Use of Power Mobility for a Young Child With Spinal Muscular Atrophy

**Background and Purpose.** Young children with severe motor impairments, such as spinal muscular atrophy, are often unable to move around their environment independently; therefore, they may be at risk for delays in areas of development not directly related to their motor limitations. Power mobility is an intervention that provides young children a means of independent movement and enables them to independently explore their environment. **Case Description.** The participant was a 20-month-old girl with type II spinal muscular atrophy. **Intervention.** The authors provided the child with a power wheelchair and gave her mother and physical therapist general guidelines to encourage her use of the power wheelchair. **Outcomes.** Within 6 weeks after receiving the power wheelchair, the child operated the wheelchair independently. She showed developmental gains in all domains of the Battelle Developmental Inventory and the Pediatric Evaluation of Disability Inventory over 6 months. The authors conducted an interview with the child’s mother before and after intervention. She reported that the child was more independent after receiving the power wheelchair. **Discussion.** The power wheelchair may have been associated with the changes in the child’s mobility and her developmental changes over 6 months. [Jones MA, McEwen IR, Hansen L. Use of power mobility for a young child with spinal muscular atrophy. *Phys Ther.* 2003;83:253–262.]

**Key Words:** Developmental skills, Power mobility, Young children.

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Motor skills develop rapidly during the first 3 years of a child’s life\(^1\) and provide a means for exploration of the environment and socialization with others. For children with severe neuromuscular or musculoskeletal impairments, exploration and socialization often are limited because of the difficulty these children have moving on their own.\(^2,3\) Power mobility devices allow children with severe physical disabilities to move independently within their environment and to compensate for mobility limitations. Hays\(^4\) identified 4 categories of children who are thought to benefit from power mobility, including children who: (1) will never walk, (2) cannot efficiently move in a walker or manual wheelchair, (3) lose their ability to move as the result of a traumatic injury or progressive neuromuscular disorder, and (4) require temporary assistance for mobility, most commonly due to surgical intervention. For children in each of these categories, power mobility is believed to promote independence and prevent functional limitations and disabilities that the children otherwise might encounter.\(^4,5\)

Even though children with disabilities under the age of 3 years experience functional limitations and disabilities similar to those of older children and adults, physical therapists often do not consider power mobility as an option to assist young children.\(^2\) Advocates for power mobility consider it an essential component of a child’s early intervention program\(^2,6,7\) and have demonstrated that young children are capable of successfully using power mobility.\(^8–12\) Only one child less than 2 years of age has been shown to use power mobility,\(^12\) and our case report provides further support.

Not only are young children capable of using power mobility, but independent mobility may promote development in other areas. Independent mobility is believed to be essential for perceptual-motor and social skill development.\(^8,13\) Self-produced locomotion also is believed to have an impact on cognition, communication, and psychosocial development.\(^14,15\) Campos and Bertenthal\(^16\) contended that self-produced locomotion is an organizer of psychological changes in typically developing infants, especially developmental changes in social understanding, spatial cognition, and emotions. Locomotion influences the development of infants’ fear of heights,\(^17\) successful retrieval of hidden toys,\(^14,18–20\) performance on Piagetian search tasks,\(^14,15\) and the development of social behaviors and physical play.\(^21,22\)

Although a growing body of literature suggests that early power mobility could enhance the development of children who have severe mobility limitations,\(^7,10,14–16\) little research has addressed the developmental effects of power mobility on children of any age. McEwen,\(^7\) Butler,\(^10\) and Kangas\(^23\) have suggested that service providers should consider providing children with severe motor impairments a means of independent mobility at an early age, when other children are crawling and walking to explore their environments. In our view, service providers, including physical therapists, also should be prepared to teach young children how to use power wheelchairs so they can achieve independent mobility in a variety of settings.\(^24–26\)

In our opinion, applying motor learning principles may assist physical therapists in teaching young children to use power mobility. Motor learning has been defined as processes that lead to relatively permanent changes in a person’s ability to produce a skilled action due to practice or experience.\(^27\) Application of the concepts of transfer of behavior or generalization, practice, and feedback may be important when training a child to use power mobility.
When training a child to use power mobility, we believe physical therapists should design practice and provide feedback to ensure the skills performed will transfer and generalize across all environments in which the child will use the device. Practice opportunities, we contend, should occur in familiar environments, such as the backyard, on sidewalks going to and from the home, and in the grocery store. Opportunities for practice should not be limited to times when the physical therapist visits the child one time per week for an hour (blocked practice), but should be incorporated into daily activities (random practice), such as going to and from the car, transitioning between rooms, and playing on the playground. Research indicates that blocked practice may be necessary for initial skill acquisition, but random practice is necessary for learning, retention, and refinement of a skill.

Feedback is another important consideration. Research suggests that although feedback is important and may be beneficial for initial skill acquisition, but random practice is necessary for learning, retention, and refinement of a skill. Tefft et al suggested that the use of power mobility for young children is not widespread. There is little literature that describes intervention strategies used to promote independent mobility and documents the developmental changes that occur when young children receive power mobility. The purpose of this case report is to show that a child as young as 20 months of age can learn to use a power wheelchair. We also describe the procedures used in training a young child to use a power wheelchair and in evaluating the developmental changes made after receiving the power wheelchair.

Case Description

Participant

This case involves a 20-month-old girl, Molly, with spinal muscular atrophy. Molly was part of a larger study conducted to determine whether the Battelle Developmental Inventory (BDI) and the Pediatric Evaluation of Disability Inventory (PEDI) were responsive to change in children 14 to 30 months of age with severe physical disabilities and to pilot test procedures to be used in research on power mobility. Molly was the first child with whom we tested the procedures, and we selected her for this case report because she was the youngest child (17 months of age) referred for the study.

Molly lives with her mother and her typically developing twin brother in a rural town in the south-central United States. Molly was diagnosed with type II spinal muscular atrophy when she was approximately 9 months of age. Her mother described her as developing normally through 6 months of age, when she was rolling over and pushing up into a sitting position. By the time she was 7 months of age, she could not perform these activities. Shortly after her diagnosis, physical therapy services through an early intervention program began. A physical therapist provided services every other week in the home of her day care provider. The focus of intervention was on attaining developmental milestones. Molly spent approximately 9 hours a day in home day care with her brother and occasionally with a grandchild of the day care provider.

Molly’s intervention team, which consisted of a physical therapist, a resource coordinator, and her mother, determined that her primary limitation was her motor development. Molly’s mother and the physical therapist said they thought that she was “bright,” but they were concerned that she was becoming frustrated because she could not move to explore and play. Her mother expressed interest in finding a way that Molly could move on her own. The only specialized equipment that Molly used prior to recruitment for the study was a TriStander.

Examination

Examination of Molly included obtaining a brief history from her mother and the physical therapist, observing Molly in her daily environments, and administering tests to obtain data for later comparison of developmental and functional skills. During our observations, Molly was attentive to people, objects, and activities in her environment. She consistently made choices by either saying or shaking her head for “yes” and “no” and by pointing or reaching for or verbally naming the desired object or person. Some of Molly’s favorite activities appeared to be playing “dress up,” taking care of her baby dolls, and watching cartoons. She could play with toys that were within her reach. Molly was unable to roll, crawl, and walk. She could sit independently on the floor when placed there, but she could not shift her weight in any direction without losing her balance and falling over. Molly’s attentiveness to and interaction with people, objects, and activities in her environment, as well as her desire to be engaged in activities, led us to believe that a power wheelchair would allow her to interact independently in her environment and would have a positive impact on other aspects of her development.

Although the administration of standardized tests is not typically done to determine a child’s need for power mobility, we administered tests to track Molly’s develop-

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ment over a 6-month period. The tests administered included a standardized developmental evaluation (ie, the BDI)\(^\text{34}\) and a functional evaluation (ie, the PEDI\(^\text{35}\)). The BDI is a norm-referenced tool that is commonly used to measure a child’s development in 5 domains: personal-social, adaptive, motor, communication, and cognition. The BDI test manual reports intraclass correlation coefficients (ICC) ranging between .90 and .99 for test-retest reliability and interrater reliability of the BDI total scores in a combined normative and clinical sample of 183 children. Using the Cohen Kappa, we calculated the interrater reliability of the BDI total scores as part of the larger study, and coefficients ranged between .92 and .98. Several researchers\(^{34,36–38}\) have examined and generally support the content, construct, concurrent, and predictive validity of the BDI.

The PEDI measures a child’s ability to perform basic skills, but also includes items related to the amount of assistance or adaptation a child requires.\(^\text{35}\) The PEDI manual reports good internal consistency, with coefficients ranging between .95 and .99 for all 6 scales using Cronbach coefficient alpha. The test developers used the ICC to calculate inter-interviewer reliability, and coefficients ranged from .96 to .99 on all scales in a normative sample of 30 children and from .84 to 1.00 in a clinical sample of 12 children. Using the Cohen Kappa, we calculated the inter-interviewer reliability of the PEDI total scores on the functional skills and caregiver assistance scales as part of the larger study and achieved coefficients between .92 and 1.00. Other researchers\(^{35,39,40}\) have examined and provide support for the content, construct, concurrent, discriminative, and evaluative validity of the PEDI.

**Intervention**

The interventions that we provided to Molly included providing a wheelchair that would meet her needs, fitting and adjusting the seating system, and then training her to use the wheelchair. To decide on the features of a wheelchair to meet Molly’s needs, a team that included a durable medical equipment supplier, a physical therapist with assistive technology experience, Molly’s early intervention physical therapist, and her mother discussed wheelchair options. We took physical measurements of Molly, including her thigh length, hip width, lower leg length, chest width, shoulder width, and shoulder height. Because Molly required support to sit without leaning to the side, we ordered the chair with an Invacare UltiMate seat cushion\(^\text{†}\) and UltiMate curved back cushion.\(^\text{†}\) The seating system included a back support that extended to the top of Molly’s shoulders; swing-away, curved lateral trunk supports; a generically (not custom-made) contoured seat cushion to keep her hips centered in the chair and to position her knees in line with her hips; and a pelvic belt. Joystick placement was an important consideration because of Molly’s limited arm movement and muscle force. During our observations, we noticed that she had difficulty manipulating toys or other objects that were positioned to the right and left sides of her body. When items were positioned in midline or slightly to either side of midline, Molly could use both hands to pick up the items and pull them toward her. A standard joystick on a wheelchair would be mounted to the side of the chair and would require her to push the joystick to move it forward. Because of Molly’s limitations, she needed a midline joystick that would allow us to “reconfigure” the joystick, so that pulling the joystick toward her caused the chair to move forward. The chair ordered for her, an Invacare Action Power Tiger,\(^\text{†}\) provided this option.

After delivery of the wheelchair, when Molly was 20 months of age, the physical therapist with assistive technology experience adjusted the seating system to fit her. Seating system adjustments included raising the footrests, positioning the lateral trunk supports, and adjusting the depth of the seat to leave approximately 2.5 cm (1 in) between the bend of her knee and the edge of the seat cushion. The durable medical equipment supplier programmed the electronics on the wheelchair so that pulling the joystick toward her caused the chair to go forward and pushing the joystick away from her caused the chair to move backward.

We applied motor learning principles when providing practice opportunities for Molly in her power wheelchair. The principles included giving Molly daily opportunities to use the wheelchair in natural environments, with adults providing verbal encouragement for her to move in the chair but refraining from giving her directions of where and how to move. When we delivered and adjusted the wheelchair, we showed her one time how the joystick worked, moving it in each direction and allowing Molly to experience the different movements. Without providing any additional feedback, we allowed Molly to “explore” on her own. She immediately placed her hands on the joystick and pulled it toward her, causing the wheelchair to move forward. We asked Molly’s mother, who was sitting on the floor in front of the fireplace, to provide her with encouragement to move the power wheelchair by saying, “Come see Mommy.” Following this verbal prompt, Molly moved toward her mother. As she approached her mother and was about to collide with her, Molly removed her hand from the joystick to make it stop. Molly consistently moved the chair forward for approximately 0.9 m (3 ft) without stopping. She also was able to turn the wheelchair to the right, but she could not turn to the left or move backward without physical assistance. Her inability

\(^{†}\) Invacare Corp, One Invacare Way, Elyria, OH 44036-4028.
to move the joystick to the left and backward was due, we believe, to her lack of postural control, not her understanding of the operation of the wheelchair. When she wanted to move backward, but could not generate the muscle force necessary to push the joystick, she would say “back,” indicating her desire to move backward.

Following the initial training, which focused on Molly, we shifted our training to Molly’s mother and the physical therapist, who would be providing the practice opportunities for Molly. We gave written guidelines to Molly’s mother and the physical therapist, following suggestions published by Wright-Ott for helping young children learn to use power mobility (Tab. 1). Molly’s mother and the physical therapist were primarily responsible for providing practice opportunities. We asked Molly’s mother to provide her with daily opportunities to sit in the device with the motor turned on during supervised play in natural environments, such as her home and yard, the day care provider’s home and yard, the park, and the mall. We asked Molly’s physical therapist to provide the same opportunities during her typical therapy sessions. We initially asked them to encourage Molly to experiment with movement in a relatively large space under close supervision. We advised Molly’s mother not to be concerned if Molly spent a period of time driving in circles, because we believed it was important for Molly to experience the intrinsic feedback (becoming dizzy) of going in circles. We emphasized the importance of parental supervision, as one would supervise any young child.

To facilitate the use of her wheelchair and to ensure that Molly’s mother and the physical therapist were comfortable with the use of the device, we made weekly telephone contacts with them until Molly could proficiently maneuver her power wheelchair according to the criteria of Butler et al (Tab. 2). We visited Molly to either solve problems identified during the telephone contacts or to observe Molly’s skills using the power wheelchair. In the first 6 weeks, we visited Molly twice: once to adjust the lateral trunk supports of her wheelchair and once to observe Molly’s skills. To determine the frequency of Molly’s practice opportunities with the power wheelchair, we asked her mother to complete a power mobility record that tracked the amount of time and locations of Molly’s practice opportunities. Molly sat in her wheelchair daily, and the duration of time varied from 15...
minutes to 3 hours. The average amount of time Molly used her wheelchair over the 6 weeks was 1.68 hours a day. The duration gradually increased over time and as she became proficient in using the wheelchair. The main practice environments included her home, her grandmother’s office, and the park. We provided a list of the proficiency skills (Tab. 2) to Molly’s mother and asked her to call us immediately when Molly could perform all the skills listed. Molly’s mother called us 6 weeks after Molly received the power wheelchair. At that time, we visited Molly to verify that she could perform all the skills listed and to videotape her progress.

Outcomes
We measured Molly’s ability to maneuver the power wheelchair using the skills listed in Table 2, her overall development using the BDI, and her functional skills using the PEDI. We also interviewed Molly’s mother. Administration of the BDI and PEDI occurred at the beginning of the study and 3 and 6 months later. Molly received her power wheelchair between the 3- and 6-month re-evaluations, so the 6-month re-evaluation is described as post-intervention. She received her power wheelchair 10 days after the 3-month evaluation and 2 months 27 days prior to her 6-month evaluation. Figures 1 through 4 show the changes in her scores on the BDI and the PEDI.

The BDI results indicate that Molly’s development in all areas continued after being provided a power wheelchair. With typically developing peers, we expect age-equivalent scores to increase by 3 months over a 3-month time period, but children with severe motor impairments often do not demonstrate the same increases in age-equivalent scores over time. In Molly’s case, however, her age-equivalent scores increased by greater than 3 months in the following domains: (1) communication, (2) personal-social, and (3) cognition. Between the second and third evaluations (3 months chronologically), Molly’s age-equivalent scores in communication increased by 5 months, whereas the scores increased by only 1 month between her first and second evaluations. These results indicate that prior to the intervention, Molly’s communication skills were developing at a slower rate than occurs in typically developing peers.

Molly’s personal-social skills increased by 4 months between evaluations, which is greater than we would expect of typically developing peers. Her cognitive skills increased by 7 months between the first and second evaluations and by 6 months between the second and third evaluations. Based on typical development, we expected Molly’s age-equivalent scores to increase by a total of 6 months; however, she demonstrated a total gain of 13 months, which is 7 months more than expected. Molly’s adaptive and motor skills increased by 3 months between the first and second evaluations and by 1 month between the second and third evaluations. These results indicate that Molly’s adaptive and motor development slowed in comparison with that of typically developing peers. This finding is not surprising given Molly’s diagnosis, which indicates she has pathology that
limits her ability to perform motor and self-care tasks and results in the need for modifications to accommodate her functional limitations.

The PEDI results indicate a positive trend in all 3 domains (self-care, mobility, and social function). Because the PEDI was designed for people with disabilities, it detected changes that the BDI did not. The changes between her second and third evaluations indicated improvement in her functional mobility skills and a decrease in the amount of assistance she required from her caregivers for mobility, which we believe she would not have achieved without the power wheelchair.

After 6 weeks of power mobility training, Molly became skilled in moving her power wheelchair. She was 21 months of age. We believe she gained postural control that allowed her to move the joystick in all directions. Examples of skills Molly was able to accomplish in her wheelchair included: (1) driving up and down the ramp leading to her house and making a 90-degree turn through the doorway without hitting the door frame, (2) moving from room to room in her small house (approximately 92.9 square meters [1,000 square feet]) without hitting walls and door frames, and (3) chasing her brother around the yard while avoiding obstacles. Her mother reported that she never had to worry about Molly getting into trouble or getting into dangerous situations before receiving the power wheelchair; however, after Molly received the power wheelchair, her mother reported, “I’ve never had to deal with stuff like this with her, but I’ve done it with Chris (her twin brother), so I can do it with her.” Just as parental supervision is necessary for any young child to ensure safety, we observed that it also is important to provide supervision when a child receives a power wheelchair.

During the initial interview, which occurred prior to Molly receiving the power wheelchair, we asked her mother to describe Molly’s independence, and she replied,

…”[she’s] fairly independent, I mean, as much as she can be…if she was more mobile and things like that, she would be very independent, but right now, she’s really dependent on me for moving her from one place to another.

During the postintervention interview, Molly’s mother described her independence as “something she is learning to exert very well…I think that’s a good thing.” She also said,

…without the chair, she wouldn’t be able to get around to see different things. Before, I was always having to carry her and take her to the kitchen to show her something or take her to the bedroom, and now, she can…I put her in her chair and she can go those places on her own. She can explore and get into things…just like her brother.

Discussion
This case report describes procedures we used in teaching a 20-month-old girl to move independently in a power wheelchair. Although the research on power
mobility suggests that young children can quickly learn to use power mobility, only Zazula and Foulds have described a child younger than 24 months of age using such a wheelchair. Zazula and Foulds designed a powered cart for an 11-month-old with phocomelia and reported that it took the child 10 months to gain “complete control over all operations of the cart.” We were surprised by how quickly Molly learned to maneuver the wheelchair, even with limited practice opportunities. While we expected that she would gain basic maneuvering skills in the weeks following the delivery of her wheelchair, we also were surprised by the advanced skills (going up and down ramps, maneuvering in tight spaces) she mastered in such a short period of time.

Although we demonstrated that a child as young as 20 months of age could learn to maneuver a power wheelchair, it would be inappropriate for us to conclude that Molly’s developmental and functional gains were the direct result of the power mobility intervention. In addition to the power mobility intervention, Molly received early intervention services that focused on the acquisition of developmental skills. However, we believe that the power mobility intervention provided her independence and allowed her to explore her environment without the assistance of others. We contend it also allowed her to experience a variety of situations that she otherwise would not have encountered. These additional experiences may foster the acquisition of greater developmental and functional skills. Although maturation also could have played a role in the developmental and functional improvement Molly made, we would expect her developmental and functional improvement to be only the same as that of her typically developing peers. Because Molly’s age-equivalent scores increased more in communication, personal-social, and cognitive skills than is typical for her peers, we believe that the power mobility intervention, not just maturation, may have been a contributing factor.

Our experiences with Molly are similar to those reported by other authors who indicated that children younger than 2 years of age can learn to competently maneuver a power wheelchair. This case, however, indicates that a child as young as 20 months of age can learn to competently maneuver a power wheelchair. The case also describes changes in age-equivalent scores on the BDI and scaled scores on the PEDI that could be used to track Molly’s progress over time.

In our opinion and the opinion of others, children with limited mobility experiences often fall behind in other areas of development because they cannot independently explore and act on their environment. Motor skills develop rapidly during the first 3 years of life and become the bridge to more advanced learning, socialization, and psychological development. We believe that physical therapists should consider power mobility as an option to augment a young child’s mobility at a time when their peers are mobile, which, in turn, may prevent or minimize detrimental effects caused by immobility. Based on the interviews with Molly’s mother and the changes in Molly’s developmental and functional skills using the BDI and PEDI, we believe that providing children with power mobility should be considered an intervention that may promote independence and positive trends in all areas of development.

In this case report, we described the procedures used to teach a 20-month-old with spinal muscular atrophy to use a power wheelchair, and the application of the results to children with different diagnoses should be done with caution. A study of children under 24 months of age is needed to determine whether children with spinal muscular atrophy and other types of disabilities would acquire the skills necessary to successfully maneuver a power wheelchair at the same rate as Molly. Research comparing the development of communication, personal-social, and cognitive skills of children who receive power mobility with those who do not receive power mobility is necessary to demonstrate that power mobility leads to greater development in these areas. Qualitative research evaluating parents’ perceptions of the impact power mobility had on their children’s lives and their perception of their children’s development would provide physical therapists with information they could use when discussing power mobility as a mobility option for young children.

**Summary**

We described the intervention strategies used to support a 20-month-old girl with spinal muscular atrophy in learning to use a power wheelchair, and we tracked her developmental changes over 6 months. The intervention we used was based on principles of motor learning and anecdotal experiences of teachers and therapists who work with children with disabilities. Within 6 weeks, Molly was independently mobile in her environment. Molly also showed continued progression of communication, cognitive, and personal-social skills. We believe that power mobility can be beneficial to young children with severe motor impairments. For this reason, we recommend considering power mobility as an intervention that may promote independence and continued development for young children with severe motor impairments.

**References**

very young children with locomotor disability that affect mobility control.


