

Independent Mobility is Key to Overall Child Development

BY PATRICE M. KUNTZLER

We can all recall the milestones as children and adolescents that made us feel free, confident and, most of all, independent—riding a bicycle, walking to the neighborhood deli on our own, that first solo drive or trip to the movies with friends. We'll forever carry the feelings these life experiences gave us. They are precisely why we need to find ways to give children with motor disabilities a chance to savor them. Every life experience is also a learning experience. Collectively, they help us explore the world in a different way, gather knowledge, interact with others and develop a sense of self.

Encouraging independent mobility can help pave the way for overall independence and play a crucial role in a child's growth and development. From infancy, children learn through their everyday activities. Children with severe motor impairments have more limited opportunities to explore their environment; therefore they are considered to be at risk for secondary impairments such as cognitive, spatial-perceptual and social-emotional delays. (Hansen, L. "Evidence and Outcomes for Power Mobility Intervention with Young Children." CASEmakers. September 2008, Volume 4, Number 1. Print.)

"When you talk about mobility, you need to think about what it means in terms of education and life," explains Janet Gambitsky, an occupational therapist at the Henry Viscardi School in Albertson, New York. "It's never too early to start thinking about mobility, there is no downside or drawback. When children are mobile and can get around on their own, they are more alert and their capacity for learning increases."

Independent mobility is known to:

- *increase a child's level of engagement in activities, whether they be educational or recreational, and often improves attention spans;*

- *positively impact behavior since children with disabilities can become frustrated when they can't get what they want, go where they want to go or need constant assistance;*
- *allow for fuller participation in school, social or local communities;*
- *promote problem solving, an instrumental life skill and one that is part of growing up;*

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- *enhance the quality of interactive behavior a child has with others, building socialization skills needed for the classroom, play and the transition to adult programming and employment;*

- *facilitate deeper exploration of their world by providing the ability to move closer to things as well as bring objects closer to themselves;*

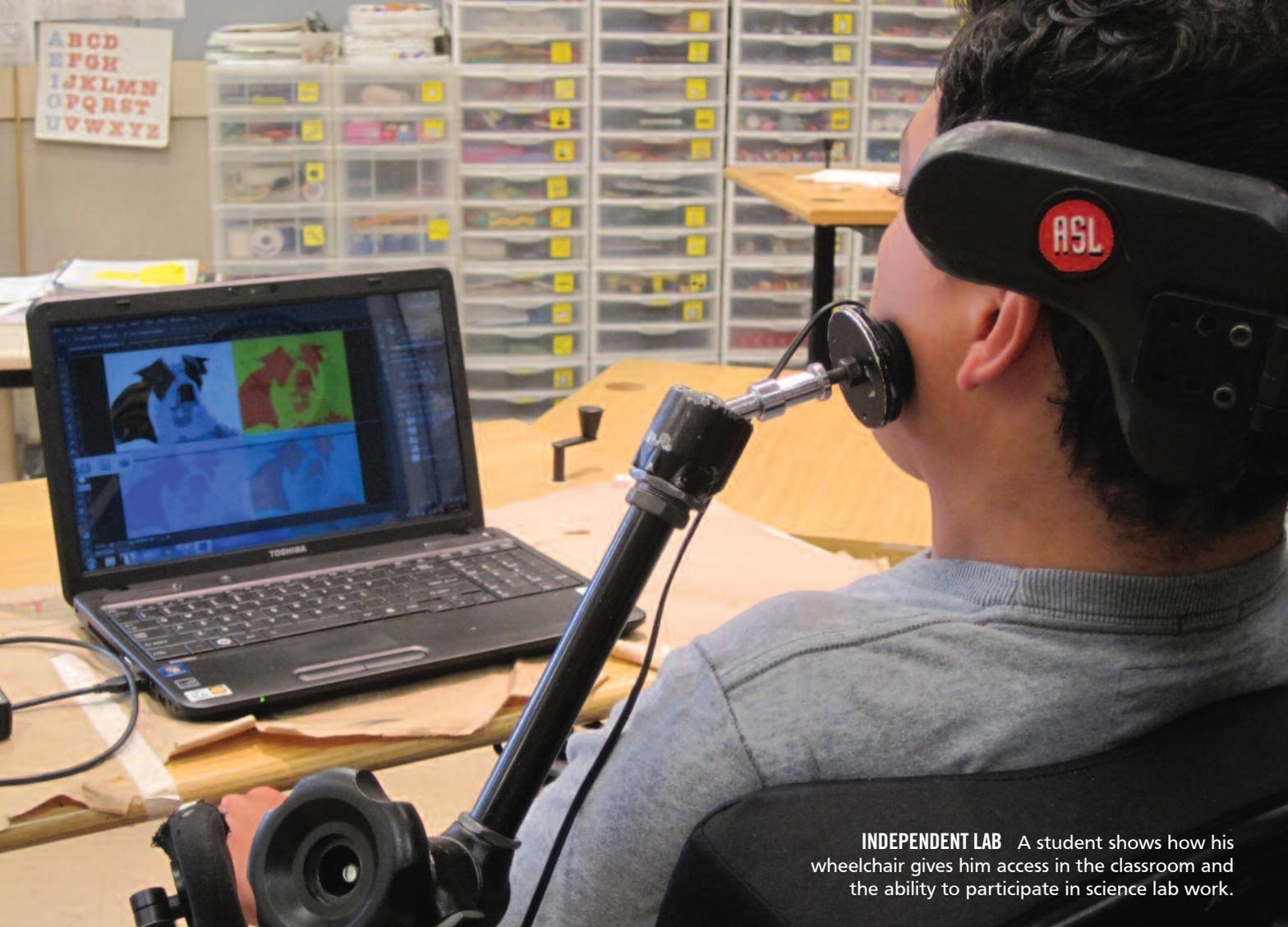
- *build perception and spacial relations as children learn how to navigate around obstacles, recognize drop-off points such as stairs and curbs, map routes, to get*

from one place to another and establish and respect personal space.

"Dylan's use of a power chair has opened up a whole new world for him," says Debbie Cuevas, whose fourth grade son was diagnosed with spinal muscle atrophy (SMA). "As he tells us, his chair is his legs. He now has the freedom to go wherever he wants. Whether it is playing freeze dance with his sister or wheelchair basketball on his school team, the independence Dylan has gained from his power chair is something we never dreamed was possible."

USE OF EQUIPMENT MAY OPEN NEW DOORS

Some visitors touring the Henry Viscardi School are positively surprised to discover that the majority of its students are moving about the building on their own in powered mobility such as a wheelchair or scooter, walking, or utilizing wheeled mobility like a walker or self-propelled manual wheelchair. The School serves



INDEPENDENT LAB A student shows how his wheelchair gives him access in the classroom and the ability to participate in science lab work.

children, Pre-K to grade 12, with severe physical disabilities and often medically fragile yet, few students are aided by an adult.

“Often, people with disabilities are perceived differently when they are dependent on a parent, caregiver, or other adult to get around,” notes Debra Davis, a physical therapist at the school. “Conversation is directed at the person with them, versus the individual, and a cognitive disability is sometimes assumed.”

While the introduction of a walker or wheelchair can assist with independent mobility, one common concern is that it will interfere with motor skill development for walking or the child’s desire to walk. Professionals have seen the opposite. The ability to be more interactive has fueled motivation and the added agility allows children to better integrate into their environment and lead a more active lifestyle.

While Mariah is ambulatory, her physical disability and unsteady gait prevents her from walking quickly, or finishing long distances, or playing traditional sports. She has chosen to use a manual wheelchair at times so that she can easily navigate the school hallways and participate on the basketball team with her peers, so she

can enjoy all of the benefits of being part of a team.

Chris Marotta, an occupation therapist at the Henry Viscardi School, tells of how the use of crutches by one child limited the use of her hands, thus the ability to perform tasks herself. “She was unable to carry her own books or get her lunch money out if she was standing, and needed regular assistance because she could only accomplish certain things if she sat down. This reduced her ability to act like her peers.” Wheeled mobility might have allowed for her to be able to act more independently.

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MANUAL VERSUS POWERED MOBILITY

For those parents whose child uses a wheelchair, one common discussion point is the use of manual versus power wheelchairs. There have been many studies conducted

regarding the appropriate time to introduce power wheelchairs, their benefits and whether or not they adversely affect motor skill development.

Rehabilitation Engineering & Assistive Technology Society of North America (RESNA) highly recommends early utilization of powered mobility as reported in the “RESNA Position on the

Application of Power Wheelchairs for Pediatric Users.” According to the report, independent mobility in children with disabilities has been shown to improve cognitive and perceptual skills, reduce learned helplessness, increase confidence, and increase participation with their peers in everyday activities. Children see power mobility for what it is, a way to augment their goal of efficient, successful exploration and movement within their environment to satisfy their curiosity and to experience, participate, socialize and learn.

CASEmaker’s “Evidence and Outcomes for Power Mobility Intervention with Young Children,” noted that none of the research substantiated the commonly held fear that children will regress in motor skills due to use of power mobility. (Hansen, L.) The article also explored parents’ perspectives about their child’s power wheelchair use. Common themes included increased child independence and personal control, increased child engagement in meaningful life experiences and a positive effect on others’ attitudes toward the child.

Families should consider the role progression from a manual wheelchair to a power chair may have on a child from learning, social, health and independence standpoints. Self propelling a manual chair, which may have the added weight of school or medical supplies, consumes a lot of energy and can make a child too tired to pay attention in the classroom or engage in social activity.

Lily, age 10, uses both a vertical walker

and a wheelchair. “Lily’s manual chair is heavy and more difficult to move so we are in the process of getting her a power assist chair. It is not fully motorized but it will allow her to move around better and also balance her since one arm is stronger than the other,” explains Lily’s father, John Murphy. “It also will let Lily be self-mobilized during basketball games. Since she won’t have to rely on being pushed during the game, she will be able to keep up with the play and be more involved in it.”

Today, there is a plethora of power chairs, modular seating interfaces and digitally programmable drive controls to create a power mobility system that can adapt to a child’s needs and increase independent mobility. Access to power drive controls can be achieved through any body part using switches, head array, feet, cheeks, joysticks, touch pads, fiber optics and more.

POWERED UP

Power chairs are assisting users beyond mobility. They are providing increased accessibility to computers for classroom work and other enriching experiences. For instance, better and more comfortable body positions can be achieved by these versatile chairs which recline, raise and lower – and can also result in the student’s

ability to participate in art activities, as adapted brushes or enhanced computer access can be used to create digital art. They also allow children with severe mobility impairments to take part in adapted recreational and competitive sports.

Alfredo, who is non-verbal and has extremely limited mobility, utilizes a head switch to control his power chair. Several years ago, he began using a cheek switch on his chair to operate a computer. This new accessibility has made a significant

difference for him in school and at home.

“Using his computer, he now utilizes more art software programs, makes videos, downloads music,

sends emails and surfs the Internet,” says his father, Raul Alfredo Montez, who moved his family to the U.S. several years ago because of the opportunities he felt the move would offer Alfredo. “He is graduating high school and going to college in the fall to study computer programming.”

So where do children with disabilities rank independent mobility on their scale of importance? It turns out, at the Henry Viscardi School, extremely high. So high that a group of second graders there recently wrote and signed a letter to their classmate’s insurance provider who had turned her down for a power wheelchair because she was “a kid.” The provider obviously felt it was acceptable for her to be pushed around by an adult. The students, on the other hand, pointed out in their letter that, “Veronica would be very proud to be able to drive herself to music, art, gym, swimming and the cafeteria without help from anyone.” These self-advocating eight year olds summed it all up for the reader, “Children with disabilities want to be like any other children. They work very hard to be as independent as possible.”•

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STARTING INDEPENDENT MOBILITY EARLY IS CRUCIAL

Independent mobility is a way of life according to Chris Brown, a graduate of the Henry Viscardi School. Monday to Friday, Brown commutes on the subway from his home in Queens, New York to Manhattan for his corporate sales job with a national wireless telephone company. While a public bus is an option, he finds the accessibility and reliability of the subway to be easier. “Public transportation is far more cost effective than driving in and paying for parking and gas and you don’t have to sit in traffic,” he notes.

Brown is also a frequent user of public transportation for social outings. He takes it to the ball park, beach, shopping mall and for day trips outside of New York and is a firm believer in encouraging independent mobility in children. “I started getting out on my own when I was in college. Learning to get around on your own as a child translates to adult life. It is what lets you fully participate socially, attend college and become employed,” explains Brown.

Brown encourages parents to begin by having their children take small steps, and to also teach them how to navigate the public transportation system near their homes, read maps, and design a backup plan, just in case an elevator is broken, or the usual route is interrupted. “Get out there and live life,” recommends Brown.