WITH HELP FROM THEIR GRANDMOTHER, Linda, 15-month-old twins Riley and Madison Smith line their vehicles up in the driveway for a race. Madison quickly pulls ahead, and Riley, not surprisingly, gets frustrated.

Scenes like this are played out in homes across the world every day, but the normalcy of it is cause for celebration at the Smith farmhouse. Born at 24 weeks gestation, Riley and Madison both face formidable physical challenges and exhibit some of the developmental delays expected with extreme prematurity.

But a team of researchers from the University of Delaware hopes to make a difference, especially for Riley, whose disabilities are more severe. The baby has been supplied with a custom-built power mobility device that enables her to experience the world along with her sister, who is able to scoot around with an off-the-shelf baby “walker.”

“I was thrilled to see the video Linda took of Riley pulling at her joystick in annoyance when she couldn’t make her vehicle go as fast as Madison’s,” said Cole Galloway, associate professor in the Department of Physical Therapy at the University of Delaware.

“We want to see her competing with her sister and getting mad at being beaten. Activities like this are a normal part of growing up.”

Galloway and collaborator Sunil Agrawal, professor of mechanical engineering at the University of Delaware, have become nationally recognized within the last few years for their work on the use of specially designed robotic power chairs to increase the mobility of infants and toddlers with disabilities.

Infants with Down Syndrome, cerebral palsy, spina bifida, and a range of bone and joint disorders can have mobility limitations that disconnect them from the ongoing exploration enjoyed by their peers. However, Galloway has found that early improvement of mobility can lead to the enhanced cognitive and social interactions which are critical to human development.

“These kids typically have to wait until they’re 3- to 5- years old to get power chairs,” Galloway said. “It’s not a coincidence that this is also the age when they’re old enough to obey adult commands and can, at least in theory, be safer drivers. But in normal development, kids are exploring the world long before they’re ready to be obedient. We’ve all seen how it is when a toddler learns to walk—it’s the time when bananas go into VCRs and cats dive for cover. Early mobility is when cognition, perception, socialization, and language development all skyrocket.”

According to Galloway, the key words for driver training are “early” and “everywhere,” because they are critical to the device becoming “embodied,” or viewed by the child as an integral part of him or herself.

One of the research team’s first subjects, Andrew Peffley, who has spina bifida, began driving a prototype joystick-controlled
device with an onboard computer and video camera, known as UD1, at the age of 7 months. As he mastered the technique with the help of family and therapists, his cognition and language scores increased at a rate greater than his chronological age. Now 3 years old, Andrew has graduated to a more typical pediatric power chair and is attending preschool with children his own age.

It’s a dream come true for his mother.

“What I want for him is to be in the mix, doing what the other kids are doing as much as possible,” she said. With continued physical and occupational therapy, Andrew is actively working on independent walking, and he benefits from power mobility the majority of the day when he is not in therapy.

“Power mobility provides indoor and outdoor mobility as an adjunct to locomotor training that a walker or manual chair simply can’t,” Galloway points out.

Amy Meyer, PT, ATP, pediatric & standing specialist with Permobil Inc., applauds what Galloway and Agrawal are doing. “Despite the wealth of literature supporting independent mobility to promote many areas of early development,” she said, “we continue to see third-party payers denying power mobility for young children because they have caregivers available to push them around dependently.”

“This is a travesty,” Meyer continued, “given the knowledge we have on how independent mobility improves critical areas of development such as vision, spatial awareness, and psychosocial interactions. We need scientific research, like that being done at the University of Delaware, to validate that infants and young children can use and benefit from power mobility devices implemented into their daily lives at an early age. It’s also important to look at the negative consequences of withholding this intervention until a child is older.”

Galloway believes waiting to introduce power mobility later in childhood may be more difficult than starting at infancy. Will Harp, a special-needs 3-year-old in the University of Delaware’s Early Learning Center, learned to “drive” in open spaces, such as the center’s gym and playground, that are large enough to accommodate UD1. But in the classroom, he was still consigned to sitting and watching while the flurry of preschool activity went on around him. In the summer of 2009, Will received a second-generation prototype device, UD2, which is small enough to go into the classroom.

The idea was to give him the opportunity to use his driving skills to share more deeply in the experiences of a typical preschooler through all-day immersion with his peers and teachers. The researchers tracked the extent to which he drove UD2 in that environment, as well as how his social behavior changed across time.
“What we found,” Galloway said, “was a tendency for his teachers and peers—who were accustomed to Will being immobile—to continue to interact with a ‘mobile Will’ just as they had with an ‘immobile Will.’ Moreover, Will did not take the opportunity to be more mobile in the classroom either.”

“Being immobile means being passively moved when others decide to move you,” he continued. “But that’s not how it’s supposed to work. Kids need to decide when and where to move on their own—whether they want to play with blocks, look at books, or roughhouse with their friends. The freedom to move where we want, when we want, is part of the joy of life.”

Jason Curtis, senior market manager for pediatric mobility at Otto Bock HealthCare, agrees. “The earlier the process can start, the less the child is negatively impacted in the long run,” he said. “Designing and funding products that encourage early-intervention independent mobility, such as those currently being developed by the University of Delaware, would be a great step forward for children with special needs and their parents.”

While the concept of very young babies “driving” seems foreign to most people, Curtis points out that children are often more adept at understanding new technology than their parents.

“We’ve seen very young children test drive a power chair and intuitively understand how to move through their environment,” he said. “We’ve witnessed this phenomenon in our prosthetic work, too, where infants who begin using a myoelectric upper limb have a much higher rate of acceptance and better functional outcomes because of their head start.”

Although the Mechanical Systems Laboratory at the University of Delaware, where the power chairs are developed, is fairly high-tech, there is nothing high-tech about the venues where the chairs get their real test. That, according to Galloway, is the rough and tumble world of reality.

“Our lab is your living room, front yard and community playground,” he said, “because that’s where the enrichment is. The best way to enrich a baby’s life is with mom, dad, grandma, and the dog on the living room rug.”

Galloway’s greatest concern is how to provide this kind of mobility to every child who could benefit from it. “We don’t have a commercial source of small power chairs,” he said, “and there’s nothing worse than offering this

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resource to a child during a research project and knowing that we can’t sustain it with a commercially available device.”

The Office of Economic Innovation and Partnerships at the University of Delaware is working to address Galloway’s concerns. A study has been initiated to determine the economic potential for devices of this type, including identifying commercial enterprises engaged in the rehabilitation marketplace. A workable prototype unit is ready for first-level patient testing, and discussions have begun with potential business partners for advanced testing and eventual commercialization of the robot.

Within the next few months, the University of Delaware researchers expect delivery of five robust 22-pound power mobility devices built according to their specifications by Automated Research Group in Bear, Del. In contrast, the smallest currently available commercial units weigh about 150 pounds.

“Small as a baby, light as a baby, goes wherever a baby goes.” That’s our engineering design motto,” Galloway said. “A parent will be able to put one of our devices in the trunk of a Honda Civic. This is a huge advance because it eliminates the expensive vans, ramps, and remodeling that are needed for even the smallest pediatric power chair available.”

“Our lab is your living room, front yard and community playground, because that’s where the enrichment is. The best way to enrich a baby’s life is with mom, dad, grandma, and the dog on the living room rug.”

COLE GALLOWAY POSES WITH WILL IN HIS UD2 MOBILE DEVICE.
Galloway and Agrawal envision a future in which babies with a variety of developmental disorders have early access to a range of devices that can be tailored to their needs.

“While the design of UD1 uses conventional gaming joysticks,” said Agrawal, “our recent pilot studies with a force feedback joystick on UD2 and higher models show that infants and toddlers, both those who are typically developing and those with special needs, can learn to drive more quickly as well as acquire higher-level driving skills such as obstacle avoidance and navigation. We believe incorporation of these technologies into future prototypes will enable children to use them more efficiently in their homes.”

“In addition,” he said, “we have pilot tested new mobility interfaces that do not use joysticks, but employ various body movements to drive the robot—for example, an interface where infants lie prone on the robot and kick their feet to drive the robot.” Other bio-driven interfaces that will revolutionize the way children can experience mobility are in the works.

“We’re very sensitive to what families and therapists tell us they need,” Galloway said. “If they say the device is good, it’s good. Therapist-tested and mom-approved is our secret to both effective training methods and great engineering design. Logically, a prototype that has literally ‘grown up’ in the community will produce a commercially viable device fit for that community.”

“Don’t be surprised if we hire Linda, Riley’s grandmom, as an expert consultant,” he added, “and she’ll need to bring her dog too.”

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JASON, AGE 41, WAS REFERRED TO OUR office in March of 2008, after suffering an accident which left him with a T-12 incomplete spinal cord injury. In addition to this injury, he was being seen for skin breakdown on his right Ischial, with a semi-flexible obliquity on the same side along with a right shoulder injury. Jason had been transferred to a specialty facility for therapy including the recommendation of an appropriate seating and mobility system.

Like most individuals, he was scared and unsure of his future. During our first visit, it was discussed that an ultra light-weight wheelchair would be appropriate but there was concern on whether to recommend a folding or rigid wheelchair. Jason was provided both types of chairs, and with a second visit to determine which chair would provide the best benefits and cause the least amount of compromise.

For Jason, it was clear that a rigid frame wheelchair would provide him with the best mobility, while keeping the overall size of the system compact, to reduce the strain on his shoulders, increasing his mobility. Jason’s goals were to allow him to continue his marriage, his vocation in the IT industry, and to have as normal of a life as possible. This new equipment would need to allow him to tolerate sitting for extended periods, while allowing him to get around his work and home, and allowing transportation of the equipment into the community. Another important consideration was the seat-to-floor height and eye line as Jason would be driving a vehicle with hand controls.

The seating clinic had spent many hours testing cushions and backs and determined with the use of a pressure mapping system that the combination of a Jay 3 back support and a Roho Quadro cushion would be used. We had also chosen the Adjustable, Rigid Frame, Crossfire by TopEnd as we were unsure of what seat angle would best suit him post delivery. Spinnenergy Wheels were selected to reduce the weight and help reduce impact to his impaired shoulders.