

ABUNDANT



LIFE

for Little Ones Who Need More



C400 Power Chair/Stander by Permobil



Up N Go by Easy Walking

by Keith Waller

Getting time to meet and talk with Kathleen Ganley is difficult. Her schedule is very tight, and more often than not, to talk with her means talking while walking as she prepares for her next client. And her next client is 3 years old.

Abundant Life Physical Therapy

Kathleen is a licensed physical therapist with a focus on pediatrics for orthopedic and neurological conditions. She was inspired to embark on this challenging career through her experiences recovering from car accident injuries and from growing up with a cousin, Mark, who was born with severe spastic quadriplegia athetoid cerebral palsy. She witnessed firsthand his struggle and the strain felt by the entire family coping with his care. His mother, Kathleen's aunt, became a widow and single mom, struggling alone to look after Mark and be his advocate.



Toucan Stander by SNUG Seat

Kathleen's facility, Abundant Life Physical Therapy, in the Lake Carolina development in northeast Columbia, is one of the few remaining pediatric facilities in that region, as many have closed due to financial and budget constraints. "We're fortunate to have this campus set-up in Lake Carolina," says Kathleen. "There's a playground, pool, park, stairs and curbs to challenge children,

and it's very quiet. That's important for children with autism and other sensory integration and sensory processing disorders." Abundant Life Physical Therapy is treating several of the increasing number of autistic children in our population. "In the late '80s, there used to be only a few, and now we see hundreds and hundreds."

The Path Forward

Research shows that physical activity stimulates development of cognitive and speech skills. A child who is unable, for whatever reason, to move, run, play and interact with his or her environment will fall far behind in potential intellectual and social development, missing the opportunity to become independent, engaged and productive members of society. To stagnate in development means a life dependent on constant care and support from family and the community. Physical therapy gets them moving properly and interacting with their environment and surroundings. It also helps work through sensory problems related to autism.

Caregiver Work and Stress

Parents of clients come in through the day, and also weekends and evenings when they can afford to take off work, bleary eyed and weary, struggling with long work hours and time at home caring for a developmentally disabled child who needs constant care and attention, sometimes through the night. "Families of special needs children come in exhausted," says Kathleen. "Families may have several very young children, trying to cope. And there are single moms trying to work, trying to bring children to school, totally

exhausted, eating fast food, getting no beneficial exercise, functioning in survival mode. Some look like they shouldn't even be behind the wheel of a car."

With fewer alternatives available to parents caring for these children, it becomes necessary to drive 2 to 3 hours round trip to make a 45 minute appointment for therapy. "Sometimes clients can't get here for their appointment—there's no money for gas, no time," says Kathleen. Parents of very young developmentally challenged children are young themselves, with few resources.

"We're primarily educators for parents," explains Kathleen. "They need to continue therapy lessons at home, repeating activities six times a day, if only for a few moments, like turning a child to a press-up position while singing the ABC song to pace and regulate heartbeat. For these special children we dim the electric lights and try to use natural light, and teach singing, counting, and use deep pressure. It's a regulatory issue to develop sleep patterns, eating patterns, using swings, swaddling, stretchy fabrics for calming—all tools for sensory processing disorder children. They all improve with a little work."



Creform Bathseat

Funding Budget Crunch

In the style of "penny wise and pound foolish," program funding that supports care for these children has been cut, and will cause costs to the community to actually increase as costs are passed along from one place to another. From a strictly financial perspective, we all benefit by helping these children to be more independent than to condemn them to lifelong dependency on services. According to former SC House Rep. Anton Gunn, there's no extra funding, and there will be yet more cuts in early intervention programs. "It's still very bleak."

BabyNet is the state intervention program, dependent on those shrinking state and federal funds, for infants and toddlers less than 3 years of age with developmental delays

or associated conditions. Private insurance and Medicaid can also be called to task for support if a convincing case can be made, which has become a greater and greater challenge. Letters of justification must be prepared and applications made, and time allowed for review and response when denied. In a recent case, Kathleen had a professional video made to demonstrate the improvement the child achieved with a special hydraulic walker in therapy, so her client could have her own at home and continue practice daily. Delays in making each case and fighting each denial leave clients without the braces, walkers and tools to continue improvement, extending the need for constant care.

Successes

Sensory processing disorder children can't interpret what many of us take for granted, like balance, gravity and tilting. Learning to walk is difficult if you can't tolerate the sensations of touching the ground or balance yourself, and eating is difficult if you can't feel or tolerate certain textures or sensations in your mouth. With special equipment, such as braces, walkers and training tools, children make miraculous advances. As they get older, being physically active also prevents weight gain, scoliosis and other ailments that would lead to more expensive medical services.

"We have a 13-year-old using a walker, who was unable to stand," says Kathleen. "He now can walk, run, kick a ball, and can ride a 26 inch bicycle with large training wheels. This is a child who will grow up to be able to go to work, do errands and care for himself. He can participate in life fully—but so can his family members." It's important to treat teens early for developmental problems to prevent common postural complications and weight gain. "They sit a lot, normally, but disabilities can prevent walking or running and being fit. Less activity can mean eventual obesity, with its list of health issues. We can lend a stationary exercise bicycle to use while playing video games. We have some truly wonderful success. We really work to educate parents, with instruction books and inspiring success stories to keep up hope."

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"The goal is to make everybody functional, productive and have an abundant life," adds Kathleen. The choice we must make as a community is this: As citizens, do we fund work to bring developmentally disabled children to an age-appropriate functional level, so that they can attend school, benefit from a level of independence, and live a full life, or do we spend much more later to provide constant lifelong care and shift the burden to schools that may be poorly equipped to provide for special needs children? Quality of life for these children is poor, without taking special measures, and the loss for deferring developmental support is not just to the children. Parents, families and communities also suffer.

"It is very exciting doing this work," says Kathleen. "The sooner we have children doing age-appropriate skills, we have fewer complications, fewer problems in school. Schools are already overburdened. Children with these disabilities can be the most difficult to have in the classroom. They don't want to be touched, and might hit if their protective space is violated. Some cannot take pressure on their feet and walk on their toes and fall. They end up placed in wheelchairs to prevent falls. If we can provide what children need sooner, we can prevent expensive issues later, like surgery, scoliosis, cognition problems, and not be a burden to school classrooms. Not only is the child healthier, the family is healthier, the community is healthier and parents can work and pursue careers."



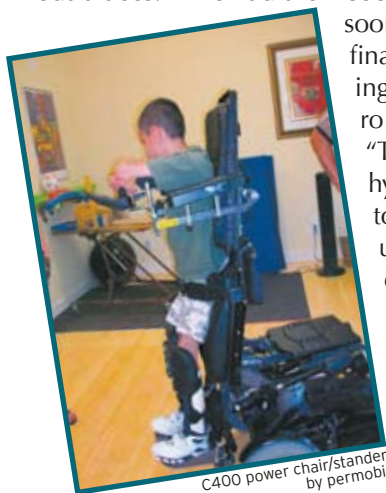
Rifton Mini Pacer and SPiO (spinal pressure input orthosis)

Filling the Gap

Many of the parents are part of the new working poor. BabyNet used to be able to assist with providing walkers, braces and other items, but no longer. "As an example, we have parents, a working mom and dad who have health insurance with a very high deductible, and could not pay the \$3,000 needed out of pocket. We asked BabyNet, and then turned to Medicaid, but the child went months without braces. If we had them sooner, she would be walking

sooner. Now, with braces, she is finally walking without crouching, and knees and ankles don't roll inward.

"There is one walker with hydraulics that you don't need to hold with hands, and if the user squats, it lifts you up," explains Kathleen. "Classified as a gait trainer, the \$1,500 cost has been denied by Medicaid and private insurance. With a regular walker, this client falls to her knees, which will lead



C400 power chair/stander by permobil

to orthopedic issues and delayed development. Some Physical Therapists can offer this equipment in therapy, but lack the resources to lend them out in quantity for clients to take home and use as they should.

"The Up and Go Walker is a wonderful tool, but I can't get insurance to pay, so I try to buy them myself and lend them out like a lending library," adds Kathleen, who regularly dips into her own savings to try to help her tiny clients. "The walker has this child not only walking, but aware of her environment and asking questions. Without it, she falls and vocalizations stop."

"Easter Seals gave away equipment when they shut down some facilities, and I grabbed what I could for my clients," says Kathleen. "Sometimes I can get vendors to lend equipment." But aside from equipment, sometimes clients can't afford the therapy or even the drive in for their appointments. "It would be great to see a church or other entity raise money for gas cards for 'working poor' families to make the drive in for their appointments when they live hours away. If anyone can help the more needy of these clients and their families—offers can be large and small, from large expensive equipment and motorized chairs or funds for services and equipment to used bicycles, swings and even small trampolines (all very useful in physical therapy for clients) we will honor any supporter with a plaque in our therapy studio.

"It's unfortunate that South Carolina is a relatively poor state, but there are still people with the means and generous hearts who can help these children live full lives. As we pay it forward, we are all blessed."

For more info, call Abundant Life Physical Therapy, 212 Eascott Place in Lake Carolina, Columbia, 803-736-9406, or visit AbundantLifePT.com. See ad page 13. For info on BabyNet, visit SCFirstSteps.org/Babynet.html.

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