasks (moving the power mobility device forward, turning the power mobility device, driving through a doorway, etc.), often on command.[14] Within the WSP and the PMP, assessment is used to identify specific power mobility tasks that could be improved with intervention.[14] Intervention is then used to help the child work toward safe and proficient performance of power mobility skills, from basic skills (such as turning the device on and off, and maintaining contact with the joystick for five seconds) to community mobility skills (such as avoiding people and objects, and staying on one side of the hallway).

Power Mobility Learner Group	**ALP Phases**	**ALP Stage**
Exploratory Power Mobility Learners	1 – Novice 2 – Curious Novice 3 – Beginner	Stage 1 – Explore functions focused on exploring cause and effect with the power mobility device.
Operational Power Mobility Learners	4 – Advanced Beginner 5 – Sophisticated Beginner	Stage 2 – Explore sequencing focused on sequencing the operations to maneuver the power mobility device.
Functional Power Mobility Learners	6 – Competent 7 – Proficient 8 – Expert	Stage 3 – Explore performance focused on using the power mobility device in daily life.

TABLE 2 *Aligning the Power Mobility Learner Groups with the ALP Phases and Stages*

The PMP may be downloaded at no cost on ResearchGate. Field and Livingstone suggest while the PMP can be used with children in all three power mobility learner groups, many of the tasks, especially those performed on command, imply the child already has a foundational understanding of the function of the access method and how to grossly operate the powered mobility device.[18] As such, task-based power mobility implementation packages may be best suited for use with children who are in the operational or functional power mobility learner groups.

In contrast, process-based power mobility implementation packages, such as the Assessment of Learning Powered mobility use tool version 2.0 (ALP), focus on assessing and progressing an individual's understanding of how to use a powered mobility device.[14, 18] Comprised of the ALP assessment instrument and the ALP facilitating strategies for intervention, the ALP tool allows clinicians to guide and promote each learner's understanding of how to use a powered mobility device along the broad continuum of learning represented by all three power mobility learner groups. Although the ALP tool can be used with any power mobility learner of any age, research suggests the process-based approach exemplified in the ALP may be especially beneficial for exploratory power mobility learners who have not yet developed a conscious understanding of how to operate a power mobility device.[14, 21]

USING THE ALP INSTRUMENT TO ASSESS OUTCOMES

The ALP instrument for assessment of the learning process defines:

- Eight phases of learning: Phase 1 – Novice to Phase 8 – Expert
- Encompassed within three learning stages:
    - Explore Functions – ALP Phases 1-3
    - Explore Sequencing – ALP Phases 4, 5
    - Explore Performance – ALP Phases 6-8

As detailed in Table 2, the three ALP Stages align nicely with the three power mobility learner groups.[14, 18]

Categories of observation within each ALP phase include:

- Attention: centers on a learner's ability to regulate and shift their attention.
- Activity and Movement: focuses on a learner's performance of activity.
- Understanding of tool use: refers to the learner's level of conscious understanding regarding the operation of the tool and is the primary, observable cognitive component within each ALP phase.
- Expressions and Emotions: provides information about a learner's motivation.
- Interaction and Communication: concentrates on the expression of interpersonal relationships and social interplay amongst the powered mobility device, the environment and available social partners.

Detailed criteria for each of these categories are provided for each ALP phase. Table 3 provides a brief overview of the ALP phases and stages. The ALP instrument has excellent inter-rater reliability (linear weighted kappa of 0.85) and is appropriate for use by any clinician, as it is not restricted to use by licensed therapists.[22] Once identified, the leaner's ALP stage and phase are then used to select the specific ALP facilitating strategies as outlined below.

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SELECT POWER MOBILITY INTERVENTION/TRAINING TECHNIQUES FOR YOUNG CHILDREN

Power mobility interventions provided within an atmosphere of mutual respect, collaboration and partnership may help the child (and their family) to feel safe and secure, thereby optimally supporting learning.[16, 18] Incorporating developmentally appropriate play activities and a fun approach into power mobility interventions will also help to engage and motivate learners at all levels. Power mobility intervention sessions should be individualized to meet the needs, motivations and play preferences of each child.

USING THE ALP FACILITATING STRATEGIES

Once the learner's ALP stage and phase are identified, the 11-page ALP facilitating strategies document is used to select specific facilitating strategies. In this manner, clinicians are able to best support each learner's growing understanding of how to use a powered mobility device. Table 4 provides select examples of ALP facilitating strategies at each stage and for each power mobility learner group. Additional details regarding use of the ALP in young children can be found online in "A Guideline for Introducing Powered Mobility to Infants and Toddlers" (https://www.permobil.com/research-innovation).

In addition to the ALP facilitating strategies, a recent study by Kenyon et al.[16] explored the key aspects of pediatric power mobility interventions that may be helpful for children in each power mobility learner group. An overview of these key aspects is provided in Table 5 and detailed below.

KEY ASPECTS FOR EXPLORATORY POWER MOBILITY LEARNERS[16]

- Allow safe collisions: focuses on permitting the child to safely bump into walls, objects, etc. to assist the child in learning about both movement through space and movement of the device.
- Encourage child-led learning centers on allowing the child to explore the powered mobility device, the access method, the environment and movement in general. This includes letting the child spin safely in circles.
- Promote accidental activation of the access method: encourages repeated, non-intentional activation of the access method (typically a joystick or a single switch at this learning level). Over time,

ALP Phase	Attention	Activity & Movement	Understanding of Tool-use	Expressions and Emotions	Interaction and Communication	ALP Stage
8	Attention well-established and sustained	Occupation composed of two or more activities	Integrated tool use	Dependent on the doing of "other" activities	Multi-level integrated interactions	***Stage 3: Explore Performance: Body, tool(s), environment, occupation***
7	Multi-channeled attention, Generally focused	Occupation for its own sake	Fluent, precise use of the tool	Happiness, Satisfaction	Concurrent interactions	
6	Multi-channeled attention, but easily disrupted	Goal directed activity	Competent use of the tool	Serious, Content, Laughing, Excited	Consecutive interactions	
5	Two-channeled attention	Sequences of chains of acts	Idea of competent tool-use is born	Eager, Smiles, Serious, Frustration	Reciprocated interactions, Triadic interaction	***Stage 2: Explore sequencing: Body, tool(s), environment***
4	Single channeled attention, but able to shift spontaneously	Chains of acts	Exploration of extended tool use	Serious, Smiles, Sometimes laughs	Mutual interactions	
3	Single channeled attention, but able to shift attention	Acts directed	Basic use of the tool	Serious, Contented, Smiles	Initiates interactions	***Stage 1: Explore functions: Body & tool(s)***
2	Single channeled, at times more alert, at times, passive	Pre-act	The idea of basic use is born	Contented, Curious, Anxious, Angry	Responds to interactions	
1	Extreme distractibility	Excited, Non-Act, Rejection	No idea or vague idea of tool use	Open, Neutral, Anxiety	No response, Avoidance	

TABLE 3 *A Brief Overview of the ALP Phases and Stages*

this may help the child to develop an understanding of the effect of the access method on movement of the device.

- Provide manual guidance and demonstration: consists of taking the child's hand and placing it on, or removing it from, the access method and demonstrating how to activate the access method.
- Provide simple and consistent verbiage: focuses on building a vocabulary for power mobility use and includes pairing action of the device with simple words, for example: "Stop" and "Go." At this early learning stage, it is important everyone working with the child use the same vocabulary so the child does not become confused. It also includes the clinicians not talking "too much," which may overwhelm or confuse the child. This is particularly true if processing delays are present.

As noted in Table 1, children who have visual impairments, including cerebral visual impairments (CVI), are typically exploratory power mobility learners. While parents and clinicians may be concerned about providing power mobility experiences to young children who have visual impairments, these children may benefit from the self-initiated mobility provided by power mobility use.[23] The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) position on the application of power mobility devices for pediatric users[23] specifically states limited vision, in and of itself, should not be a limiting factor when considering power mobility for children. Each child is unique, however, and decisions must be made based on the needs of the specific child. Table 6 provides helpful suggestions when providing power mobility interventions with children who have visual impairments.

KEY ASPECTS FOR OPERATIONAL POWER MOBILITY LEARNERS[16]

- Build vocabulary for safety: emphasizes the need to help children develop a vocabulary for and about safety and includes beginning to recognize and respond to safety instructions. It is important

CONTINUED ON PAGE 16

ALP Stage 1 – Explore Functions Exploratory Power Mobility Learners	***ALP Stage 2 – Explore Sequencing Operational Power Mobility Learners***	***ALP Stage 3 – Explore Performance Functional Power Mobility Learners***
• The main focus is on the child's own body and the device. • Introduce device use in a gentle way to establish a safe and secure relationship to the device. • Focus the child's attention on the device itself in a small and controlled environment. • Allow the child to explore the different parts of the tool and each tool's function. • Give the child time to adapt to the device's movement and the effects of external forces. • Understand that the child may reject the device, display anxiety, passivity or frustration at these stages. This is normal! • Encourage 1:1 interaction. • Incorporate both physical (guided) and social (verbal) interactions. • Resist the urge to shout or increase your voice if collisions or unexpected events occur.	• Encourage exploration and experimentation with pattern building. • At this stage, focus on the child's exploration without interference. • Utilize manual guidance and verbal cueing. • Introduce variations in device speed. • Begin to introduce vertical spatial relationship by directing the child's attention to just below tray height. • Provide external motivators to convey the idea of a goal for tool use. • Accept the child's specific expressions of frustration. • Comfort and calm the child to reduce their frustration to a level that does not interfere with learning. • Introduce simple, 1:1 interactive activities, and then gradually increase the complexity.	• Encourage exploration of tool use in everyday environments. • Help facilitate synchronization of your child's movements with the device to achieve precision use. • Encourage and facilitate the child's development of strategies to decrease frustration with device use. • Introduce and encourage unstructured variation in device use. • Encourage group interaction with other children or siblings. • Introduce free play with the device or games with rules at a complex level. • Label the child's expressions of emotions with regard to the outcome of device use. • Provide instructions for the child to carry out.

TABLE 4 *Sample ALP Facilitating Strategies for Each ALP Stage and Power Mobility Learner Group*

Exploratory Power Mobility Learners	*Operational Power Mobility Learners*	*Functional Power Mobility Learners*
• Allow safe collisions. • Encourage child-led learning. • Promote accidental activation of the access method. • Provide manual guidance and demonstration. • Provide simple/consistent verbiage.	• Build vocabulary for safety. • Encourage navigational problem-solving. • Facilitate multi-directional control. • Foster goal-directed mobility. • Promote awareness of device boundaries.	• Encourage self-advocacy skills. • Facilitate typical childhood roles. • Foster advanced skills & functions. • Promote dual and multi tasking. • Utilize scaffolding.

TABLE 5 *An Overview Key Aspects of Power Mobility Intervention for Each Learner Group*

Suggestions for providing power mobility interventions with children who have visual impairments.

- Use brightly-colored tape or contrasting colors (e.g., a red switch placed on a black background) to highlight the access method.
- Cover the switch or joystick handle with aluminum foil or the use of foil wrapping paper may also be helpful.
- Begin powered mobility training in a smaller, uncluttered, visually simplified environment. Employing very intentional environmental adaptions is often helpful.
- Clinicians should wear non-patterned or even solid black clothing as a way to decrease the visual complexity of the environment.
- When working on turns, try placing an audio device playing the child's favorite song or talk to the child when on the left or right side to help the child orient to the direction of the turn.
- Use motion-activated musical toys or other auditory cues to help increase environmental awareness in children with visual difficulties.
- A consistent and predictable environment may be particularly helpful, especially in the early stages of learning to use a power mobility device.

TABLE 6 *Suggestions for providing power mobility interventions with children who have visual impairments.*

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(CONTINUED FROM PAGE 15)

to have reasonable expectations in this area and remember typically developing children do not always respond to safety instructions 100% of the time!

- Encourage navigational problem-solving: focuses on allowing children to figure out and try navigational routes and how to get themselves "unstuck" when a problem arises. It includes, within the limits of safety, letting a child make navigational decisions and discovering the consequences of these choices.
- Facilitate multidirectional control: emphasizes helping children learn the effect the access method has on the device and how to maneuver the device around stationary or slowly moving obstacles.
- Foster goal directed mobility: accentuates the need for children to develop an understanding of how the powered mobility device allows them to act on and within their environment.
- Promote awareness of device boundaries: stresses the need for children to envelop the footprint of the powered mobility device into their body scheme. Using visual and auditory cues to bring awareness to the boundaries of the device may be helpful.

KEY ASPECTS FOR FUNCTIONAL POWER MOBILITY LEARNERS[16]

- Encourage self-advocacy skills: involves helping children learn to speak up for themselves in matters pertaining to powered mobility device use. This includes encouraging a child, if they are able,

WHY SHOULD A CHILD WHO HAS MOBILITY LIMITATIONS BE RESTRICTED TO A SINGLE FORM OF MOBILITY?

to ask people to move out of their way.

- Facilitate typical childhood roles: includes learning to use the power mobility device to do age-appropriate chores/household tasks. Typically developing toddlers and preschoolers frequently enjoy "helping" with laundry or cleaning the floors. Young children who have mobility limitations often "miss out" on these opportunities, yet for functional power mobility learners, these activities can be valuable learning experiences!
- Foster advanced skills and functions: focuses on helping children to learn to use their power mobility device in complex community settings, such as in preschool, at the grocery store or at the park.
- Promote dual and multitasking: centers on learning to drive while simultaneously performing another motor or cognitive task to facilitate involvement in functional, play and social activities.
- Utilize scaffolding: involves initially simplifying both a task and the environment to facilitate children's learning, and then gradually increasing task and environmental complexity as the child progresses. This aspect of intervention also includes scaffolding a child's independence to take on increasingly complex tasks with age-appropriate supervision.

PROVIDING YOUNG CHILDREN WITH MOBILITY OPTIONS

Power mobility is often considered to be a dichotomous "all or none" phenomenon: Either the child uses a powered mobility device, or they don't. But typically developing children and adults choose from a wide variety of mobility options each day. A typically developing toddler crawls and walks, but they also might scoot along using a ride-on toy without pedals. As adults, we match different forms of mobility with different purposes: We walk the dog, we take a train to work, and we go on a run for exercise. Why should a child who has mobility limitations be restricted to a single form of mobility? Perhaps a child may use a powered mobility device to freely explore and keep up with their peers, a gait trainer to run around with their siblings, a stroller at the mall, and a posterior/reverse walker in their therapy sessions. When thinking about mobility options for a child, it is important to think energy efficient, functional mobility. Think for a second about doing cartwheels. Maybe you could do one. Now imagine having to do cartwheels, one after another, all day long to get from one place to another. There is no way you could keep up this level of physical activity as you move throughout your day. You would be exhausted. Children who must perform at the limits of their physical abilities all day long get exhausted too. Mobility practice sessions and exercise opportunities should never be confused with functional mobility.[23] Mobility is only functional when it is efficient.

CONCLUSION

This article has explored the developmental implications of powered mobility device use in young children and provided an evidence-based overview of power mobility assessment and intervention/training techniques for young children. Although adequate supervision must be provided to ensure safety, young children who have mobility limitations typically benefit from power mobility use.

CONTINUED ON PAGE 18

> **ALTHOUGH ADEQUATE SUPERVISION MUST BE PROVIDED TO ENSURE SAFETY, YOUNG CHILDREN WHO HAVE MOBILITY LIMITATIONS TYPICALLY BENEFIT FROM POWER MOBILITY USE.**

Scan the QR code to watch the following videos:

Video 1: This video series follows a young boy with hypotonia and developmental delays during his first few months of powered mobility device use.

Video 2: This video series follows a 2-year-old girl who had several medical diagnoses. Her future ambulatory status was unknown.

Video 3: This video series provides some tips and tricks about introducing powered mobility devices to young children.

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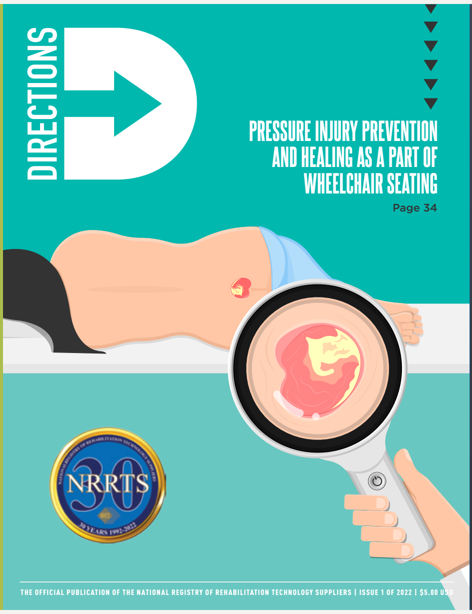

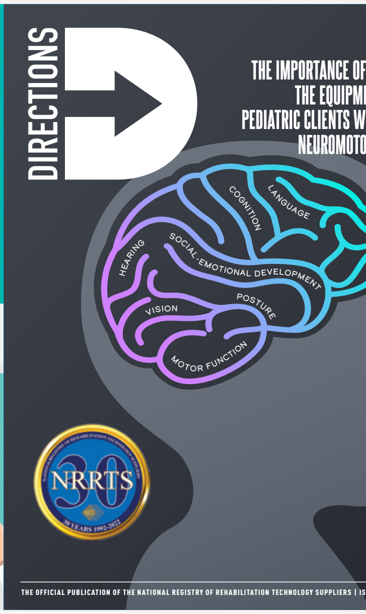

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WHAT PEDIATRIC POWER MOBILITY NEEDS IN THE FUTURE

Written by: **SAM LOGAN, PH.D.**

PEDIATRIC POWER MOBILITY (PPM) IS STILL IN ITS PUNK PHASE, AND THAT'S NOT A GOOD THING.

For the past decade, I've been involved with the Go Baby Go (GBG) program. GBG modifies commercially available, off-the-shelf and low-cost (~$200) ride-on toy cars for children with disabilities to use for mobility (see Figure 1). Punk and GBG are grounded in do-it-yourself culture and activism. Punk bands are known for starting in garages with little to no music experience, trying out new sounds and speaking out against injustice. GBG relies heavily on the do-it-yourself spirit of families, clinicians, teachers, researchers and community members to modify ride-on cars, often with very little technical expertise. GBG embraces mobility as a human right, in alignment with the United Nations and advocates on behalf of children with disabilities. Like the early punk scene, GBG is enthusiastically embraced by like-minded individuals, but PPM is still on the fringe of rehabilitation culture. My vision is PPM gains widespread acceptance in rehabilitation culture and broader society.

MY VISION IS PPM GAINS WIDESPREAD ACCEPTANCE IN REHABILITATION CULTURE AND BROADER SOCIETY.

PRODUCTS:

Permobil's release of the Explorer Mini (EM) for children aged 12-36 months is a major step forward for the industry because of the lack of other commercially available power mobility options for young children in the United States. The EM also represents a significant upgrade in functionality compared to modified ride-on cars. The EM requires a doctor's prescription for trial or purchase and costs $2,803, which is low for Complex Rehabilitation Technology, but high for families to pay out-of-pocket. The EM prescription requirement and cost establishes a massive class divide and creates systemic inequity in access. White and middle-to-upper class families over represent PPM access, at least partly due to the resources needed for home, vehicle and lifestyle adaptations required for standard motorized wheelchairs. Equitable PPM device access could be addressed through realignment of funding priorities.

FIGURE 1 Modified ride-on car with a large, easy-to-press activation switch and customized seating support. Photo credit: Alan Calvert, College of Public Health and Human Sciences, Oregon State University.

FUNDING:

One lesson of COVID-19 is funding priorities and health care decisions can change overnight, especially when able-bodied people become at risk for a debilitating infectious disease. Imagine a world where a global pandemic permanently caused young children to be unable to walk. Oh, right — polio and the resulting federally-funded vaccine program eradicated its existence in the United States (see "Polio: An American Story" by David M. Oshinsky for further reading). I am NOT suggesting mobility disabilities should be cured with medical treatment, but rather the response to polio is an example of how societal priorities can impact children's lives. People with disabilities are not valued in our society, and children with disabilities are oppressed and relegated

Explorer Mini = $2,695 * ~409,315 children in the United States who receive early intervention services = $1,147,309,945 total cost to purchase a device for every eligible child

$1,147,309,945 total cost / $4,790,000,000,000 United States Government Budget for 2020 = 0.02 percent of federal budget

FIGURE 2 Napkin math of the pediatric power mobility funding problem and solution. For the most part, the ~$1.15 billion is a one-time cost that will establish a sustainable national lending library program for the Explorer Mini. This is still feasible, even if we assume an annual budget of $50 million ($1 million per state) to purchase/rent infrastructure (i.e., building space), hire stakeholders to run the program (i.e., caregivers, clinicians, Assistive Technology Professionals), and miscellaneous costs (i.e., insurance).

> **ANYTHING IS POSSIBLE WHEN SOCIETY DECIDES IT IS READY FOR A PARADIGM SHIFT.**

to wait their turn for mobility access. It's all about priorities, and anything is possible when society decides it is ready for a paradigm shift (see Figure 2).

INTERVENTIONS:

Interventions are rarely early and almost always late. PPM should be provided on time (Sabet et al., in press). Children with typical development crawl at around 7 months. Children with disabilities must gain mobility access at the same time.

FINAL THOUGHTS:

I consider myself an outsider to PPM. I'm not a power mobility user, a clinician, parent of a child with a disability, or an Assistive Technology Professional. I'm not sure what the future holds. PPM will likely continue on the same slow and steady path it has always been on. A federally-funded EM lending library is ideal. A low-cost, off-the-shelf ride-on car with built-in accessible features is also an encouraging option. Children with disabilities deserve equitable access to mobility. We must all do better to achieve this goal. I love punk and what it stands for (see Figure 3), but it's also time for PPM to go pop and never look back.

"PUNK IS ABOUT EMPOWERMENT AND AUTONOMY"

FIGURE 3 Quote from Alice Bag, lead singer of the L.A. based punk band The Bags, found in "Teaching Resistance" (p. 175) edited by John Mink. This quote simply states the potential of power mobility: empowerment and autonomy.

Disclaimer: The author has received funding from Permobil in the past to help with a feasibility study of the Explorer Mini.

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PEDIATRIC POWER WHEELCHAIRS

A COMPARISON OF AVAILABLE OPTIONS

Written by: **MICHELLE L. LANGE, OTR/L, ABDA, ATP/SMS**

Early pediatric power wheelchairs were mostly sized-down versions of adult power bases. Some current pediatric power bases are the same size as an adult base, just with smaller seating. Other pediatric options are built for children's needs from the ground up. In the comparison chart on pages 24 and 25, current pediatric power wheelchairs are shown side-by-side with features such as available seating dimensions, drive wheel configuration and power seating options. No one power wheelchair will meet every child's needs, and many of these bases include options to further customize the final product.

Growth is an important consideration for children. Each of these pediatric power wheelchairs includes growth in the frame, which is also dependent on the starting width, depth and height for an individual child. Growth can also be built into many seating systems. As this creates quite a potential range of growth, available growth is not included in this chart. It is important to consider available growth in each power base and seating system combination. In addition, this chart does not address transport issues as this is a complex issue we hope to address in a future article.

Current pediatric power wheelchair options are varied and innovative! Let's get those kids moving!

Links for Pediatric Power Wheelchair Comparison chart (See pages 24 and 25), in order:

Amylior Alltrack PR3 Hybrid- Wheel Drive
bit.ly/3ODr85v

Amylior Alltrack PM3 Mid-Wheel Drive
https://bit.ly/37Mverp

Invacare AVIVA Storm
https://bit.ly/3OG2ml0

Invacare TDX SP2
https://bit.ly/3rU9gtc

Permobil Koala
https://bit.ly/3OPaXSO

Permobil K450 MX
https://bit.ly/3vhM8XN

Permobil M300 PS Jr.
https://bit.ly/3vNNmZJ

Permobil K300 PS Jr.
https://bit.ly/3kgbQ8O

Permobil Explorer Mini
https://bit.ly/3OGIazK

Quantum Rehab Stretto
https://bit.ly/3LzQKyp

Rovi X3
https://bit.ly/3vK16VE
https://bit.ly/3MywTQc
https://bit.ly/3EQMQ1p

Rovi A3
https://bit.ly/3w4EKOT
https://bit.ly/3kcuYV9
https://bit.ly/3LjyJE5

Sunrise Medical ZM-310
https://bit.ly/3KjNl5l

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Michelle Lange, OTR/L, ABDA, ATP/SMS, is an occupational therapist with 35 years of experience and has been in private practice, Access to Independence, for over 15 years. She is a well-respected lecturer, both nationally and internationally, and has authored numerous texts, chapters and articles. She is the co-editor of Seating and Wheeled Mobility: a clinical resource guide, editor of Fundamentals in Assistive Technology, Fourth Edition NRRTS Continuing Education Curriculum Coordinator and Clinical Editor of NRRTS DIRECTIONS magazine. Lange is a RESNA Fellow and member of the Clinician Task Force. She is a certified ATP, certified SMS and is a senior disability analyst of the ABDA.

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PEDIATRIC POWER WHEELCHAIR COMPARISON CHART

Power Wheelchair	***Amylior Alltrack PR3 Hybrid-Wheel Drive***	***Amylior Alltrack PM3 Mid-Wheel Drive***	***Invacare AVIVA Storm RX Ultra Low Maxx***	***Invacare TDX SP2 Ultra-Low Maxx***	***Permobil Koala***	***Permobil K450 MX***	***Permobil M300 PS Jr.***
							
Seat Width / Depth	11″ x 11″ to 20″ x 20″	11″ x 11″ to 20″ x 20″	11″ x 11″ to 15″ x 15″ Ultra low Mini 14″ – 22″ / 14″ – 23″	14″ – 22″ W 14″ – 23″ D	10″ x 10″ 12″ x 12″ 14″ x 14″	W: 10″, 12″, 14″, 16″ D: 10″ – 18″, 1″ increments	W: 11″ – 16″, 1″ increments D: 10″ – 18″
Back Height	21-22″ min. (Tilt/Recline) 16″ (Tilt)	21-22″ min. (Tilt/Recline) 16″ (Tilt)	18″ – 27″	18″ – 27″	14″, 16″, 20″	14″, 16″, 20″ (MX) 16.5″ – 22.5″ (PS Jr)	16.5″ – 22. 5″ (1″ increments)
Seat to Floor Height	15.25″ – 19″ (tilt, tilt/recline or elevate) 17.25″ or 18″ (elevate)	15.5″ – 19″ (tilt, tilt/recline or elevate) 17.5″ or 18.25″ (elevate)	16.75″	16.75″ 17.25″ 18.25″ 19.25″	15″ (elevate)	3″ – 26″ (elevate)	17″ (elevate) 17″, 17.75″, 18.5″ (fixed)
Base width	23.375″ (GP22 batteries)	21″ (12.5″ or 14″ wheels) or 23.375″	22.4″ (narrow) or 24.4″ (standard)	24″ 25.5″ (GP24 batteries)	23″	25″	24″
Base width	35.875″	35.125″	33.5″	35.6″	32″	35″	36.5″
Min. Turning Radius	21.75″	20″	25″	20″	21″	28″	20″
Ground Clearance	3.5″ (14″ wheels) 2.875″ (12.5″ wheels)	3.5″ (14″ wheels) 2.875″ (12.5″ wheels)	3.2″	3″	2.5″	2.5″	3″
Drive wheel configuration	HWD	MWD	RWD	MWD	FWD	RWD	MWD
Max. User Weight	300 lbs.	300 lbs.	300 lbs. 175 lbs. UL Mini	300 lbs.	80 lbs.	125 lbs.	165 lbs.
Weight of Base	355 lbs.	355 lbs.	Up to 385 lbs.	Up to 156 lbs. (without batteries)	226 lbs.	337 lbs.	313 lbs.
Tilt	Power 50° (optional)	0-50° (optional)	50° (optional)	50° (optional)	0 – 25° (power)	0 – 45° (power)	0 – 45° (power, optional)
Recline	0-162° (optional)	0-162° (optional)	170° (optional)	170° (optional)	85 – 120° (manual)	85 – 105° (manual)	85 – 120° (manual)
ELRs	12.5″ to 15.5″ leg lengths (optional)	12.5″ to 15.5″ leg lengths (optional)	Yes (optional)	Yes (optional)	90 – 150° (manual)	90 – 125° (manual) Fully extends when seat is in lowest position	90 – 150° (manual)
Seat Elevate	11″ (optional)	11″ (optional)	12″ (optional)	12″ (optional)	8″ (power)	8″ (power)	8″ (power, optional)
Max. Speed	6.5 mph or 8.5 mph	6.5 mph	5.8 mph	5.8 mph (standard) 7.5 mph (optional)	4 mph	5 mph	6 mph
Electronics	PG Drives VR2 or R-Net	PG Drives VR2 or R-Net	LiNX	LiNX	R-Net	R-Net	R-Net
Tracking Technology	Smart-Track technology	Smart-Track technology	G-Trac	G-Trac	ESP optional	None	ESP optional
Other	-Lithium iron battery pack optional, approved for travel, 40 lbs. less than standard gel. -Dedicated battery gauge and charger.	-Lithium iron battery pack optional (except on 21″ width), approved for travel, 40 lbs. less than standard gel. -Dedicated battery gauge and charger.	-Standard LED lighting. -Compatible with Motion Concepts' Ultra Low Maxx.	-Optional lighting. -Compatible with Motion Concepts' Ultra Low Maxx. -Sure Step and Stability Lock suspension.	-Optional: foot-plate bumper, remote stop, light kit, USB charger, BT controller. -Custom power recline and power ELR available.	-Optional: remote stop, memory seating, light kit, USB charger, BT controller. -Seat moves forward and down to nearly floor level.	-Optional: Remote stop, light kit, USB charger, BT controller.

Power Wheelchair	***Permobil K300 PS Jr.***	***Permobil Explorer Mini***	***Quantum Rehab Q6 Edge 3 Stretto***	***Rovi X3 Ultra-Low Mini System***	***Rovi A3 MPS Mini Maxx***	***Sunrise Medical ZM-310***
						
Seat Width / Depth	W: 11” – 16”, 1”increments D: 10” – 18”	7.5” x 8.7” Saddle seat	12” x 12” to 20” x 20”	11” x 11” to 15”x 16”	12” - 17” W 12” – 17” D	10” x 10” to 16” x 19”
Back Height	16.5” – 22. 5” (1” increments)	15.7” Max user height 39”	14” – 25”	11” – 20”	16” – 22”, 6” gap req. for Stander	15.5” – 26”
Seat to Floor Height	16.5” (elevate) 16.5”, 17.25”, 18.5” (fixed)	12.1” – 21.7”	16”-18” (TB3 static seat) 17.5”–19.5” (tilt or tilt/elevate) 16.5”–18.25” (flex seating)	18.375”	18.5”	15.5” – 22.4” (BC) 17.6” – 21.8” (SC)
Base width	24”	19”	20.47” (12.5” wheels)	23.25”	25.5”	24”
Base width	40”	25”	32.5”	36.5”	36.5”	34”
Min. Turning Radius	25”	19”	21”	19.5”	20.5”	19”
Ground Clearance	3”	1”	2.9”	3”	3”	3”
Drive wheel configuration	FWD	FWD	MWD	MWD	MWD	MWD
Max. User Weight	165 lbs.	35 lbs. 39 max. height	300 lbs	300 lbs 175 lbs UL Mini	200 lbs	165 lbs
Weight of Base	272 lbs.	52 lbs.	126.4 lbs	157 lbs (without batteries)	159 lbs (without batteries)	235 lbs (BC) 260 lbs (SC)
Tilt	0 – 45° (power, optional)	No	Power 50° (optional)	50°	45°	Power 50° Manual 45°
Recline	85 – 120° (manual)	No	Manual 20°(optional)Power 175°(optional)	163°	165°	Manual 40°
ELRs	90 – 150° (manual)	No	Optional, dual or center mount	No	Yes	S/A 90–180°(manual) Center mount 0 – 180° (manual)
Seat Elevate	8” (power, optional)	No	12” (optional)	12”	7” (10” 5/1/22)	9” or 12” (optional)
Max. Speed	5 mph	1.5 mph	6.25 mph 3.5 mph (Elevate)	5.8 mph (standard) 6.2 mph (optional)	6.2 mph	6 mph
Electronics	R-Net	nVR2	Q-Logic	R-Net	R-Net	R-Net
Tracking Technology	ESP optional	None	Accu-Trac (optional)	onTraxx enhanced driving module	onTraxx enhanced driving module	None
Other	-Optional: Remote stop, light kit, USB charger, BT controller.	-For children 12 – 36 months old. -Can be used in sitting or standing. -Joystick use only. -Not designed to accommodate after market seating. -Total chair height 29”–37”.	-Standard USB charger port LED fender lights. -Optional Full lights and Back-up camera.	-Active Ride Control (ARC) independent suspension. -Optional 5° fixed anterior assist, 5° fixed pre-tilt, 8° or 30° precline. -Standard USB charger. -Motion Concepts’ Ultra Low Mini Power Positioning System required.	-Power stand. -Active Ride Control (ARC) independent suspension. -Standard USB charger.	-Standard Ctrl+5 switchbox 3-amp USB charger.

LET'S GO BABY GO!

Written by: **ANDRINA SABET, PT, ATP**

Go Baby Go (GBG) is an international grassroots movement focused on real-time, real-world solutions for mobility and play. The movement began with Cole Galloway, a professor at the University of Delaware, to "help empower individuals with the ability to co-create their world through mobility." Go Baby Go utilizes a combination of disruptive innovation, formal academic research and community outreach focused on low tech/high impact solutions for children to experience social mobility that creates opportunities for independence and self-expression.

GBG is best known for modifying power ride-on cars from local toy stores. This open-source movement has expanded around the world and, without any formal organization, has led to over 150 chapters that have modified over 10,000 cars. These chapters can be found almost anywhere: at therapy and engineering university level programs; high school, middle school, and elementary school classrooms through STEM/STEAM programming; and as after school organizations, such as the Boys and Girls Clubs of America. GBG has even created impact in the adult world where corporations and volunteer groups participate in workshops and mobility related projects.

Toy cars are typically modified in two ways: electrically and structurally. Electrical changes include modifications to the wiring, which can range from simple (changing the activation method to a switch which can be mounted anywhere in or on the car) to complex (adding a joystick, motors to reduce turning radius or speed controllers). On the other hand, structural changes involve modifications to the body of the car such as adding a variety of postural supports to improve child stability, steering wheel adaptations or accommodations for medical technology such as ventilators or oxygen tanks/concentrators. In contrast to demands placed on durable medical equipment, these toys can be designed for short duration play and allow for unique configurations such as cars that activate by standing rather than sitting.

Fisher Price employees modify Power Wheels for local families

But in reality, GBG is not about the car, it is about the kid.

> "Sophia certainly enjoys her time in her adapted car (sometimes a little too much, as she is a bit of a daredevil) and has much more independence during play with other children. It is easy to get her outside and just let her explore and play in a very similar way with the other kids in the neighborhood. As a parent of a child with special needs, there is nothing more rewarding than watching them being engaged with their peers, seeing smiles, and hearing nothing but nonstop laughter throughout play. The other thing I love about the adapted cars is it's an easy way to work on goals, whether it be vision, head control, coordination, motor planning, or even just following directions because the kids are highly motivated by the fun and novelty of the car and being with friends. I have taken Sophia's car with us to the park to "race" other kiddos, baseball games to keep her busy, and even to people's homes to have play dates. It's been wonderful!"
>
> - Charlene (mother of Sophia)

Just try to catch me!

Lovin' my new ride!

Trouble to go!

Mobility is a human right as determined by the United Nations, yet there is a substantial gap in mobility equity between children with mobility disabilities and those without. This gap has been sustained by practices in the medical model and medical research often prioritizes walking over alternative mobility strategies. Inequity is further substantiated by the Durable Medical Equipment industry and funding policies too often centered on adults rather than the unique needs of the birth to age 3 population. GBG has evolved in an effort to reduce this gap and improve mobility equity. Our principles provide a peek "underneath the hood" at the engine that powers our collective.

THE SCIENCE OF DEVELOPMENTAL PSYCHOLOGY:

GBG recognizes mobility is a major causal factor in a child's general development, daily learning and joy, and a family's structure and quality of life as supported by research within the theory of "embodied development."

THE FINANCING OF SOCIAL ENTREPRENEURSHIP:

GBG is committed to providing free mobility solutions for children. This requires a deep and meaningful collaboration with local community resources including funding, volunteers and fun spaces for workshops.

OUR ROLE AS COMMUNITY ORGANIZERS:

GBG recognizes being effective is not leading community efforts in the traditional sense but rather working in service to the actual leaders: kids and families. We strive to be designated as advocates by those with lived experience in the disability community.

JOIN THE MOVEMENT FOR MOBILITY!

There are multiple ways to participate in GBG. The most common way is by teaming up with families and kids to modify ride-on cars in your local community. Anyone can join the do-it-yourself movement at www.gbgconnect.com, an online forum where groups and individuals post instructions, solve problems and share resources. This is a great way to locate and connect with a chapter in your area. There are three important considerations when getting started. First, safety is a critical element with any GBG project. An engineer must be involved to maintain safety standards with any wiring modifications. Second, GBG is a partnership where cars are modified with kids and families rather than for kids and families. This is a critical distinction, because design can be unsuccessful when users are not part of the process. Finally, keep it simple. Any modifications should be necessary and low profile to keep the focus on fun.

Other individuals or organizations are not looking to build cars but would like to increase the availability of cars to share with specific families or for general use in community spaces. Community partnerships are an effective strategy to connect donors, families

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LET'S GO BABY GO!

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and builders. For example, STEM classrooms from elementary school through high school are frequently looking for projects that involve skill building and community outreach and, simultaneously, local businesses such as car dealerships are ready to fund a community project. A local therapy clinic can complete the partnership by introducing these collaborators to a driver who is ready to roll. Once established, these partnerships can be a sustainable source of cars for the community.

Finally, GBG participation includes partnering with the disability community to prioritize mobility experiences and opportunities for young children. For instance, the availability of modified cars in public spaces such as children's museums, parks and libraries, provides kids of all abilities the opportunity to be part of the action as well as providing inclusive programing for young children that encourages a variety of mobility strategies. Let's reframe mobility conversations toward an evolving collaboration with families that embraces and celebrates the dynamic nature of early childhood.

Siblings building for siblings, World DS Conference

Smiles for miles!

"As a parent with a child who has limited mobility due to significant developmental delays, it makes access to typical play and normal socialization activities really challenging. The cars allowed my son to explore and see whatever environment he was in. He explored our yard, our neighborhood, he went to some community events and explored parts of the zoo, botanical gardens, and children's museum in the car. Most kids walk and run around these places. My son cannot. Oftentimes the car allows him to make some choices as to what to explore."

- Sarah (mother of Max)

Scan the QR codes to watch videos about GoBabyGo

Video 1: GoBabyGo Goes to Cleveland and teams up with UCP and National Interstate Insurance for an amazing day.

Video 2: Team 1939 and GoBabyGo 2018

Collectively, we have a responsibility to not only raise awareness but, most importantly, to also be active in reducing the mobility inequity gap.

Now let's Go Baby Go! To get involved now, email gobabygomobile@gmail.com or Google "Go Baby Go" in your city or state.

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Andrina Sabet, PT, ATP, is a physical therapist at the Cleveland Clinic Children's Hospital for Rehabilitation and owner of Mobility Matters, LLC. Her clinical practice includes infants and toddlers through young adults in the Mobility and Seating Clinic, where independent mobility options are a focus for every client. She is the national projects coordinator with Go Baby Go, a grassroots, open-source movement centered on social mobility opportunities, clinical research and technological innovation. Sabet has presented locally and internationally on mobility and positioning and frequently collaborates with manufacturers regarding product development.

POWER MOBILITY: THE KEY TO MY SUCCESSFUL CHILDHOOD

Written by: **JENNY SIEGLE, BA**

I cannot remember a time in my life I did not use a wheelchair for my daily mobility. I was paralyzed at 9 months old from a rare virus, transverse myelitis. It was the first time I was ever sick as a baby. I had the flu, and my mom took me to my pediatrician's office that morning. By that afternoon, I was experiencing spreading paralysis. I spent the next three months in the hospital and was diagnosed with an incomplete spinal cord injury at the C4/C5 level. I was originally paralyzed from the neck down and could only move my head from side to side (See Figure 1).

FIGURE 1 Jenny Seigle after she was paralyzed with her sister, Shanon

THE NEED FOR EARLY MOBILITY

I was incredibly blessed to have the medical team that I had, but I was even more blessed to have a family to fight for me when I was too young to fight for myself. We were originally told I would likely never get out of bed. My mom did not accept that fact and was determined to get me whatever I needed to be a happy and productive child. One of the first things she fought for was a power wheelchair. Despite being paralyzed, I was an active and energetic toddler. I can remember my mom saying she couldn't keep up with me, and I needed to be able to go where I wanted to on my own. In 1984, at 2 years old, I became the first child in the state of Colorado to get a power wheelchair. It was an Everest and Jennings, and I absolutely loved it (See Figures 2 and 3)! It was the first time I could move around independently. It also gave me the opportunity to learn how to play with other kids. My sister and I were close to our cousins, so we would often be together. One of our favorite things to do was hang a sheet on the clothesline, and I would be on one side, and they would lay on their bellies on the other side. I would then drive through the sheet. When they saw me coming, they would run away, and I would try to chase them!

MOBILITY NEEDS MOVE OUTSIDE

As I got older, my family and I realized how important it would be for my next power wheelchair to be able to navigate outdoor terrain and have a longer battery life. I was a tomboy growing up, and the majority of my friends were boys. I loved sports as well so, needless to say, I was always on the go! When my friends would be outside

FIGURE 2 Jenny Siegle, 3, in her first power wheelchair, an Everest & Jennings, with her mom, Barb, and sister, Shanon.

IN 1984, AT 2 YEARS OLD, I BECAME THE FIRST CHILD IN THE STATE OF COLORADO TO GET A POWER WHEELCHAIR.

FIGURE 3 Jenny Siegle at 5 years old in her first power wheelchair, an Everest and Jennings.

> **AS I GOT OLDER, MY FAMILY AND I REALIZED HOW IMPORTANT IT WOULD BE FOR MY NEXT POWER WHEELCHAIR TO BE ABLE TO NAVIGATE OUTDOOR TERRAIN AND HAVE A LONGER BATTERY LIFE.**

riding their skateboards, I would be pulling them along with my power wheelchair. I could also be found on a half-pipe or playing football and basketball.

The second power wheelchair I had was an Arrow XT (See Figure 4). I got it when I was in elementary school, and it was perfect! We called it my 'mountain mover,' and I definitely tested its limits! We did a lot of camping with my best friend's family, and it was during a specific trip my wheelchair earned its nickname. My friend and I were out exploring, and we found a beaver dam. He wanted me to see it, so we got as close as we could without getting my wheelchair stuck, or fully stuck I should say! He and our other friend had to push me through the muddier areas, but we made it. We had some explaining to do when we returned to the campsite covered in mud past our knees, me included!

This power wheelchair also gave me the opportunity to participate in many memorable activities. I was named an Ambassador Child for the Children's Hospital in 1991. One of my main responsibilities was to represent the hospital at fundraising events. Two of my favorite appearances were the Run for a Child's Sake race (See Figure 5) and when I was able to play on the basketball court with Denver Nuggets point guard Michael Adams during halftime. Perhaps my biggest honor though was when I was one of two kids selected to appear in a Perry Mason movie (See Figure 6).

MOBILITY NEEDS STAND UP!

As I continued to get older, my needs started to change again. During my elementary school years, I attended physical and occupational therapy sessions, including a home program. But when I began

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FIGURE 4 Jenny Siegle at 9 years old in her second power wheelchair, an Arrow XT. She is with her friend, Nick, at their field day in elementary school.

FIGURE 5 Jenny Siegle at 9 years old with Denver Broncos wide receiver Mark Jackson at Run for a Child's Sake.

FIGURE 6 Jenny Siegle at 9 years old with Raymond Burr and the cast from "Perry Mason: The Case of the Glass Coffin."

POWER MOBILITY ...

(CONTINUED FROM PAGE 31)

middle school and became more involved with extracurricular activities, I had less free time for therapy. My rehab doctor told us about a new power wheelchair that would also give me the option to stand. The Hi-Rider (See Figures 7 and 8) allowed me to attend everything I wanted to, but still get the weight bearing and range my legs needed.

I used a Hi-Rider power wheelchair until my junior year of college. At this point, I started thinking about the next chapter of my life. I was majoring in journalism and mass communications with an emphasis in telecommunications and minoring in speech communication at the University of Northern Colorado. I wanted to be a sports broadcaster, so I did my first internship at an NBC affiliate in Denver, Colorado, and saw how small the control room and edit bays were. Unfortunately, I realized the Hi-Rider was not going to work for me as a young adult as the base was wide and maneuvering in small spaces was difficult with a rear wheel drive. Also, the Hi-Rider was no longer being manufactured, so it was nearly impossible to find replacement parts.

FIGURE 7 Jenny Siegle at 14 years old with the Westminster High School girls' basketball team. She was the team's manager.

NO MATTER WHICH POWER WHEELCHAIR I CHOOSE TO USE NEXT AS AN ADULT, THERE ARE TWO POINTS OF CRITERIA THAT REMAIN THE SAME. IT MUST BE ABLE TO HANDLE AND KEEP UP WITH MY ACTIVE LIFESTYLE.

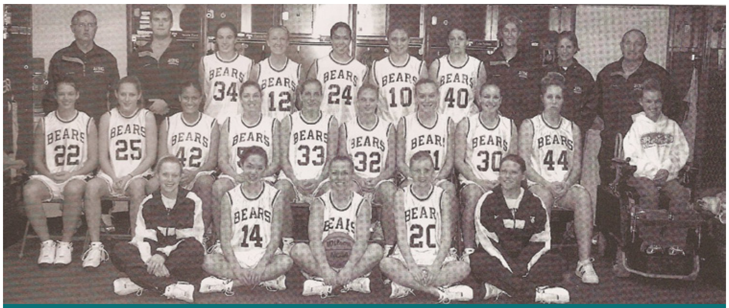
FIGURE 8 Jenny Siegle at 21 years old with the University of Northern Colorado's women's basketball team. She was the team's manager.


FIGURE 9 Jenny Siegle as Miss Wheelchair Colorado with her parents, Rob and Barb Siegle

With the help of my therapists at Craig Hospital and after doing some research, I decided the TDX SP would be my next power wheelchair (See Figure 9). I continued to spend a lot of time outdoors, especially during my internships, so the mid-wheel drive option was a game changer. The TDX SP had a narrow wheelbase as well so I had access everywhere I needed to at a news station.

CONCLUSION

Selecting a power wheelchair has always been based around what my needs are at that time. No matter which power wheelchair I choose to use next as an adult, there are two points of criteria that remain the same. It must be able to handle and keep up with my active lifestyle.

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Jenny Siegle is a full-time producer for Altitude Sports in Denver, Colorado. After working in this industry for almost two decades, Siegle knows sports fans want to get the headlines but have it delivered in a unique and entertaining way. In addition to her productions that air on Altitude Sports, Siegle's work has landed in publications such as Mile High Sports Magazine and the Buffalo Stampede. Siegle also works as a replay operator for the Colorado Rockies during baseball season, and in 2021 she joined the Denver Broncos public relations game day staff.

She is currently producing "You Bet Tonight," a new sports betting show that launched in October 2021. Some of her other productions include the "Fantasy Football Hour," a nationally syndicated show that airs coast to coast: "Let's Talk Sports" with Vic Lombardi, Colorado Rapids pre-games and games, Colorado Mammoth games, and various sporting events for the University of Denver. Siegle had the privilege of covering the 2007 World Series, the Super Bowl 50 victory parade, and the Colorado Avalanche and Denver Nuggets playoff runs in 2019. Additionally, she coordinates, produces and posts content for Altitude Sports' social media platforms.

Siegle was Miss Wheelchair Colorado in 2004, enjoys public speaking and is a disability advocate.

She graduated with a Bachelor of Arts in Journalism and Mass Communications from the University of Northern Colorado in 2004.

A PARENT'S PERSPECTIVE ON PEDIATRIC POWER MOBILITY

Written by: **MICHELLE L. LANGE, OTR/L, ABDA, ATP/SMS**

MEET ASHER

Kory, Elizabeth and their two boys are a typical busy family in Missouri. Kory worked in communications at a nonprofit, and Elizabeth is a school psychologist. The family was excited to welcome their third child, Asher. After Asher's midwives noticed some progressive weakness and loss of reflexes, his pediatrician admitted him for a neurological and genetic evaluation, and he was diagnosed with spinal muscular atrophy, type 1 (SMA) at just 1 month of age. Within a week of his diagnosis, he began treatments to help slow the progress of this disease; but in the meantime, Asher also developed a cold, was intubated and had to be airlifted to the St. Louis Children's PICU. Eventually, he underwent a tracheotomy to manage his chronic respiratory issues and copious secretions. Today, he has a mostly stable airway but still sometimes needs suctioning, mechanical coughs, ventilation, and occasionally, supplemental oxygen. Asher also has a gastrostomy tube and is not currently eating by mouth. He was born with a right club foot which, in the past, would most likely not have been treated as improbable ambulation. As newer medications and gene therapies have changed the prognosis for children with SMA, his parents decided to have it surgically corrected. Finally, Asher has developed some scoliosis and wears a TLSO about 60% of the time. Due to Asher's medical needs, Kory left his work position and has been a stay-at-home dad ever since (he likes to call himself the "CEO" of Asher's complex care).

Asher is now 3 years old and can sit independently and stand with assistance. His primary language is American Sign Language (ASL); however, he is beginning to vocalize around his trach often, especially when using a Passy Muir valve. He also has a communication device to help him speak clearly. He is in preschool and loves "Blippi" videos and nature documentaries, being outside, taking walks and swinging, anything with wheels, and music. And, he is an amazing power wheelchair driver!

ASHER'S EQUIPMENT JOURNEY

Asher received an adaptive stroller as an infant (See Figure 1). This not only provided a dependent mobility base and postural support for Asher but also supported his extensive medical equipment and supplies. Before age 2, his family was already exploring a manual wheelchair to provide some independent mobility for their youngest son. The Panthera Micro allowed Asher to propel short distances, exploring his environment at peer level (See Figure 2). If the family went anywhere, they brought along a wagon to carry all his equipment and supplies. He also began using a gait trainer, which provided limited mobility and weight bearing. Asher works with Keith Jolicoeur, ATP, CRTS® at Alliance Rehab and Medical Equipment. It was very important to Kory and Elizabeth to have everyone on the same team. If someone was not on board or seemed disinterested or unconvinced about giving Asher a fair shot at independence, they were not eager to work with them.

Kory and Elizabeth were the first to bring up power mobility. Despite having some independent mobility, Asher was getting frustrated he couldn't keep up with his brothers and peers. They knew Asher would need to navigate school and keep up with the other kids in the future. His parents brought this up to his therapists who arranged for Asher to try several devices, such as an

FIGURE 1 Asher in his adaptive stroller.

FIGURE 2 Asher in his manual wheelchair having fun bowling!

adapted ride-on car and a Permobil Explorer Mini, while at therapy. Although he did well with each of these options, his parents realized Asher would eventually need a power wheelchair to truly get him mobile in his community; he was ready now, and there was no reason to delay.

Asher proceeded to trial five different pediatric power wheelchairs in the therapy gym during the summer of 2020, between the time he was 18 and 24 months of age. He was able to drive using a joystick placed at midline, primarily using his left hand. During this time Asher's skills improved, and his therapists had plenty of justification for their Letter of Medical Necessity. The family narrowed down the field to a few options, which Asher also trialed at home. His driving was best in the home with the Quantum Rehab Stretto, which he seemed to navigate intuitively. He was able to navigate hallways and corners even before the paperwork was filed! His parents also appreciated the small footprint, as he had quite a bit of equipment to carry around.

The team discussed the recommendations in detail. Kory and Elizabeth appreciated being involved in each decision. Asher appreciated picking out colors! A power tilt, recline and elevate were recommended, as well as an appropriate seating system. Keith and the team at Alliance worked hand-in-hand with Asher and his parents to custom fabricate all of the extra equipment-toting pieces that were not available for the chair from the manufacturer.

The power wheelchair was funded on the first submission, and Asher received his very own power wheelchair in March 2021 at age 2 ½

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> IT'S NOT JUST INDEPENDENCE FOR HIM. IT'S INDEPENDENCE FOR OUR FAMILY.

> "When working with Asher and his family, I was excited to see they were open to trying power mobility with him. Asher and his family are exceptional people who don't let life's challenges hold them back, and they are always trying to find ways to allow Asher to be as independent as possible. It has been my experience with kids, no matter their age or disability, find a way to surprise us and often do much more than what we think they can. Working with someone who has SMA can be challenging as they will require a specific set up due to their active range of motion and strength limitations. These children will also require a programmed chair to meet their limitations. With patience, perseverance, and a team who is willing to try, I believe in most cases you will have a successful outcome."
>
> - Keith Jolicoeur ATP, CRTS®

A PARENT'S PERSPECTIVE ...
(CONTINUED FROM PAGE 35)

years (See Figure 3). Asher didn't receive very much mobility training as he had practiced quite a bit during the power wheelchair trials and was quite proficient. After initial programming, Asher began practicing with his family.

A FAMILY'S JOURNEY

Before Asher began trialing power wheelchairs, the family had moved into a home with a ramp at the garage door entrance and off the back deck. Once they were comfortable, the power wheelchair would be funded, his parents began looking at accessible vehicles. They were able to purchase a full-size van and convert it with a lift right before a very special extended family vacation in summer 2021 to Disney World! The family drove Asher, his brothers, his beloved medical assistant, his power wheelchair, and lots of equipment and medical supplies to Florida. Despite his young age (nearly 3 years old at this point), Asher was able to drive with supervision about 50% of the time the family was in the park (See Figure 4). The primary reason caregivers took over driving the rest of the time was because of large crowds.

FIGURE 3 Asher in his power wheelchair in the new adaptive van.

When asked about power mobility limitations, Kory stated Asher can drive up the driveway and ramp into the home, but it is hard to open the door. It is also hard to drive up to the dinner table, as the armrests and joystick are level with the table surface. The power wheelchair is bulky at preschool, and Asher prefers to be in the gait trainer in the classroom, because it is easier to get up to a table next to a peer. Asher doesn't use the recline as much as anticipated, as he has "too much stuff" behind the back of the wheelchair.

When asked what the family likes about the power wheelchair, Kory states they haven't had a lot of issues. The power wheelchair has performed nicely, is an appropriate size for Asher, and works well in the house. Programming the driving parameters was critical, and he was very appreciative of Alliance doing such a good job. Kory also likes they can mount Asher's communication device and other items readily to the Stretto. The power wheelchair created a level of stress-relief for all of his caregivers, as well, especially when facing rougher surfaces and inclines where Asher struggles to stay safe and mobile in his manual devices. And since much of his emergency equipment, such as the vent, has a designated space on the power wheelchair, it is easier and less time consuming to leave the house. Packing up to go anywhere used to take up to 2 hours – and now takes about 30 minutes.

Asher is an adorable little boy who is exploring his world and participating not only because of his own amazing skills but also due to his parent's desire and passion for him to reach his full potential!

FIGURE 4 Asher and his family at Disney World!

Scan the QR code to watch the following videos

Video 1: Asher's first Easter egg hunt.

Video 2: Asher trying an adaptive ride-on car and the Permobil Explorer Mini.

Video 3: Asher driving his power wheelchair outside!

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Michelle Lange, OTR/L, ABDA, ATP/SMS, is an occupational therapist with 35 years of experience and has been in private practice, Access to Independence, for over 15 years. She is a well-respected lecturer, both nationally and internationally, and has authored numerous texts, chapters and articles. She is the co-editor of Seating and Wheeled Mobility: a clinical resource guide, editor of Fundamentals in Assistive Technology, Fourth Edition NRRTS Continuing Education Curriculum Coordinator and Clinical Editor of NRRTS DIRECTIONS magazine. Lange is a RESNA Fellow and member of the Clinician Task Force. She is a certified ATP, certified SMS and is a senior disability analyst of the ABDA.

REHAB CASE STUDY

PEDIATRIC POWER MOBILITY CASE STUDY: LYDIA

Written by: **STEFANIE SUKSTORF LAURENCE, OT REG. (ONT)**

Who initiates the decision to pursue power mobility for a child? A parent with their child's needs at heart? A therapist with a clinical feel? A sales rep with a questioning mind?

And what roadblocks prevent the pursuit of power mobility from moving forward? Physical, cognitive or emotional shortcomings of the child? Fear or lack of commitment by team members? Accessibility barriers? Cost? Lack of opportunity?

Whether verbalized or unspoken, all these factors arise when evaluating a child for seating and mobility — which brings me to my story about one little girl.

MEET LYDIA

I met Lydia in October 2018 after being asked to assist in creating custom seating for her. At the time she was 3 years old, with a diagnosis of nemaline rod myopathy. She was using a ventilator and fully dependent for her care secondary to global hypotonia. But she had a twinkle in her eye and a non-stop chatter of questions, comments and songs - albeit muffled due to her profound muscle weakness. She lived at home with her parents and dog in a small split-level bungalow in Northern Ontario. She was supported by both the care team at her local children's treatment center and community mobility supplier. But she was at least an eight-hour drive (or a non-urgent ambulance flight) from any provincial treatment center that was experienced with a client of her complexity.

THE NEED

Up to this point, she had been using a Thomashilfen adaptive stroller for her positioning and mobility but, as she had grown, the local team reported the seating system was no longer providing adequate trunk support (See Figure 1). I flew up to assist with the shape capture of a custom seating system, and the prescription of a new manual tilt wheelchair that could accommodate her ventilator, humidifier, suction machine, cough assist and associated medical supplies (See Figure 2). The idea of power had been floated by her mother, but more to accommodate the volume of her equipment than to provide independent mobility. Funding for power was not an option as she could not drive a power chair herself.

FIGURE 1 Despite modifications, Lydia's trunk would collapse in her seating – 2018.

FIGURE 2 Lydia molded for new seating – 2018.

THE SEATING THERAPIST WAS ABLE TO JURY-RIG A SEATING SYSTEM INTO A CHAIR WITH POWER TILT, AND TRIALS WITH A MICRO JOYSTICK WERE UNDERWAY.


FIGURE 3 Assessing upper extremity supports – 2021.

Despite her profound weakness, Lydia had the ability to manipulate small, light toys with her fingers when her arms were well-supported. Her mom, Megan, fashioned small supports under her wrists that could easily slide on her tray to enable lateral movement of her hands. This minor adaptation was just one of many small but ingenious creations that mom fabricated to capitalize on Lydia's abilities.

Fast forward to October 2021. In the intervening three years, Lydia had continued to thrive and grow. She was followed at a provincial children's center twice a year for medical needs, and the therapy team there, excited by the potential of new modular equipment, had prescribed a modular cushion and back with lateral trunk support for her manual tilt chair. Despite their best efforts, the back was too soft and just not able to provide enough support through Lydia's trunk to maintain her comfort and breathing. Mom inquired about going back to a custom seating system.

POWER WHEELCHAIR ASSESSMENT

Lydia was scheduled to be at the provincial treatment center for one week for her biannual medical appointments. The plan included assessment at the seating clinic for her ability to learn to drive a power chair. Government funding in Ontario only covers one primary wheelchair for mobility and the seating mounted in that chair. I initially met with mom and the seating therapist to discuss options and outline a game plan.

Lydia was demonstrating promising skills in maneuvering a power chair. The seating therapist was able to jury-rig a seating system into a chair with power tilt, and trials with a micro joystick were underway. Numerous set-ups were trialed to support her upper extremities to maximize her limited strength and range of movements. They even included using those little wedges mom designed previously. These components were finicky but were a better option than the overhead arm slings mom had fashioned to create gravity eliminated movement for Lydia in the manual chair (Did I tell you this mom really should be considered an honorary occupational therapist?) (See Figure 3). Scan the QR code located at the end of the article to view videos of Lydia driving during the assessment.

The dilemma was what to do about her seating. Should a power chair be prescribed with new seating – but she was only in the initial stages of use – or should the seating be prescribed for her manual chair, potentially interfering with getting new seating for the power chair in the future?

Compounding the dilemma had been COVID. The family lived in a very small split-level house with very little room for a power chair to maneuver. Lydia would continue to need a manual chair, and they did not even have a garage in which to store an extra chair. House prices had soared during the pandemic, pushing the

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> THE DILEMMAS THIS FAMILY WERE MULLING OVER WERE NOT UNIQUE. WE JUST DIDN'T TEND TO SEE ALL OF THESE BARRIERS IN ONE CLIENT SITUATION.

PEDIATRIC POWER MOBILITY CASE STUDY …

(CONTINUED FROM PAGE 39)

dream to move to a more accessible home into the distant future. Due to Lydia's medical complexity and COVID, she was not attending in-person school, so utilizing the school as a place for driver training was out of the question, even if we could secure a chair for trial. And winter had already descended on her home community, so outdoor training was also off the table for at least another six months, as were community settings where she might risk virus exposure.

All options were laid out to the parents. I continue to be in awe of this family's dedication and resourcefulness for their daughter as they processed information, asked questions and problem solved barriers. Funding windows, product options, using their accessible van to store an extra chair, developmental goals – nothing was off the table. The dilemmas this family were mulling over were not unique. We just didn't tend to see all of these barriers in one client situation.

FIGURE 4 Lydia gifted her favorite sales rep with a special thank you for her new manual chair and seating - 2019.

In the end, the decision was made to proceed with a new seating prescription for the manual wheelchair. The prescribing therapist did not feel comfortable enough to prescribe a power chair with power tilt and all the customizations Lydia would require at that point in time. The modular cushion was working, so we only needed to mold her for a new custom back. Hardware was selected to allow mounting of this back to a power chair in the future, if needed. I had hoped we could consider a different custom back to allow a little more ability to change on the fly but respected the family's wish to have something tried and true. I suspect distance from resources certainly played into their decision. In the interim, her old custom molded back was resurrected. When we molded for the new back, I took a plaster cast of the current shape. This was used to guide cutting and carving to accommodate for Lydia's growth – less than ideal, but more supportive than the modular back.

THE FUTURE

The plan is to retry the power chair at her next biannual appointment. We are hoping to have the new back in place and gain benefit from the support it can offer. Would the plan have been different if she lived closer to resources? Perhaps, but one thing is for certain, the commitment by her family and team to achieve the best outcome for Lydia is unrivaled (See Figure 4).

Scan the QR code to watch the following videos:

Video 1: Lydia driving an evaluation power wheelchair during her assessment.
Video Credit – Tara Prevail, Children's Hospital, Eastern Ontario

Video 2: Lydia driving an evaluation power wheelchair during her assessment – front view
Video Credit – Tara Prevail, Children's Hospital, Eastern Ontario

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Special thanks to the seating team at Children's Hospital in Eastern Ontario.

Stefanie Sukstorf Laurence is an occupational therapist who has been working with people with special needs in a variety of settings and roles for over 40 years; the last 34 as an occupational therapist. While the terms wheelchair lady, commode queen, seating specialist and equipment geek have all been used as worthy descriptors, she is the clinical educator for Motion across Canada. When she's not on her soapbox at colleges, universities, group homes, hospitals and conferences across North America and even as far as Europe, you can find her with her arms wrapped around a client helping to create a custom seating system or elbows deep with a team to sort out a challenge. Laurence is a NRRTS Registrant and NRRTS.

TEAMWORK & CONSENSUS BUILDING

Written by: **LISA ROTELLI**

Navigating the complex needs of children with multiple disabilities can be challenging.

So can navigating the large amount of people working with a child – each with their own goals and ideas. Many children with a disability have an overwhelming number of adults and professionals working with them daily. Parents are trying to decipher all the information they are getting from each person, all while wanting their child to be able to participate with those around them.

Some of the people included in this process are:
- Aide
- Teacher
- School OT/ Clinic OT/ Private OT
- School PT/ Clinic PT / Private PT
- School AT professional
- Speech language pathologist (SLP)
- Vision therapist
- And more

Each of these people has their own goals, expectations and judgment of the capabilities of the child, and rarely do any of them match.

Imagine being judged by this many people, with their own tests and expectations. Our education system is set-up to test capabilities of all children and then teach to minimize any deficiencies. This simply does not work for children with multiple disabilities. Motor pathways develop from experience, which these children are sorely lacking in.

We must use a different approach when we are not sure what the child understands. For this reason, starting with motor learning can diminish doubt in a child's potential. Augmenting mobility with consistent and easy access develops understanding, expression, wants and likes. This process develops both switch sites and training protocols. Once we understand access and training requirements, we can develop lessons, goals and expectations. Literally "Moving to Learn."

> EVERY PERSON ON THIS TEAM HAS A ROLE AND OBLIGATION TO HELP A CHILD GROW AND LEARN, STARTING WITH THE BELIEF AND KNOWLEDGE ALL CHILDREN LEARN THROUGH ACTIVITY AND EXPERIENCE.

If the team members cannot agree on whether to use powered mobility as a clinical tool for learning and how to do so, the child will not have the opportunity to move past being tested on things that they may not understand — let alone be successful at expressing understanding. Building consensus is key.

Every person on this team has a role and obligation to help a child grow and learn, starting with the belief and knowledge all children learn through activity and experience. The entire team should be a part of developing an activity to encompass all their professional requirements.

For example, activity-based mobility training is not just addressed by occupational and physical therapists. Depending on the age and experience of the student, the following team members can participate:
- Teacher: Colors, numbers, letters and whatever the rest of the class is learning.
- Physical and occupational therapists: Mobility, manipulating objects.
- Speech/School Assistive Technology Professionals: Understanding the use of augmentative communication devices, communicating, writing.
- Aide: Training and care of the student, supporting wants and needs.

Designing an activity with all the goals and needs of each team member is critical and continues to build consensus.

An Example:

A power wheelchair set-up for access with switches must use consistent switch placement. One switch assigned for each direction that will be required, going to something, and turning to get something. The power wheelchair or the switches are not the activity. Getting to the designated activity is.

If the classroom is learning numbers or colors, have multiple stations set up along a route with colored objects to pick up and take. The end goal may be gathering one of each color and then counting how many as the objects are placed in a basket. The child can also use an AAC device with one of the driving switches to communicate how many colors, which colors, or where the colors went.

In this example, giving a child experience with colors and counting can be used to work on educational concepts, communication and even mobility. This is oversimplified and needs to have meaning for the child but is an example of how we can work as a team for the development of a child and not in isolation on our own goals. This type of training is supporting motor development that you can build on — going, stopping, turning, navigating and communicating.

Certainly, everyone can get on board with teaching activities to support development.

Everyone on the team needs to be a part of this educational path. We must stop testing and start teaching to achieve positive outcomes.

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Lisa Rotelli, director of Adaptive Switch Laboratories Inc., has had a lifetime of experience starting as a clinical coordinator for a rehab hospital in Northern California. She also served as a rehab manager for a large rehab equipment supplier and a rehab specialist for one of the major manufacturers of rehab wheelchairs. She is certified by the University of Tennessee at Memphis as a seating specialist and the University of Misericordia in Pennsylvania in pediatric seating. She specializes in alternative access and drive control systems and has designed several drive control systems for severely involved clients. She presents at national conferences to all levels of clinical therapists, suppliers and educators.

DOCUMENTATION & FUNDING CONSIDERATIONS FOR PEDIATRIC POWER MOBILITY

Written by: **JENNITH BERNSTEIN, PT, DPT, ATP/SMS, AND JIM STEPHENSON**

The difference in the provision of Complex Rehabilitation Technology (CRT) between adults and children does not stop once the evaluation and equipment recommendations have been completed. The next steps of funding and procurement are equally specific. This article will highlight some of the keys to success when documenting and funding pediatric power mobility including how to define functional independence, what the push of "least costly alternative" could mean for children, how to proceed when something does not fit into a specific code, and useful resources.

To begin, pediatric power mobility is often treated the same way as adult power mobility meaning a child must have a certain level of independence with daily tasks or a specific competence with power wheelchair skills. The first task in documentation is clearly defining what "independence" means for a child. First, this should be age and developmentally appropriate. For example, one would not expect any 2 year old to navigate to and from a destination without adult supervision (Jones, McEwen and Neas, 2012; Kenyon, Mortenson & Miller, 2018). Second, depending on the age and developmental level of the child, self-initiated mobility can simply provide movement for movement's sake, develop neural pathways and facilitate exploration of the environment. If a child is older or at an advanced learner stage when being evaluated for power mobility, mobility may be more destination focused and task-specific (Bray, 2020) (See Figure 1).

FIGURE 1 Play as an activity

A common misconception in documenting for pediatric power mobility is a child must be "ready" to drive.

FIGURE 2 Example of a photo diary

Available standardized measures should be used to determine readiness and not independence. No single prerequisite skill is required to initiate power mobility skill training, rather skill development unfolds through driving (Nilsson and Durkin, 2014). As described in "A Guideline to Introducing Powered Mobility to Infants and Toddlers" by Feldner, Plummer and Hendry, the authors state "[t]here is no expectation of pre-existing abilities, rather abilities emerge through interaction, trial and error and guidance." In addition to written documentation, using a photo narrative or diary to compare equipment trials can be very useful in the pediatric population to paint a picture of how the correct equipment can make a difference (Feldner, Logan and Galloway, 2019) (See Figure 2).

Funding in the United States for pediatric power mobility can go down several different paths as typically directed by Centers for Medicare and Medicaid Services (CMS) coding policies. Equipment may be categorized as Group 5, which is specific to pediatrics; Group 3, which is for general complex rehab; or products that don't fall within a specific group or HCPCS code.

FIGURE 3 Example of Group 5 power wheelchair

GROUP 5

Group 5 power wheelchairs are built specifically for pediatric clients' needs. These have a smaller footprint and include adjustability for growth (See Figure 3). There are only two HCPCS codes (K0890-K0891) in this group with a limited number of product options available. Some payers may not recognize Group 5 codes nor have set fee schedule amounts for reimbursement. This uncertainty can slow the funding process and lead to some equipment suppliers being hesitant to use these codes.

Group 5 power wheelchairs often include a lower seat to floor height appropriate for preschool height tabletop and peer-level activities as well as developmental exploration of the environment (See Figure 4). Group 5 power wheelchairs typically have a shorter and narrower base with the seating system appropriately sized and balanced over the base to enhance maneuverability and intuitive driving.

GROUP 3

Group 3 power wheelchairs are typically built for adult complex rehab clients but can be available with smaller size seating systems to create pediatric solutions (See Figure 5). There are multiple HCPCS codes (K0848-K0864) in this group with a much broader selection of products to choose from. Most payers recognize the codes in Group 3 and have set fee schedules in place, which provide more confidence in navigating the funding process.

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> **NO SINGLE PRE-REQUISITE SKILL IS REQUIRED TO INITIATE POWER MOBILITY SKILL TRAINING, RATHER SKILL DEVELOPMENT UNFOLDS THROUGH DRIVING.**

FIGURE 4 Example of low STF height on Group 5 PWC.

FIGURE 5 Group 3 power wheelchair with pediatric seating.

DOCUMENTATION AND FUNDING ...
(CONTINUED FROM PAGE 45)

TYPICAL PERFORMANCE REQUIREMENTS:

	Group 5	***Group 3***
Weight capacity	Up to and including 125 lbs., although some do go up to 165 lbs	Up to and including 300 lbs.
Length	≤ 48 inches	≤ 48 inches
Width	≤ 28 inches	≤ 34 inches
Minimum Speed	4 miles per hour	4.5 miles per hour
Minimum Range	12 miles	12 miles
Obstacle Climb	60 mm	60 mm
Stability Incline	9 degrees	7.5 degrees

NO GROUP OR HCPCS CODE

Some products on the market do not neatly fit in any group or HCPCS code. This doesn't prevent anyone from providing the products, but it means there are no specific code or coverage guidelines to follow. Not otherwise specified codes, such as E1239, can be used in these scenarios. The documentation should clearly explain what the product is and how it is the best solution to meet the individual's needs. This should include why a Group 3 or Group 5 solution is not appropriate.

LEAST COSTLY ALTERNATIVE

The term "least costly alternative" is used by payers to ensure clients' needs are met at the least possible expense, not only for themselves but also the client. Least costly alternatives for pediatric power are often dependent mobility solutions. So, it is important to thoroughly document the value of autonomy and self-directed mobility and the child's ability or potential ability to safely operate a power wheelchair.

CONSIDERATIONS FOR CANADIAN DOCUMENTATION AND FUNDING

Power mobility device documentation for all populations varies extensively from province to province in Canada, and there could also be variations within a specific jurisdiction. When documenting for pediatric power, know the policies of the source you are applying to and use the information above to reply directly to the questions required by the funding source. Use as much comparative support as possible that can be related to specific chair characteristics, as mentioned above.

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RESOURCES:

1. POLICY ARTICLE FOR CODE REQUIREMENTS FOR CMS: ARTICLE – POWER MOBILITY DEVICES – POLICWWWY ARTICLE (A52498) (CMS.GOV)
2. ASSISTANCE WITH WORDING AND LETTER CONSTRUCTION: LMN GENERATOR WWW.PERMOBILLMN.COM
3. INFORMATION ABOUT HOW TO BILL AN ITEM WITHOUT A CODE. FUNDING ALTERNATIVE FOR EXPLORER MINI (US)
4. CONTACT INFORMATION FOR FURTHER ASSISTANCE WITH FUNDING:
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Jennith Bernstein, PT, DPT, ATP/SMS, is a physical therapist based in Atlanta, Georgia. She worked at The Shepherd Center, focusing her time in the Wheelchair Seating Clinic. Bernstein completed her Master in Physical Therapy at North Georgia College & State University and transitional Doctor of Physical Therapy at the University of Texas Medical Branch. Bernstein has presented at national and international conferences such as RESNA, ISS, LASS, Expo Ortopedica, and the APTA NEXT and CSM conferences. She joined Permobil in 2016 as a clinical education manager for the central region and started in November 2021 as clinical affairs manager.

Jim Stephenson is the reimbursement and coding manager at Permobil. Over the past three decades, he has worked on all sides of the health care reimbursement spectrum, the last 18 years in the Complex Rehab Technology/Durable Medical Equipment industry. His broad background has provided him with vast experience and a unique perspective in working with payers, providers, physicians/clinicians and consumers. He is a member of the DME MAC Advisory Councils, Complex Rehab and Mobility Council (CRMC), Regulatory Council for AA Homecare, and several state associations. At Permobil, he works closely with the product development, clinical education, sales and marketing teams.

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