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I've asked myself several times who has been impacted most over this past year. Was it my son whose life has been changed forever because of the efforts of a group of college students? Or was it the college students themselves whose lives were changed because of my son? As they met together throughout the last year, a bridge was formed over the gap of generations and also over the gap of acceptance of people with disabilities. This allowed the students to see the person my son really is and to look beyond his physical disabilities. The bridge that was formed also helped me to realize the possibility of my son moving toward true independence and a higher level of freedom than I ever thought was possible.
One warm summer day, a man and his family strolled into our greenhouse business looking for flowers. He introduced himself as Dr. Enderle from the Biomedical Engineering program at the University of Connecticut. Dr. Enderle became immediately intrigued by our son Sean, who is an 11 year old impacted by cerebral palsy. Sean gave him his usual hello smile and was immediately excited when the professor mentioned he had some students who might be interested in helping Sean out. Dr. Enderle explained that his senior engineering students must complete a challenging design project in order to graduate. They were required to apply learned principles and concepts towards the development of a device which addresses a real biomedical need.

In September of 2008, several groups of UConn students began coming to our home and getting to know Sean. Although Sean is non-verbal and non-ambulatory, the students could clearly see that Sean understood everything they discussed. They asked him what things he would like them to build for him. Sean indicated using his eyes, facial expressions, and limited vocabulary that he would love a go-kart and with assistance from his cousin Chris, a trampoline. When the students talked with my husband Pat and me they soon learned that living in New England can be a challenge when trying to get a child to experience the outdoors. We discussed how difficult it was to get Sean through the snow or even to transport him onto the beach. One young team was eager to take on this issue.

Further discussion centered around how to include Sean in our family business, Sean Patrick’s Plants. Each day when we were working in the greenhouses we would carry the Rifton Freedom Stander from our home to the greenhouse – a distance of 750 feet. Another young team excitedly took on the challenge of creating a standing greenhouse gardener so Sean could work productively alongside his family. Sean was thrilled with this idea. The last wish we had was a way to mount Sean’s Dynavox 2 (Augmentative Computer) in the car so he could communicate while traveling.

From September through May all eleven students came to our home regularly – getting to know Sean, learning how his body works, researching him as well as cerebral palsy, and determining what specific adaptations he would need. The students researched doctors’ reports and therapy evaluations, met with physical therapists, watched videos of Sean, and spent countless hours paying attention to details. These wonderful students were hooked by Sean’s charm and truly began to care about helping him improve his life.

As time progressed it was unclear whose life was becoming more impacted by the projects. Sean definitely was benefiting, but the students themselves were becoming so fond of him. It was wonderful to see this relationship growing.

Finally, May came, and to be honest, I was a bit skeptical. I wasn’t sure if all along we were getting our hopes up too high. The first device to come to our house was the trampoline, along with a cement mixing truck. The trampoline was designed by Kelly Valentine, Caitlin Martin, and Blaine Ericson. The students arrived excited and apprehensive. They explained that they needed to put into the ground a 64 cubic foot cement block to secure the steel crane arm that would be necessary to suspend Sean’s harness apparatus. My husband and I turned and looked at one another with the same question on both our minds: Are we really going through with this? Once the heavy steel crane was in place, the students put together the trampoline; they worked until their hands were blistered and they were covered in sweat. They checked and rechecked their lists to make sure they had everything in place. They had an incredible determination that was obvious; they were going to make this work!

Finally, it was time for Sean to try it. I was very nervous, asking myself over and over in my mind: Could Sean actually do this? Sean was clear he was up for the challenge and would do whatever he needed to do to prove that the trampoline was a success. Once securely in the harness Sean swung, with assistance from the crane arm above, onto the trampoline.
His sister Brandi took his hands and began to teach him how to jump. This was a totally new experience for Sean. The elation in his smiles told it all. The students began high-fiving each other with tears in their eyes as Sean jumped literally for the first time.

Suzanne Davis, PT, stated that “Gravity pushes us down to the earth. Normally, we use our postural muscles to come up against gravity. Children with cerebral palsy have difficulty activating their postural muscles. The equipment that Sean has assists in decreasing the earth-bound effects of gravity and gives him the chance to feel the freedom and joy of movement.”

The second project was designed by the same team: a unique mounting system for Sean’s Dynavox VMax. This apparatus is secured to the headrest in our car. It allows Sean access to his device en route. Sean is a double-head switch user: his switches were put into the sides of his car seat allowing him to talk with family and friends during our drives. Sean loves it and is excited he can be riding and talking at the same time. During our first ride while Sean was accessing his device, he stated, “Very cool!” And it was!

The third project, a go-kart designed by James Laolino, Eric Leknes, Alex Jadezak, and Tarek Tantawy, was truly exciting. Sean is all boy, and has loved cars (or anything with an engine) since he was very little. His eyes lit up like a Christmas tree at the sight of his own car.

Nervousness doesn’t even come close to the feeling I had seeing Sean sit behind the wheel for the first time. I was ready to run alongside him and rescue him if even the smallest thing went wrong, but my husband Pat thought it was great. He tried to encourage me by telling me, “Let him have his fun!” The students, therapists, friends, and family all became overjoyed at the sight of Sean riding through the fields all by himself. Once again, we were brought to tears and my nervousness melted away. It felt like I was sending him off to college. The students explained that the go-kart can be operated using four different controls: joystick, remote, head switch, or wheel. There is also the ability to switch seats and allow for other family members to have fun, too.
It was wonderful to have some of Sean’s therapists sharing in our joy that day. His physical therapist, Usha Kanithi, felt the project was a great success:

“In my years of experience working with children and families, I’ve come across many special families. However, the environment that was created for Sean by his family in attending to minute detail of how to include him in everything the family does on a daily basis is remarkable. The family’s, especially his mother’s strength to explore all avenues and the endurance to fight the battles to make thoughts and hopes become reality is a true gift for Sean.”

“When I saw Sean take off on the go-kart and how he started to laugh with his dad while all of us were worried was a moment I will never forget in my life. The warmth I felt in my heart when I saw the freedom and the power of independence Sean felt at that moment was unforgettable. Thanks UConn for making this happen for Sean and his family!”

It was obvious that the student designers were amazed and delighted to see how their hours of hard work and creativity paid off as they watched their go-kart provide Sean with incredible independence, joy and freedom. Sean finally has his own wheels!

The last two projects were designed by Fryderyk Karnas, Robert Knapp, and Peter George. The multi-terrain portable wheelchair allows Sean to travel in the snow or on sand. The tires come off and deflate easily and the chair folds. Each year our family vacations for a week at the Jersey shore. I always dreaded trying to find a way to get Sean onto the beach. In addition, we have a large family and no space to fit a huge chair in our vehicle. This all-terrain chair is easily portable which is most welcome. We are looking forward to using it this summer and winter!

Lastly, the students designed a truly unique standing gardener. Our family is very busy every spring working hard in the greenhouse. Each day we would have to carry his stander to the greenhouse and back. This new device is made completely of stainless steel and is equipped with anything Sean’s body needs as well as a turntable for filling pots of various sizes. It has a soil drawer and bars with sponge grips for Sean to hold onto for stability. It includes an area for trays, tools, and even a cup holder for when he needs a drink. Sean loves having his own work station. Sean Patrick’s Plants was named after Sean and we often say he is the boss. Now he really is!
“It is amazing how independent these devices make my little brother. I’m so grateful the UConn students have been able to provide him with abilities he’s never known before. It was so cool to see him zoom around in his go-kart because he looked like he was having the time of his life,” said Brandi, Sean’s sister.

In addition to giving Sean new and exciting experiences, his new inventions also benefit his current therapies. One of Sean’s physical therapists, Stephen Moran, was quoted as saying, “The input Sean’s body receives while using the trampoline is a perfect adjunct to his therapy routine. It helps to integrate many of the new things his body is learning to do. It also improves his quality of life and interactions with his family and friends. What a blessing!”

So I ask myself again: who was impacted the most through this incredible experience? The obvious answer is Sean, as the thrill of the trampoline continues every day, both with his friends and family, the joy of the go-kart will never fade, and the assistance Sean gives us daily as we work with our plants brings us immeasurable pride. Yet I know for the students it wasn’t about the grade they were receiving on their projects, but the joy and change they were bringing into the life of a child. We will be forever grateful to the students and Dr. Enderle for all of their hard work. It is truly by God’s grace and divine plan that these students and Sean were brought together, changing each other’s lives forever.

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THE HEALING INSTITUTE
1308 A/B North State Road 7
Margate, FL 33063

Office 954-975-3563
www.thehealinginstitute.net