DIRECTIONS

Why Should We Care

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CALLING ALL CRT STAKEHOLDERS!!!

Written by: **ELAINE STEWART,** ATP, CRTS®

Where do you go to access information and guidance?? NRRTS is the perfect place to begin. NRRTS continues to be a resource for products, services, legislative up dates, advocacy support and consumer experiences. Our audience is anyone in the Complex Rehab Technology (CRT) community: clinicians, doctors, case managers, consumers, etc. to name a few.

If you do not fit the criteria to be a NRRTS Registrant, you can be an Individual Friend of NRRTS (IFON). This membership allows participation on the NRRTS Listserve, which connects CRT professionals all over the country. You can ask a question, share an idea or just make a comment.

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WE HAVE A VOICE...IT JUST NEEDS TO BE LOUDER!

Written by: **ROSA WALSTON LATIMER**

Anticipating a milestone birthday and facing an empty nest, Karen Roy decided to "up" her game ... her advocacy game. "It is amazing to me how things came together," the reigning Ms. Wheelchair America said. "Everything had to fall into place in a certain way for me to get involved in the Ms. Wheelchair (America) competition. I moved from being a social worker to working in sales with Numotion, a wheelchair and mobility company. My youngest child was starting college. This along with some other changes in my life brought me to this perfect coming together of events for me to increase my advocacy efforts."

Roy admits she was surprised that at age 50 she decided to put herself "out there" in such a public way. "This was the first time in my life when I could 100 percent devote myself to the time needed for the travel and the advocacy work that the title deserves."

The Louisiana native has lived her life in a wheelchair for 31 years. "My spinal cord injury is the result of being the victim of a random armed robbery. I was a sophomore in college and hadn't decided on a focus for my education; however, after the shooting I knew I would pursue a career that would allow me to help others with disabilities. That's when I decided to earn a degree in psychology," Roy said. "And, I was determined to live as 'normal' a life as possible. I got married and had my daughter, Caroline, after graduation from LSU (Louisiana State University) with my undergraduate degree. I began graduate school when she was 9 months, and I finished when she was almost 3 years old. My two boys were born after that."

Even though Roy's children are now living on their own, they remain an important part of her life. "Caroline is 24, Austin is 21 and Joseph is 18. I spend time with my kids whenever possible," she said. "Two of them are enrolled at Louisiana State University where I earned both of my degrees, so we are always cheering for my Tigers! I love LSU football and go to as many games as I can."

"AND, I WAS DETERMINED TO LIVE AS 'NORMAL' A LIFE AS POSSIBLE. I GOT MARRIED AND HAD MY DAUGHTER, CAROLINE, AFTER GRADUATION FROM LSU WITH MY UNDERGRADUATE DEGREE. I BEGAN GRADUATE SCHOOL WHEN SHE WAS 9 MONTHS, AND I FINISHED WHEN SHE WAS ALMOST 3 YEARS OLD. MY TWO BOYS WERE BORN AFTER THAT."

Until 2015, Roy was a social worker working with patients in physical rehabilitation hospitals in Baton Rouge, Louisiana. "I realize now that choosing a career that offered me an opportunity to help others was a way of processing the grief of losing the use of my legs," Roy said. "There are parallels between my decision then, at age 19, and my choice to become a more active advocate at age 50. Almost three years ago, I experienced the accidental death of my husband, and I believe I chose a similar path to help me through the grieving process. It was a powerful healing instrument for both experiences to transition to something that gave me purpose and joy. When you can help someone else through a difficult experience, that takes your mind off whatever you are personally experiencing. Being Ms. Wheelchair America is 100 percent about advocacy efforts. It is another way for me to focus on what I can do to help others rather than focusing on myself. Everyone grieves differently. I believe my best coping mechanism is helping others.

"I began at Numotion on the complex rehab side of the business and now I have moved to the medical supply side. I cover Louisiana, Mississippi and Alabama and oversee urology and ostomy, wound and wound care supplies for the population that we serve. Our goal at Numotion is to make life easier for those we serve and many of our clients that need custom

Best friend since junior high school, Anne Bynum, with Karen Roy in Grand Rapids, MI when Karen was selected Ms. Wheelchair America 2018.

Karen Roy at the Boston Abilities Expo.

"MY FIRST STANDING DEVICE WAS A SIMPLE RECIPROCATING BRACE. I ALWAYS ADVISE THAT IF THAT IS ALL YOU CAN GET YOUR HANDS ON, THEN DO IT. STAND BY ANY MEANS POSSIBLE AND THEN FIGHT FOR THE REST."

wheelchairs also need these supplies. Even as a social worker I often provided bowel and bladder education to patients and staff. I love it!

"My experience in the Ms. Wheelchair competition has opened many doors to allow the opportunity for me to speak to groups that I would not have otherwise had," Roy said. "I'm looking forward to interacting with lawmakers, insurance companies, medical professionals and the disabled community. We're fighting the fight. We have a voice, but it needs to be louder!"

Roy especially wants more interaction with the medical community. "I've been talking for years with my doctors as well as those I've worked with and, frankly, have not always been taken seriously when I asked why we continue to fix the broken-down bodies of people who sit in wheelchairs all day when other options exist?"

The options Roy is referring to include standing devices and functional electrical stimulation both of which she credits for her years of wheelchair use with no pressure wounds, contracture or other medical problems.

"This is important. This greatly impacts the quality of life and health of those in wheelchairs. Continuing to have individuals who are septic because of a pressure wound is not OK," Roy said. "My first standing device was a simple reciprocating brace. I always advise that if that is all you can get your hands on, then do it. Stand by any means possible and then fight for the rest." Now Roy uses a standing robotic device and a functional electrical stimulation bicycle. "I have a standing desk at home and use my standing device while I do my emails and telephone calls. I've tried to build what would be considered physical therapy into my lifestyle."

As with anyone, maintaining healthy habits can be a challenge with Roy's job responsibilities as well

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WE HAVE A VOICE
(CONTINUED FROM PAGE 7)

as serving as Ms. Wheelchair America. "Helping people and being a voice for those with disabilities is the positive side of my life," Roy said. "The difficult part is I do have a disability. I'm in a wheelchair. I keep preaching about exercising, and I've been out on the road constantly. It would be terrible if I'm being outspoken about taking care of yourself and then I end up with a wound. I have to try to balance this!"

From the very beginning of Roy's life with a disability she was shown an impressive example of advocacy through the dedication and action of her parents, Alan and Carlyn Fernbaugh. "Parents will try to do anything to make things better, but my father especially had a personality that was going to fight to keep his daughter healthy and happy. Perhaps I wouldn't walk again but at least my parents were going to do everything possible to help me be the best I could be. No one wanted to go up against my dad!" she said. "His example of persistence has helped me be successful despite my disability and gave me my fight going forward. I don't necessarily take 'no' for an answer just because someone says so."

Another personal, more recent advocate and positive example for Roy is her boyfriend, Roy Harris. "Roy and I went to high school together and a while back became reacquainted at a wedding," she said. "We went to a couple of dances together when we were in the Tenth grade. He loves to tell people that he is one of the only guys who danced with me when I could stand and now he dances with me again in my standing robotic device."

Harris has been a tremendous support to Karen especially as she fulfills her

Karen Roy with her sons: Austin, 18, (left) and Joseph, 21, (right) both students at Louisiana State University.

Karen with her "right hand man" and boyfriend, Roy Harris at a fundraising event.

ABOVE: Karen Roy with her daughter, Caroline, 24.

RIGHT: Roy Harris and Karen Roy at Ms. Wheelchair America 2018.

responsibilities of Ms. Wheelchair Louisiana and America. "I'm not sure I would have won either without his help. Roy has been a driving force with fundraising. He helps me keep up with my event schedule and when I'm too tired to drive, he does that too. Roy also shares my dedication to promoting the Ms. Wheelchair organization."

Ms. Wheelchair America (www.mswheelchairamerica.org) is a non-profit program that provides an opportunity of achievement for women who happen to be wheelchair users to successfully educate and advocate for those living with disabilities. Ms. Wheelchair America is not a contest to select the most attractive individual. It is instead a competition based on advocacy, achievement, communication and presentation to select the most accomplished and articulate spokeswoman for persons with disabilities - according to the organization's website. The program currently includes 30 states and the District of Columbia.

Roy is helping the organization reach representation in all 50 states in time to celebrate its 50th anniversary in 2022.

"I pursued the Ms. Wheelchair 'crown' because I had a message, not the other way around. The fun, somewhat glamorous experience of the competition is, as we say in Louisiana, "lagniappe." That's French for 'a little something extra.' Actually, I've have been saying the same thing for 31 years, but until I had a tiara on my head I don't feel as though people listened!"

CONTACT

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Karen Roy is a consumer advocate and Ms. Wheelchair America who works for Numotion in Baton Rouge, Louisiana.

‘MR. DAN,’ THE WHEELCHAIR MAN

AFTER THREE DECADES AS A PEDIATRIC REHAB SUPPLIER, WEATHERLY IS STILL RIGHT WHERE HE BELONGS

Written by: **DANETTE BAKER**

In his hometown of Savannah, Georgia, Dan Weatherly, ATP, CRTS®, is known as the wheelchair man. That’s because he’s been fitting children in southern Georgia with complex rehab equipment for three decades – and he doesn’t plan to stop anytime soon.

On a recent weekday, Weatherly spoke about a young man named Jamario, a local high school student who needs a power chair. The previous Friday night Weatherly had watched Jamario led his classmates – the football team and cheerleaders – onto the field. “Jamario,” Weatherly said, “was leading them on his walker.” The young man, whom Weatherly fitted with his first walker as an elementary student has cerebral palsy and an infectious energy and a smile that never fades, he said.

Because of severe deformity from the disease, Jamario struggles to walk. Every day, Weatherly said, he misses the final minutes of each class period because it takes him the entire passing period to walk to his next class – and he always arrives well after everyone else. “I want to see him keep walking as much as possible, but I’d give anything to get him in a power chair (with the proper seating system) to give him a little bit of a break—and to see him lead his team as they run onto the field,” Weatherly said.

The desire, to help Jamario and all the others—keeps Weatherly in the business. “They do more for me than I’ve ever done for them.”

Weatherly began his career in pediatric rehab working for an Atlanta-based company that had a joint venture with a local Savannah hospital. The now-defunct company also serviced the Shephard Center, a spinal cord and brain injury rehab hospital. That’s how Weatherly got introduced to the world of pediatric rehab.

Dan Weatherly and his daughter, Shannon Weatherly, in the White House Rose Garden. She served two White House administrations working for children’s causes. “I couldn’t be more proud of her; and I know she is proud of me,” Weatherly said.

As a member of the Allcare Pharmacy & Healthcare Services mobility team, Dan Weatherly gets to be a “worker bee,” fitting children with rehab equipment.

Jessie and Dan Weatherly

“You don’t want me doing your plumbing or electrical work, and I’m not the one you want to call if your car broke down. But the first time I put a little fellow in a wheelchair and that kid got to move on his own, I realized was what I was meant to do. Anyone could have done it, but I got to, and I became good at it because desire makes you want to do the best you can for someone.”

That was in the late 1980s, but Weatherly has never wavered in his purpose. He joined the mobility team at Allcare Pharmacy & Healthcare Services about three years ago after 25 years as owner and operator of

Jessie is all smiles after Dan Weatherly fitted her with an elevator seat on her power chair.

Weatherly Medical Consultants. Being self-employed required long hours in the field—and longer ones back in the office and in his home shop where he built custom wheelchairs, "at night and into the am," Weatherly said.

But for years it allowed him to do what he loved—pediatric rehab.

At the time, he said, it wasn't unusual for rehabilitation equipment suppliers to be self-employed and to "do it all." And then, things began to change. "The amount of paperwork and governmental regulations that created so many hoops you had to jump through," Weatherly said. "It wears you out."

Fortunately, the industry has fought back – for the clients to get the equipment they need and deserve and for the suppliers to be recognized as professionals and paid for their expertise. Credentials such as the ATP and CRTS® and organizations such as NRRTS and RESNA have brought about a way to validate those working in the industry, Weatherly said.

"They're opening doors for us that were never open before. We get educational opportunities and connections to others in the industry who are facing some of the same things. We can share information and resources.

"And they are giving the end user a voice and us a way to show that we aren't just slapping someone in a chair and going on our way, so we can get paid.

"I WANT TO SEE HIM KEEP WALKING AS MUCH AS POSSIBLE, BUT I'D GIVE ANYTHING TO GET HIM IN A POWER CHAIR (WITH THE PROPER SEATING SYSTEM) TO GIVE HIM A LITTLE BIT OF A BREAK—AND TO SEE HIM LEAD HIS TEAM AS THEY RUN ONTO THE FIELD."

"We go to bat for those we serve because they deserve to have the products, so they too can live independent lives."

When Weatherly decided to close his business, he wasn't quite ready to quit work altogether. Initially, he stopped accepting new clients but continued over the next six months servicing wheelchairs for his clients free of charge and quickly recognized, "At that time, I really just wanted to be a worker bee and let someone else run the company."

Allcare Pharmacy & Healthcare Services didn't have a strong emphasis on pediatric rehab services, and so it was a natural fit. "Being part of team means lot professionally and helps me better serve my clients. And I get to work in the side of this business that I truly love. Rehab."

Like many in the industry, Weatherly has stories that ground him. So, when the struggles to get equipment funded or when elevator seats or specialized headrests are labeled luxury items, stories of his "kids" come quickly to mind. The 28-year-old college graduate that he fitted with her first chair at age 2; and the young lady, who at 21 finally got to stand face-to-face with her 5-foot 2-inch mother because she now has a chair with an elevator seat that raises her 12 inches. And Jamario, who struggles to take each step yet reassures Weatherly, "Everything is going to be OK, Mr. Dan. It's going to be OK."

And he's right – as long as there is a Dan, the wheelchair man.

CONTACT
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Dan Weatherly, ATP, CRTS® is a NRRTS Registrant who lives in Savannah, Georgia.

YOU CAN BE A BEACON OF HOPE

Written by: **ROSA WALSTON LATIMER**

Allison Fracchia, PT, ATP/SMS, works closely with clinicians and assistive technology practitioners throughout Mississippi as the Permobil sales manager for the state. "I started with Permobil in 2015, and my ability to work in this capacity has been enhanced by my educational background of physical therapy, the years I managed a clinic, and over 20 years' experience of performing mobility and seating assessments for thousands of individuals with a variety of diagnoses," Fracchia said. "I have a desire to help others and I get to achieve that by working for a company that has a heritage built on the goal of assisting people." Working with Permobil has placed Fracchia in a position to be a valued resource to others as she layers her previous experience with her product knowledge.

When she started college at Mississippi State University, Fracchia knew that she wanted to work in the medical field in some capacity. "About a year later my mother was diagnosed with breast cancer, and I had my first exposure to physical therapy while she was in the hospital," Fracchia said. "She would sleep a lot, so my twin sister, Amy, and I would go down to the therapy gym and observe. This spiked my interest and put me on the path to earning a degree in this field." Amy Knighton also pursued a career in physical therapy and now works in the home health setting.

After receiving her bachelor's degree in physical therapy from the University of Mississippi Medical Center, Fracchia began working at the Methodist Rehabilitation Center (MRC), the only free-standing inpatient rehab facility in Mississippi. "I had the opportunity to work with individuals who had brain injuries, CVAs, MS, MD and a variety of other neurological conditions," Fracchia said. "However, it was my love for working with patients with spinal cord injuries that led me to where I am now in my career. I still remember one of my first SCI patients. He was 15 years old and had sustained a C5 injury that resulted in quadriplegia. I was so nervous about introducing him to power mobility but quickly realized that the chair gave him hope for a better life and a means of independence that he could not achieve otherwise. Instead of seeing the chair as something sad for him, I began to see it as an opportunity."

"I WAS SO NERVOUS ABOUT INTRODUCING HIM TO POWER MOBILITY, BUT QUICKLY REALIZED THAT THE CHAIR GAVE HIM HOPE FOR A BETTER LIFE AND A MEANS OF INDEPENDENCE THAT HE COULD NOT ACHIEVE OTHERWISE. INSTEAD OF SEEING THE CHAIR AS SOMETHING SAD FOR HIM, I BEGAN TO SEE IT AS AN OPPORTUNITY."

This was Fracchia's "aha" moment and sparked a passion for assisting others in finding the best mobility device to meet a patient's needs that she still carries today. "Now as a manufacturer's rep, I see mobility devices used in a real-world environment, and I have the opportunity to teach and encourage therapists. I always try to make clinical suggestions based on values and would never encourage a therapist or ATP to recommend a product just because I sell it. The needs of our end user are the priority."

Eventually, with the support of MRC, Fracchia developed and implemented the Assistive Technology Clinic with an emphasis on seating and wheeled mobility. "This was the first dedicated seating and mobility clinic in Mississippi," she said. "For 15 years I managed the clinic and spent my days doing evaluations, fittings and training for people who could no longer functionally ambulate. Now most of the ATPs and many of the therapists that are involved in the 'wheeled mobility world' have been friends of mine throughout my career. They are my work family, and these relationships make my job that much more fulfilling."

During a career of over two decades Fracchia has witnessed many changes in

her field. "I believe technology and funding have changed the most since I began this journey," she said. "Originally getting coverage for a seating and mobility device was not very difficult. However, there were not many products available, and the electronics and capabilities of the chairs were limited. Now we have products that have technological and mechanical advances that would allow a person to be more independent. Yet the ability to get these products covered by insurance is a struggle, and at times, impossible. Instead of being proactive, many insurance companies are reactive. An individual must first develop a problem before a company will pay for a means to prevent it."

"MY TWIN SISTER, AMY, IS MARRIED AND HAS TWO DAUGHTERS WHO ARE THE SAME AGES AS MY TWO SONS. I FEEL AS THOUGH THE GIRLS ARE MINE TOO! I AM SO FORTUNATE TO HAVE SUCH A CLOSE RELATIONSHIP WITH THEM. FOR YEARS MANY PEOPLE IN OUR HOMETOWN THOUGHT THERE WAS JUST ONE OF US WHO HAD 4 CHILDREN! AMY AND I HAVE HAD A LOT OF FUN THROUGHOUT THE YEARS AS TWINS. WE SWITCHED CLASSES IN SCHOOL, AND WE'VE PLAYED MANY TRICKS ON PEOPLE!"

Fracchia and her husband, Jeff, an engineer, have been married 23 years and have 2 sons, Reid and Owen. "Reid is a junior at the University of Mississippi majoring in Biochemistry and hopes to go to medical school. Owen is a senior in high school at Jackson Academy. He plays football and basketball and plans to attend Ole Miss in the fall with his brother." Fracchia enjoys many activities in her free time: running, reading, cooking, entertaining, decorating and volunteering at Owen's school. She is also an active member of Christ United Methodist Church. "Most of my time outside of work is spent attending high school or college sporting events," she said. "Recently Owen played in a fundraiser basketball game in which his team had to sit in wheelchairs and play against an organized wheelchair basketball team. His classmates were amazed at how Owen could maneuver the chair around the court. He was the only one on his team that scored a goal. Little did they know that he has been around wheelchairs his entire life!

"My twin sister, Amy, is married and has two daughters who are the same ages as my two sons. I feel as though the girls are mine too! I am so fortunate to have such a close relationship with them. For years many people in our hometown thought there was just one of us who had four children! Amy and I have had a lot of fun throughout the years as twins. We switched classes in school, and we've played many tricks on people!"

While Fracchia counts her family as her greatest joy her "fur baby" Lola, a French bulldog, has a special place in her heart, too. "For 10 years Lola has been my shadow when I am home, bringing lots of challenges as well as joy," she said.

Meaningful volunteer opportunities are also an important part of Fracchia's life. "I volunteer for the Memory Impairment and Neurodegenerative Dementia (MIND)

CONTINUED ON PAGE 14

Allison Fracchia (right) with her twin sister, Amy Knighton.

Allison Fracchia with her French bulldog, Lola, dressed for Halloween.

Allison and Jeff Fracchia

YOU CAN BE A BEACON OF HOPE
(CONTINUED FROM PAGE 13)

Center at the University of Mississippi Medical Center and also serve on the Board for Young Life, a Christian ministry that reaches out to middle school, high school and college age kids," she said. "I've volunteered for the Clinician Task Force for 12 years and have served on the executive board. I currently serve on the American Physical Therapy Association Seating and Wheeled Mobility/ Assistive Technology SIG, where I was recently appointed as nominating committee member for a three-year term, and I am also a member of RESNA." In addition, Fracchia is a presenter at state and local conferences, a guest lecturer and contributor to DIRECTIONS magazine.

Allison Fracchia's family: (back row, left to right) youngest son, Owen; her husband, Jeff; niece Abbie; brother-in-law Charlie; and oldest son, Reid; (front row, left to right) niece Celeste; Allison, and sister Amy.

Experience and insight give Fracchia an awareness of what it takes to have a rewarding, fulfilling career in her field. "A strong team is the key to success. You cannot do it alone," she said. "Listen to the ideas of others, don't be afraid to give your opinion and don't be afraid to ask questions."

Permobil team: (left to right) Allison Fracchia, Jason Simpson, Sam Beck, Erik and Mary Beth Tillman, Todd Mason, Wade Medley

Fracchia also advises therapists to read the RESNA position papers. "They are full of clinically relevant information." When working directly with a patient, she believes it is very important to ask many questions and to remember the caregivers. "Many times, people have more going on than meets the eye. Ask how the patient plans to use their chair and always include the caregiver in the conversation. Be kind and compassionate. People are hurting and often you are their beacon of hope for more independence and a significant improvement in their life."

On a practical note, Fracchia makes this recommendation, "If you don't have a key pad on the door to your vehicle then hide a key somewhere on the outside. You will lock your key in your van. I've done it many times! My membership with AAA has been well worth it!"

The Fracchia family (left to right): Owen, Allison, Jeff, Reid

"Through my role as sales manager with Permobil, I have met some passionate colleagues from all over the country. It is interesting to learn about the trends, funding challenges and environmental factors in various parts of the country," Fracchia said. "The possibility I have of making a positive impact on the independence, health and well-being of individuals makes my job extremely rewarding and keeps me energized. I am reminded daily of the things we all take for granted, yet there is triumph in seeing the smile on a person's face when they achieve a level of comfort or accomplish a functional goal. I am very fortunate that I get to see those smiles often. That gives me purpose and makes me want to keep doing what I'm doing!

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YEAR-END PUSH FOR CRT LEGISLATION

Written by: **DON CLAYBACK**

With elections completed, Congress will now be back in session until mid-December. As is typical, they will likely be taking up some final legislation during this "lame duck" session. This is our window of opportunity to get Complex Rehab Technology (CRT) bills HR 3730 and S 486 passed this year.

Passage of this important legislation will stop the Centers for Medicare and Medicaid (CMS) from continuing to inappropriately use Medicare Competitive Bidding Program information to cut payment rates for critical CRT manual wheelchair components (aka accessories). These cuts are hurting people with disabilities who rely on this specialized equipment.

As of this writing House bill HR 3730 has solid bipartisan support from 119 cosponsors (58 Republicans and 61 Democrats) as does Senate bill S 486 with 25 cosponsors (11 Republicans and 14 Democrats). This bipartisan foundation is reinforced by over 50 national disability and clinician organizations who have formally communicated their support in letters to Congress.

This CRT legislation is primed for passage. However, our challenge is to translate this base of support into getting members of Congress to make this a priority for inclusion in larger year-end legislation. Your voice and those of others in the CRT community is needed. The message is simple: ask your members to tell their party and committee leaders that this critical legislation must be passed this year.

EVEN BETTER THAN EMAIL, USE THE GUIDE AT THE WEBSITE AND MAKE A CALL TO PERSONALLY COMMUNICATE YOUR REQUEST. WHETHER AN EMAIL OR CALL, REMEMBER DON'T STOP UNTIL YOU GET A COMMITMENT. POLITE PERSISTENCE WILL WIN THE DAY.

You and the rest of the CRT community can make this happen. Take just three minutes to visit www.protectmymobility.org and click on the "Send the Email" link. Supply your information and an email will be sent to your members. This site also has the related position paper that can be shared.

Even better than email, use the guide at the website and make a call to personally communicate your request. Whether an email or call, remember don't stop until you get a commitment. Polite persistence will win the day.

Thanks for acting on this information and please share the link with others to help highlight to Congress that people with disabilities need them to step up, pass this legislation and resolve this access issue before they adjourn for the year.

ELECTIONS BRING CHANGES

November elections have brought changes in the makeup of Congress for next year. If you have a new member for 2019, we need to get them on the team of CRT supporters. If you find yourself in this situation, here are some suggestions to follow.

• Make a Final Push- Your current member can still be helpful. Use the time left to follow up with your contacts to ask that they help get our CRT legislation passed this year. Focus on the health legislative assistant or other policy staff you have a relationship with. Congress will still be voting until the end of the year.

• Research Your New Member- Just because your member is leaving doesn't mean you can leave too. Start reading about the new member. Sign up for their emails or attend an event where they'll be speaking about their platforms to understand their positions on issues like health care and disability rights. Learn about where they'll be focusing their time and effort once in office.

• Develop the New Relationship- Once your new member takes office you can visit their website and submit a general contact form or email to introduce yourself and CRT. A quick phone call to the member's federal office about a month after the 2019 session begins will provide you with the name and email of your new health legislative assistant contact. Start the dialogue regarding CRT

legislation and why you'd like to have the member's support in protecting access for people with disabilities.

Changes in Congress are a fact of life. What's also a fact is the important role Congress can play in protecting access to CRT. With that in mind, thanks for taking the time to educate your new member regarding CRT and getting them on our team of congressional supporters.

SEPARATE BENEFIT CATEGORY

The legislation to establish a Medicare Separate Benefit Category (SBC) will be reintroduced next year. As we all know, this bill (HR 750) represents the comprehensive improvements needed to protect and promote access to CRT for people with disabilities. Unfortunately, our efforts to get the SBC bill passed during this current session of Congress were complicated by the required focus for legislative and regulatory action to resolve the CRT wheelchair accessories issue. Plans for 2019 will include a renewed push for this needed SBC bill. Stay tune for more details as we move into next year.

2019 NATIONAL CRT CONFERENCE

Plans are being made for the 2019 CRT Leadership & Advocacy Conference in Washington, D.C. This annual partnership between NCART and NRRTS produces a two-day conference focused on education, networking and advocacy. We're looking forward to fresh discussions and timely sessions covering industry issues and business strategies. Most importantly, we'll be making the critical visits to Congress promoting CRT awareness and our legislation. Contact NCART for additional information regarding dates and sponsorship opportunities.

CONTINUED ON PAGE 18

YEAR-END PUSH FOR CRT LEGISLATION
(CONTINUED FROM PAGE 17)

CRT NEWSLETTER

The CRT industry is fast-paced with a stream of changes and challenges. To help keep stakeholders and advocates informed in a timely manner, we have begun publishing "NCART News." The newsletter is published monthly and delivers CRT Medicare and Medicaid updates, advocacy opportunities and event information all in one place. If you're not receiving it, just visit www.ncart.us and use the "Sign Up for CRT Updates" button.

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Don Clayback is executive director of NCART. NCART is national organization of Complex Rehab Technology (CRT) providers and manufacturers focused on ensuring individuals with disabilities have appropriate access to these products and services. In this role, he has responsibility for monitoring, analyzing, reporting and influencing legislative and regulatory activities. Clayback has 28 years of experience in the CRT and Home Medical Equipment industries as a provider, consultant and advocate. He is actively involved in industry issues and a frequent speaker at state and national conferences.

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THE CLINICIAN TASK FORCE:
ADVOCATING FOR CRT ACCESS FOR PEDIATRIC POWER MOBILITY AND MORE

Written by: **LAURA COHEN** PHD, PT, ATP/SMS, AND **LAUREN ROSEN** PT, MPT, MSMS, ATP/SMS

One of the best parts of working with young children is showing kids and their parents all of the things that they are capable of achieving. Putting a nonverbal or significantly involved young child in a power wheelchair and seeing them move themselves independently for the first time re-affirms why we work in this industry. The tears of joy and gasps of surprise are nothing short of wonderful.

Once the shock of happiness wears off and the family decides that they do truly want a power wheelchair in their life, the real work begins. Unfortunately, many payer sources do not share the same perspective. They are focused on value that is defined by cost and effectiveness, and our job is to communicate the value of children reaching their full potential.

Despite an abundance of research showing the importance of early mobility and independent movement, payers continue to rely on dated misconceptions often limiting children and families from accessing power wheelchair technologies. Early pediatric power mobility can level the playing field and enable a child to reach his or her full potential for independent mobility. It is our job as professionals to help families explore, trial and, when appropriate advocate for access to coverage and payment for the right equipment.

The Complex Rehab Technology (CRT) team needs to revisit the language that we use with each other and with the clients we serve. We must be intentional and accurate in the words we choose to explain a specific client's barriers to access. In this way we will uncover options, educate and empower our clients and families to take action and advocate for themselves.

In the short-term, it may be easiest to avoid discussing or showing a client and family equipment that the team believes is 'most' appropriate, necessary, yet challenging to obtain. Some professionals even believe it is 'cruel' to show or recommend equipment a client will not be able to get. Yet, if we do not show and recommend what is most medically appropriate, we are not upholding our professional code of ethics and standards of practice - a CRT practice conundrum.

In fact, every time we do not recommend the most appropriate equipment for our client, we change practice to conform with bad coverage and payment policy. We prevent a client their due process to appeal negative decisions and/or the option of using other payment options. We permanently change practice and mask the extent of true consumer access issues. When asked by policymakers and payers, 'Where are all the people harmed by the current policy?', we have no evidence to support our known client access issues. CRT team members daily are challenged to confront these difficult practice issues and the CRT industry finds ourselves at a crossroads. Do we choose easy and fast? Or do we choose 'honest, open, and tough team conversations. Our future as an industry rests with how we proceed.

A COMMON CRT TEAM SCENARIO

An example of a common clinic scenario may go like this: the rehab technology provider (RTP) says 'XYZ payer does not cover power wheelchairs for children under ABC years of age' or 'XYZ payer does not cover DEF brand or style of equipment.' Here is where the team needs to pause and examine the words we use for accuracy. Given that the clinician does not have a financial interest in the equipment provided, often it is most effective for the clinician to lead difficult conversations with all team members included.

Is the issue a true coverage issue? Then refer to the current coverage policy (source document) and determine if the client meets the eligibility requirements. If not, decide if the clinician is able to supplement the documentation to demonstrate eligibility? Is there a qualifying diagnosis that is not adequately documented in the clients' medical record? If so, the clinician can consult with the referring physician to determine if a qualifying diagnosis can be added and the medical record addended.

In some instances, there is a real exclusion of coverage. Options available will depend upon the payer. If it is a Medicare, Medicaid or Managed Medicare or Medicaid payer, the minimum requirements are not open to interpretation. Managed Medicare and Medicaid programs can provide MORE than what is covered by the traditional program but not less.

For example, Medicare and Medicaid cannot deny equipment based on age alone. There have been multiple lawsuits looking at the reverse problem where payers do not cover equipment for people over 18 or 21 years. Case law has upheld that Medicaid cannot deny equipment to young children based solely on their age.

Saying a payer does 'not cover' a specific make/model of equipment is inaccurate. Instead, a team discussion should include the reason why a specific brand of equipment cannot be provided. Is the reason a HCPCS coding issue? Have dissimilar technologies been grouped together? Do the technologies in the same code have a range of costs that are more than the payment amount allowed by the payer? While some payer sources pay less than others, the issues need to be explained - the payment amount is below 'true cost' and therefore the CRT company cannot provide it. The team discussion is the opportunity to educate the consumer and family and gain an ally in advocacy.

Certified and licensed CRT team members adhere to one or more code of ethics and standards of practice. RESNA's Standard 13 states "Individuals shall inform the consumer about all device options and funding mechanisms available regardless of finances, in the development of recommendations for assistive technology strategies." The CRT evaluation is the time to have these conversations. It is a unique opportunity to explain the policy complexities in our industry, educate and provide resources to empower the family to join in advocacy efforts to ensure consumer access to medically necessary and appropropriate CRT technologies.

Is it easier and faster not to 'go there'? Absolutely. Is it how you would like to be treated or have your family member treated? Wouldn't you want to know all available options and be provided the opportunity to make an informed educated decision?

ADVOCATING WITH PATIENTS & FAMILIES: A CASE SCENARIO

With young children or those who are nonverbal, it is not unusual for a payer to initially deny an equipment request for a variety of reasons. Families should be prewarned to expect a denial and educated about the process that follows in the event of a denial. Clinicians (physical and occupational therapists) do not directly receive any information concerning a denial. We depend on communication with the RTP or CRT company and/or the prescribing physician. Most payers will speak directly with a physician in what is known as a 'peer to peer' consultation. Unfortunately, this seldom includes the clinician (physical or occupational therapist) involved in evaluating and trialing recommended equipment. It is important that the lines of communication are open between the clinician and the RTP/CRT company. The clinician involved in preparing the recommendation and documentation, the prescribing physician, and the patient/family all should be informed in the event of a denial. The patient/family should be allowed their due process for an appeal. For the best outcome, involvement of the treating clinician (physical or occupational therapist) and referring physician will result in expedited communication with the payer and when necessary participation in the appeals process.

Common reasons for denial of pediatric power mobility is "lack of medical necessity" and/or "child is too young to independently use a power wheelchair." In these situations, advising families to quickly request a fair hearing and pursue the appeals process is recommended. These hearings usually take time to schedule, but they often can occur by phone or video and are usually the most effective way to obtain covered equipment for clients of all ages.

At a recent hearing for a 12-month-old boy with myotubular myopathy, a type of muscular dystrophy, a request was received from a payer to find a "less expensive pediatric power wheelchair." This was not a traditional denial. There was no formal 'noncoverage' denial. This denial was related to cost Not medical necessity. The clinician responded that due to ventilator use, there was no less expensive pediatric power wheelchair that could accommodate his vent. The payer quickly responded with a denial decision stating: "The patient is a 1 year old with a diagnosis of myotubular myopathy with a request for a custom wheelchair. The requested DME is not approved as the patient is unable to cognitively operate the wheelchair safely due to profound physical mobility impairment."

The clinician composed a letter providing supplemental medical information including the medical description, functional impairment and lack of cognitive involvement for children with this diagnosis. The clinician's letter focused on the child's physical and functional abilities with and without use of the recommended equipment reiterating and describing the documented results of the equipment trial.

The requested equipment was denied at the first level, so the CRT team requested a fair cause hearing that took place five months later. The hearing was held by phone with all participants. Families may appoint a proxy e.g. clinician to speak on their behalf, yet it is recommended that the family and/or patient be present for the hearing if the hearing officer wishes to speak directly with the beneficiary. While this process can be intimidating and overwhelming, especially for the patient

CONTINUED ON PAGE 22

ADVOCATING FOR CRT ACCESS ...
(CONTINUED FROM PAGE 21)

and family, the job of the hearing officer is to let each participant speak and respond by asking additional questions or providing additional information.

It is vital that the team be prepared with information to support their request in the form of clinical rationale, evidence, practice standards, patient medical records, etc.

While the child's parents were on the call, the physical therapist was the representative for the family, as she was best prepared to present the information. She simply explained again about his normal cognition, his performance during the trial with the wheelchair and all the medical and developmental reasons he needed to be mobile as soon as possible. She cited additional research to supplement materials originally submitted.

When the physician spoke, he said that a child that age could not possibly operate a power wheelchair because he had never seen one do so. He said that if you let a child that age go into a bathroom that they will fall into a tub and drown. He similarly said that if a child that age was allowed to pull a book off a shelf that it will hit the child in the head and the child could die. He finished his argument by saying that he does not believe research because he has not read all the articles referenced so he has no idea of the quality of the research.

When the physical therapist could question the physician, she started with his comments about young children and mobility. As he asserted that any young child is not safe exploring their home environment, she asked if young children should be kept in a stroller or a playpen until they were older and more responsible? He responded by saying that was not what he intended but could not clarify why this child should be treated differently than other children.

The next questions were about the inability of this child to cognitively or physically operate a power wheelchair. The physical therapist mentioned referenced her documentation of the child's successful equipment trial. When the physician was asked about the research cited, he indicated he had not read the documents and was not familiar with the research but called into question the quality of the evidence.

In the end, the child won the hearing and received his power wheelchair because the team had rationale and evidence on their side whereas in this case, the physician had thoughts and feelings on his. In the end, this is frequently the case with many denials. It takes a prepared advocate willing to take the steps, pursue due process, and stand up with the child and their family to get the desired outcome.

The most important part of the provision process is to function as an interdisciplinary team. All participants, the client, family, therapist and RTP need to work together for best outcomes. By involving all team members from the beginning, everyone is prepared to work together to obtain the correct equipment and achieve the best outcomes.

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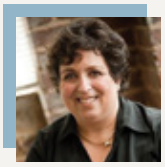
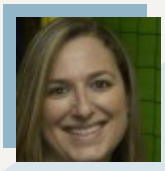
Laura Cohen is the executive director of the Clinician Task Force (CTF), a national group of seating and mobility clinicians working to influence Medicare and Medicaid coding, coverage and payment policies for complex rehab and assistive technology devices. The CTF provides clinically relevant information about seating and wheeled mobility device assessment and decision making to policymakers to ensure appropriate access for individuals with disabilities.



Lauren Rosen, PT, MPT, MSMS, ATP/SMS, is a physical therapist and seating and mobility specialist at St. Joseph's Children's Hospital in Tampa, Florida. She is the program coordinator for the Motion Analysis Center, a three-dimensional motion analysis lab where she also runs a pediatric and adult seating and positioning clinic. Rosen is a Friend of NRRTS.



IMPORTANT CHANGE FOR NRRTS APPLICANTS

NRRTS Board has approved awarding the CRTS® designation under the following criteria:

- *Applicant must have documented a minimum of three years of experience providing direct service to CRT Consumers;*
- *Be an ATP in good standing for minimum of three years at time of application; and*
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For more information, contact
Weesie Walker at **wwalker@nrrts.org**

PEDIATRIC POWER MOBILITY – NOT JUST FOR KIDS

Written by: **ALEXANDRA BENNEWITH,** MPA

As many of you know, United Spinal Association is the largest nonprofit organization, founded by paralyzed veterans, dedicated to enhancing the quality of life of all people living with spinal cord injuries and disorders (SCI/D), including veterans, and providing support and information to loved ones, care providers and professionals. United Spinal has over 70 years of experience educating and empowering almost two million individuals with SCI/D to achieve and maintain the highest levels of independence, health and personal fulfillment. United Spinal has over 50,000 members, 52 chapters, close to 200 support groups and more than 100 rehabilitation facilities and hospital partners nationwide including 10 distinguished Spinal Cord Injury Model System Centers that support innovative projects and research in the field of SCI. United Spinal Association is also a Veterans Affairs-recognized veterans service organization (VSO) serving veterans with disabilities of all kinds.

A case came by my way recently regarding an individual who is 29 and a little over 3 feet tall and who currently uses a power wheelchair with tilt and recline features as well as a seat lift. She is currently working to get a new chair with seat elevation which as you all know is a frustrating exercise since currently seat elevation is not covered by Medicare. As you all are aware, seat elevation and tilt and recline may be needed by individuals of all sizes for mobility related activities of daily living (MRADLs) inside the home and to assist with independent living outside the home. Due to limited mobility, seat elevation, for example, enables individuals to participate in MRADLs such as transferring, cooking, washing hands or doing dishes at the sink and reaching for needed items. In the case of tilt and recline, this feature enables individuals to be away from home for more hours of the day to be able to participate in work or other appointments for work or recreation outside of the home. Both features also help individuals carry out muscle movement and/or strength building as well as daily exercise as recommended by physicians and therapists.

Specific issues to be considered for pediatric power mobility chairs include batteries (which generally tend to be smaller than their adult counterparts) and performance, speed and seat frames for tilting and reclining. Additional issues include frame designs such as front-wheel drive, mid-wheel drive and rear-wheel drive (which all have different positive and negative attributes regarding maneuvrability and stability depending on what the chairs are needed for) and their corresponding weights regarding battery weight and other optional equipment, turning radius and wheel type (either for a pediatric model or a scaled-down adult version.)

Wheelchair users do not ask to be disabled. It is the responsibility of all advocates in the wheelchair space, including wheelchair users, to work together to ensure individuals with disabilities are able to live their lives as functionally as possible by having their needs met without having to fight daily insurance or existential battles to be allowed to use their own bathrooms by themselves! Individuals with disabilities fight battles with their own mobility function on a daily basis from the moment they get up to the moment they go to bed. Let's work to stop the constant battling and get people what they need!

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Alexandra Bennewith is vice president, government relations for United Spinal Association. Bennewith advocates for legislation and regulations regarding disability and health policy at both the federal and state level. She works closely with a range of stakeholders in the durable medical equipment and supplies, prescription drug, public health and disability communities. She graduated from Brandeis University and received a Master of Public Administration from American University.


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PRIMITIVE REFLEXES

Written by: **MICHELLE L. LANGE,** OTR/L, ABDA, ATP/SMS

Reflexes are an involuntary or automatic action that occurs in response to certain stimuli. There are several kinds of reflexes:

- **Protective Reflexes** – these reflexes protect the body from harm. For example, blinking when something approaches the eye. Coughing and sneezing are also protective reflexes and are used to clear the airway.
- **Deep Tendon Reflexes** – a classic example of a deep tendon reflex is when the doctor taps your knee and the leg extends. When a tendon, and the muscle attached to it, is stretched, a message is sent to the spinal cord. The spinal cord then signals the muscle to contract. This protects the muscle from damage that could occur due to excessive stretching.
- **Primitive Reflexes** – are automatic movement patterns that begin during pregnancy and are present at birth. Many of these reflexes serve a specific purpose for the developing infant. These reflexes are typically integrated to allow development of volitional movement.

PRIMITIVE REFLEXES

Primitive reflexes integrate as the central nervous system matures. This involves a transition from brain stem reflex response to a cortically controlled response. Brain injury, such as in cerebral palsy, may prevent these reflexes from being integrated. Brain injury, such as in a stroke, may lead to recurrence of reflex reactions.

Asymmetrical tonic neck reflex (ATNR) is demonstrated when an infant turns their head to one side, leading to an increase in extension on the facial side and an increase in flexion on the skull side. This reflex typically integrates between 3 to 9 months of age.

Symmetrical tonic neck reflex (STNR) is demonstrated with neck extension by extension in the upper extremities and flexion in the lower extremities. With neck flexion, the upper extremities flex and the lower extremities extend.

Tonic labyrinthine reflex (TLR) is demonstrated in prone by an increase in flexor tone throughout. In supine, extensor tone predominates.

Rooting reflex is demonstrated when the cheek is stroked, and the infant turns the head in that direction. This reflex aids nursing in the newborn.

Spinal Galant reflex is demonstrated in the newborn by stroking the low back on one side of the spine, resulting in side flexion away from that side.

Retained primitive reflexes can inhibit development of motor control and impact function. Therapeutic intervention may facilitate integration of these reflexes. Limiting triggers for these reflexes can allow a person improved function outside of these obligatory movement patterns.

Even in people who have integrated primitive reflexes and typical motor control, these reflexes can sometimes appear under certain circumstances such as high stress.

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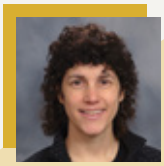
Michelle Lange is an occupational therapist with 30 years of experience and has been in private practice, Access to Independence, for more than 10 years. She is a well-respected lecturer, both nationally and internationally, and has written numerous texts, chapters and articles. She is the co-editor of Seating and Wheeled Mobility: A clinical resource guide; editor of Fundamentals in Assistive Technology, Fourth Edition; NRRTS Continuing Education Curriculum Coordinator and Clinical Editor of DIRECTIONS magazine. Lange is on the teaching faculty of RESNA and is a member of the Clinician Task Force. She is a certified ATP, certified SMS and is a Senior Disability Analyst of the ABDA.



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Lauren Rosen, PT, MPT, MSMS, ATP/SMS

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Don Clayback, NCART Executive Director

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Melissa Tally, PT, MPT, ATP

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Teresa Plummer, PhD, OTR/L, ATP, CAPS, CEAS

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Angie Kiger, .Ed., CTRS, ATP/SMS

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Mounting AT to Wheelchairs
Antoinette Verdone, MSBME, ATP

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Garrett G. Grindle, PhD & Mark R. Schmeler, PhD, OTR/L, ATP

BRUCE BAYES: A STRONG OPTIMIST

Written by: **ROSA WALSTON LATIMER**

Bruce Bayes and his wife, Judi, have been serving individuals with disabilities in Florida for 42 years. What began as a part-time DME business managed from their home office is now Custom Mobility with a staff of 80 designing, fitting, and fabricating chairs and van conversions in a 28,000 square foot facility with on-site manufacturing capabilities.

The keys to their success are work ethic and commitment to customers carried over from their early DME days. "Our customers were pleased because we were giving after hours, same-day delivery and weekend service at no extra charge," said Bayes. "In reality, that was the only time I could make deliveries because I was still working my full-time day job."

We recently asked Bayes to tell us about his journey into the challenging business of serving those with disabilities, how his experiences inform the way he finds solutions for his clients, and how he continues to meet the demands of a leader in this industry.

TO BEGIN, TELL US MORE ABOUT HOW YOU GOT STARTED IN THIS INDUSTRY AND THE TRANSFORMATION INTO WHAT IS NOW CUSTOM MOBILITY.

I relocated from Ohio to Florida in 1969 when I decided I didn't want to go to college any longer. In Florida, I went through a four-year electrical apprenticeship program that included 2,000 hours of on-the-job training and attended school two nights a week learning electronics, electrical theory and welding. I completed the program and became an inside journeyman wireman working in industrial construction, which I enjoyed very much.

My older brother, Shawn, had a DME rental business in Ohio and suggested that I partner with him to start a company in Florida. At that time, only a doctor's prescription was needed to provide equipment. My younger brother, Gary, came to Florida for about a month to teach me about the equipment and how to set it up for a client. Our DME business kept growing. In the fall 1976, I took a month's leave of absence from my job in the electrical trade to start my own company and never went back. Things progressed very well until the local hospitals formed their own organization, and instead of being our referral source they became our competitor. At that time, I was asked by the local Children's Medical Services to work with them on pediatric wheelchairs. I liked this shift in focus because it involved more of the mechanical side of things. Our company experienced a great amount of growth and made some changes in our structure. We narrowed our focus to seating and mobility products or what I would now call the complex rehab industry.

HOW DID YOU MAKE THE SIGNIFICANT MOVE TO FABRICATE ADAPTIVE WHEELCHAIR PARTS ON SITE? WHAT DO YOU THINK MADE YOU PARTICULARLY SUITED TO LEAD YOUR COMPANY IN THIS DIRECTION?

Frankly, at the time I had no idea how great the need would be for seating and mobility products. As we began working with pediatric chairs, we would order the equipment from a manufacturer but soon had trouble getting custom-built parts. The lead time got longer, often three months, and we grew more frustrated. One day, I was on the phone with a group home parent to let her know that we hadn't received the seat and back needed for one of her kids. She said, 'Why don't you just make them?'

I believe my background as an electrician and craftsman helped me see the possibility of fabricating adaptive products in-house. Drawing on my construction experience, I took my skill saw to our warehouse and cut some wood to size. I then bought some appropriate upholstery that

LEFT: (left to right) Bruce Bayes, CEO of Custom Mobility; Kyle Romano, marketing and intern coordinator; Sydney Seabaugh, intern from the University of South Florida; Jonathan Innes, former IT employee

ABOVE: Bruce and Judi Bayes

matched the wheelchair and hired an upholstery shop to complete the job. That was the beginning. When I worked with a therapist to identify the medical needs for a client, I would then put the parts and pieces together to meet those needs, similar to approaching an Erector set or Legos.

Sometimes the standard parts and pieces work, but other times we need to customize them to expand the functions for our clients. We try not to duplicate a process; so if we can get something from a manufacturer at a reasonable price within a timeframe that meets the need of our clients, we may choose that path. I believe that is what sets us apart as a complex rehab provider. We continue to hire skilled crafts and trades people who bring layers of knowledge and experience into our fabrication team. The ability to develop any device or component specifically to meet an individual's unique needs has been significant to our growth.

WHAT OTHER STEPS HAVE YOU TAKEN TO INCREASE THE LEVEL OF SERVICE TO YOUR CLIENTS?

When we transitioned to focusing on wheelchairs, we also developed a field service department with trained electronics and mechanically skilled staff. Almost 10 years ago, we acquired a local Braun wheelchair-accessible vehicle dealership, which meant adding another industry to our business and more services for our customers. Adding a garage and mechanics offers our clients the option to service their wheelchair and vehicle in one location. Converting and customizing vehicles has enhanced our understanding of the transportation needs of our clients and their families.

GIVE US SOME EXAMPLES OF WHAT YOU DO TO KEEP YOUR STAFF ENGAGED, ENERGIZED AND AT THE TOP OF THEIR GAME?

I truly enjoy helping people – both staff and clients. I believe it is important to provide opportunities for staff to increase their knowledge and expand their experience. Early on, we gave staff who worked in service or assembly and also enjoyed interfacing with the consumer and therapist the opportunity to apprentice with our top salesmen, Gary Bayes and Rick Capps. Our apprenticeship program or ATP training model continues today.

I strongly believe in delegating both authority and responsibility. Since I became CEO of the company 20 years ago, I have delegated my duties to our staff so our entire company can run without my presence. I function as a consultant within the company. For example, when an individual sees a change that needs to happen, I can help them implement the change within the organization.

CONTINUED ON PAGE 32

An untippable two-seater sail boat available through the Sailability accessible sailing program.

Sam Schmidt, former Indy Racing League driver, sailing "solo" in a Sailability accessible sail boat.

BRUCE BAYES: A STRONG OPTIMIST
(CONTINUED FROM PAGE 31)

HOW DO YOU PERSONALLY STAY UP TO THE TASK OF LEADING YOUR STAFF AND PROVIDING A HIGH LEVEL OF SERVICE TO YOUR CLIENTS?

Making sure I was more physically fit became a priority about five years ago. I took up cycling and changed my diet, leading to a well needed weight loss of 50 pounds. My increased stamina and overall feeling of personal accomplishment has been a positive, motivating factor to continue this lifestyle change. While biking, I listen to audio books relating to business and learn how others have had to deal with challenges. I especially enjoy motivational speakers, such as Dale Carnegie, Brian Tracy and Simon Sinek. I find this constant flow of positive thinking and problem solving very helpful.

Judi is an accomplished, award-winning landscape artist (Judith Edgington Bayes) and we enjoy traveling to places like southern Ohio or the Blue Ridge Mountains, where she photographs scenery that figures into her large-format and miniature paintings. I've grown to appreciate the colorful landscapes and capture them in my own photography. These travels are enjoyable, relaxing times together.

Our business is always evolving. We have some of the same challenges we had in the beginning, but I've found that new technology and innovative opportunities for our clients are a source of positive encouragement.

Several staff members and I work with Sailability, a nonprofit accessible sailing program with untippable two-seater sail boats. We adapt the boats to accommodate the sailors. The most involved and probably most rewarding challenge for our staff was fabricating a chair and system for ventilator users so they can leverage chin-control technology and become certified sailors.

I'm a very strong optimist, and I believe that we will continue to move forward with new opportunities for those we serve. Future possibilities for our industry keep me hopeful and energized!

CONTACT
Bruce may be reached at BDB@CUSTOM-MOBILITY.COM

Bruce Bayes is owner of Custom Mobility in Largo, Florida. Bayes is also a Friend of NRRTS.

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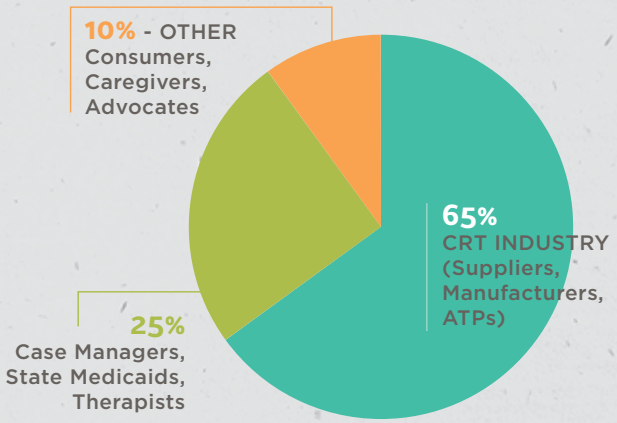

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THE POWER OF MOBILITY:

POWER MOBILITY TRAINING FOR INDIVIDUALS WITH COGNITIVE IMPAIRMENTS

Written by: **LISA K. KENYON,** PT, DPT, PHD, PCS AND **EMMA M. SMITH,** MSC, OT, PHD(C)

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OVERVIEW

A power wheelchair is often viewed as just an assistive device that provides locomotion for people with mobility limitations. But what if we expanded our view of power wheelchairs and saw them as assistive technology devices that provide not only mobility but also learning opportunities that may help to improve function in areas that are not directly related to locomotion? In this way, we might view power mobility training and power wheelchair use as an intervention process rather than solely as a means of getting from Point A to Point B. This article provides an overview of power mobility training methods for individuals with cognitive impairments across the lifespan, from early childhood through older adulthood. Throughout this article, cognitive impairments are defined as limitations in specific mental functions such as memory, judgment, attention and higher level cognitive skills.[1]

INTRODUCTION

Mobility devices, ranging from walkers to crutches and from manual wheelchairs to power mobility devices, enable individuals with disabilities to maximize independence, realize equal opportunities, benefit from human rights, and live with dignity.[2] Rehabilitation technology suppliers, therapists, and family members may have concerns about providing power mobility experiences to children and adults who have cognitive impairments. Although each case is unique and adequate supervision must be provided to ensure safety, children and adults who have cognitive impairments as well as mobility limitations may in fact benefit from power mobility use.[3-5]

A recent position paper from the Rehabilitation Engineering and Assistive Technology Society of North America[6] emphasizes limited cognition should, in and of itself, not be used as a discriminatory factor against providing power mobility for children. Children with cognitive limitations can often be classified as exploratory learners as defined by Field and Livingstone.[4] Exploratory learners may gain cause and effect skills, improved alertness and basic power mobility skills through ongoing power mobility training.[7-11] Sometimes, children or adults who have severe physical limitations may be unable to express or demonstrate their cognitive abilities. In these instances, providing power mobility training may actually allow an individual to demonstrate his or her cognitive abilities.[4] These individuals may progress into what Field and Livingstone[4] refer to as operational learners (focused on learning basic power mobility skills) or even functional learners (focused on integrating power mobility use into multiple environments). Functional learners often meet criteria for purchase of an individually prescribed power wheelchair.[4]

Although there is less existing research focused on the adult population of individuals with cognitive impairment, many of the same concepts ring true as in pediatrics. Adults with developmental disabilities may not have the necessary communication skills to demonstrate their cognitive status, but may still be able to learn to drive.[5] Cognitive impairment following stroke also raises red flags for many clinicians, however there is evidence individuals are able to learn to drive when adequate training is provided.[12] Further studies are currently underway exploring the potential for learning in individuals with mild to moderate cognitive impairments associated with age related memory loss.

Power mobility devices profoundly impact an individual's participation

THROUGHOUT THIS ARTICLE, COGNITIVE IMPAIRMENTS ARE DEFINED AS LIMITATIONS IN SPECIFIC MENTAL FUNCTIONS SUCH AS MEMORY, JUDGMENT, ATTENTION AND HIGHER LEVEL COGNITIVE SKILLS.[1]

and independence.[13] The International Classification of Functioning, Disability, and Health (ICF)[1] considers power mobility devices to be both an environmental factor (the individual actually has the power mobility device) and a personal factor (the individual knows how to use the power mobility device). Article 20 of the 2006 United Nations Convention on the Rights of Persons with Disabilities[14] states that signatories must not only provide mobility devices to people who need them, but must also provide training in the use of these devices to ensure safety and independence for people with disabilities. Simply providing a power wheelchair as a means to move often is not enough to allow most individuals who have both mobility and cognitive limitations the ability to independently use a power wheelchair. Despite directives to ensure adequate training related to the use of mobility devices and a plethora of recent research suggesting the benefits of power mobility use across the lifespan,[13,15] very little is known about best practices in the area of power mobility training for any population. Even basic questions related to straightforward training principles, such as how often and how long power mobility training should be provided, remain unanswered by the current evidence.

Although studies directly comparing the effectiveness of one power mobility training method to another have not yet been conducted, Seven commonly occurring approaches to pediatric power mobility training used in published, peer-reviewed research studies were identified in a recent systematic review.[16] These approaches were as follows: 1) goal-directed mobility, 2) incorporating play, 3) natural environments, 4) self-exploration, 5) skills-based programs, 6) technology-augmented power mobility devices, and 7) virtual reality and Computer-based Gaming.[16] Table 1 (page 38) provides a brief overview of each of these approaches. This systematic review further noted huge variability in the frequency (how often) and duration (how long) of power mobility training provided in the included studies.[16] Frequency ranged from a single day of training to providing opportunities for daily training over the course of an entire year. The length of individual training sessions ranged from 10 to 60 minutes.[16] Such variability makes it difficult to determine the ideal power mobility training parameters for any child, let alone for a child who may have cognitive limitations. There is, unfortunately, little comparable information pertaining to adult populations.

SELECT POWER MOBILITY TRAINING METHODS

The following section provides an overview of select power mobility training methods that have been used to promote power mobility use in individuals who have cognitive impairments. Where appropriate, a link to further information about the training method has been provided.

DRIVING-TO-LEARNTM[7,8] AND RELATED METHODS[5,17]

Driving-to-LearnTM[7,8] is one of the first programs to deviate from the more traditional view of power wheelchairs as merely a means of locomotion for individuals with mobility limitations. This program is a power mobility training method focused on learning from training and use rather than on learning how to use a power mobility device. Developed by Lisbeth Nilsson over a period of 12 years, 45 participants with profound cognitive disabilities (ages 12 months to 52 years) were included in the original project wherein power mobility training was provided in a modified power wheelchair using a joystick placed at midline. In Driving-to-LearnTM,[7,8] the people providing power mobility practice sessions were referred to as "facilitators." Facilitators prompted, encouraged, and guided an individual's exploration of, and experimentation with, a power wheelchair using a joystick. Practice sessions were conducted in a variety of settings (schools, homes, day cares, day centers, etc.). Driving-to-LearnTM[7,8] recognized that individuals with cognitive impairments may make slow but steady gains in their abilities to drive a power wheelchair and that the learning process may actually be more appropriately correlated to improvements in the ability to use a joystick as a tool. In Driving-to-LearnTM,[7,8] this concept of improving tool use was originally reflected by eight progressive phases of growing consciousness in the use of a joystick.[8] Additional information about the Driving-to-Learn ProgramTM[7,8] can be found at the following website: http://www.lisbethnilsson.se/en/driving-to-learn/.

A separate model developed by Durkin[17] suggested that children learn mobility use in three stages of developmental learning and that instead of teaching

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children specific power mobility skills, adults should act as "responsive partners" who engage children in motivating play activities to promote the emergence of power mobility use. Concepts related to Driving-to-Learn™[7,8] were later combined with this model by Durkin[17] to create the Assessment of Learning Powered mobility use (ALP).[5] When creating the ALP,[5] Nilsson and Durkin[5] provided an appendix detailing specific learning strategies that can be used to facilitate learning to use a power mobility device based on where an individual is positioned along the continuum of learning outlined by the ALP.[5] Additional details related to the ALP[5] are provided in the section below related to outcome measures.

WHEELCHAIR SKILLS PROGRAM[18]

The Wheelchair Skills Program (WSP)[18] details assessment and training methods for power wheelchairs and scooters, as well as for manual wheelchairs. The current version of the WSP[18] (Version 5.0) for power wheelchairs and power scooters includes 25 skills ranging from positioning and operating the controller, to ascending and descending curbs, to performing various transfers in and out of the power wheelchair or scooter. The WSP[18] manual assumes that the power wheelchair being used for training is a rear-wheel drive power wheelchair with large diameter wheels in the rear and smaller diameter, swivel wheels in front. Therefore, the WSP[18] manual notes that when other drive configurations are used (mid-wheel or front-wheel drive), some of the materials in the WSP[18] may need to be adapted to meet the specifications of the different wheelchair drive-types.

Motor learning principles form the foundation for the WSP.[18] For each included skill, the following information is provided in detail: 1) a description and rationale, 2) necessary prerequisite skills (skills that should be mastered before attempting a specific wheelchair skill), 3) considerations for the spotter (the person who is primarily responsible for ensuring the safety of a wheelchair user during the training session), 4) adjustment tips (adjustment to the wheelchair that facilitate learning the skill), 5) general training tips for the specific skill, and 6) special considerations when teaching someone the specific skill.[18] Games involving varied practice of wheelchair skills, as well as lesson plans for individual and group training sessions, are also provided in the WSP[18] manual. The WSP[18] for both manual and power wheelchairs has been widely used and studied with adults as outlined on the WSP[18] website. Studies have shown that the WSP[18] is effective, safe and practical in improving wheelchair skills and wheelchair-related confidence for therapy students, untrained caregivers and adult wheelchair users.[19-22] Use of the WSP[18] with children, however, has been limited to a single study involving manual wheelchair training.[23] Additional information related to the WSP[18] (including the manual for free download, videos, etc.) can be found at https://wheelchairskillsprogram.ca/en/.

POWER MOBILITY TRAINING TOOL

Although not technically a training method, the Power Mobility Training Tool (PMTT)[24] is an observational tool designed to assist in developing power mobility training programs for children who have multiple, severe impairments. The PMTT[24] consists of 12 items (four non motor items and eight motor items) that are scored on a five-point ordinal scale, one non-scored item, and two items that are scored dichotomously. Nonmotor items include understanding concepts related to cause and effect and stop and go, whereas motor items relate to the motor ability to activate a switch, switches or a joystick and maneuver a power mobility device. The information obtained from the PMTT[24] can be used to individualize the power mobility training methods used with a child. For example, the training methods used with a child who does not appear to understand the concept of cause and effect will be very different than the training methods used with a child who understands the concept of "stop" but who has motor difficulties actively releasing the joystick to stop. Information from the PMTT[24] can also be used to create child-centered goals for power mobility training. For example, if a child does not appear to understand the connection between activating the switch and movement of the power mobility device, a goal for this child might relate to increasing the number of switch activations by a certain percentage.

Goals created from the PMTT[24] can be combined with information about a child's likes and dislikes to set up an individually engaging environment. For example, if the PMTT[24] reveals that a child has difficulties actively releasing the joystick to stop and the child really likes a certain toy, the environment can be set up so that the child practices stopping the wheelchair by stopping to play with a toy. Standardized interviews, such as the one included in the Reinforcement Assessment for Individuals with Severe Disabilities (RAISD),[25] can be very helpful in gathering information about a child's likes and dislikes from parents, caregivers, teachers, and others.

Content validity of the PMTT[24] has been established.[24] The PMTT[24] scoresheet and manual are available free of charge. Permission to use the PMTT[24] for clinical or research purposes can be obtained by contacting the Grand Valley State University Power Mobility Project Team at kenyonli@gvsu.edu. Additional details about the PMTT[24] are provided below in the section related to outcome measures.

THE PEDIATRIC POWERED MOBILITY PROGRAM

The Pediatric Powered Mobility Program (PMP)[26] includes 34 skills ranging from basic power mobility skills (example: turning the power wheelchair on and off) and directional control skills (example: turning the power wheelchair to the right or left) to complex skills performed in both structured and unstructured environments (examples: driving down a narrow sidewalk and maneuvering around moving people). The PMP[26] was initially developed as a way to determine a child's cognitive readiness for power wheelchair use and is mentioned here as a reference. The PMP[26] can be downloaded from the following Website: https://itunes.apple.com/us/book/ready-set-go-powered-mobility-with-young-children/id991600558.

ASSESSING POWER MOBILITY OUTCOMES

There are several tools that can be used to assess power mobility training outcomes in children and adults who have cognitive impairments. For children, a systematic review by Field and Livingstone[4] identified Three outcome measures (the Wheelchair Skills Checklist (WSC),[27] the PMTT[24] and the ALP[5]) for use with exploratory power mobility learners who are at the beginning stages of learning to use a power mobility device. The WSC[27] is a Seven-item measure that examines a child's ability to perform select power wheelchair skills ranging from stopping and starting the power wheelchair upon command to backing the power wheelchair up a distance of 12 inches. As a child's power mobility skills progress and desired outcomes evolve to include integration of power mobility devices into daily routines, the ALP[5] and the PMP[26] may be more helpful in assessing outcomes.[4] The ALP,[5] PMP[26] and the PMTT[24] are all listed above as power mobility training methods and, as in pediatrics, there is often an overlap between outcome measures and training methods.

The WSP, addressed above, provides a number of assessment resources, including the power wheelchair versions of the Wheelchair Skills Test (WST)[18] and the Wheelchair Skills Test Questionnaire (WST-Q),[18] that are designed to provide information to help inform power wheelchair training and to promote safe and appropriate execution of wheelchair skills. The WST[18] is a direct-observation, performance-based measure consisting of the same 25 skills listed above in the WSP.[18] The WST-Q[18] is a self-report measure that was designed to provide a subjective rating of a person's perceptions of his or her ability to perform the same skills on the WST.[18] Both the WST[18] and the WST-Q[18] have been found to be valid and reliable for use in adult populations.[28-30] Manual wheelchair versions of the WST[18] and the WST-Q[18] are also available.[18] The WSP[18] Website (https://wheelchairskillsprogram.ca/en/) provides videos which can be helpful in developing your assessment skills.

THERE ARE SEVERAL TOOLS THAT CAN BE USED TO ASSESS POWER MOBILITY TRAINING OUTCOMES IN CHILDREN AND ADULTS WHO HAVE COGNITIVE IMPAIRMENTS.

The Power Mobility Indoor Driving Assessment (PIDA)[31] and the Power Mobility Community Driving Assessment (PCDA)[32] are tools to assess the driving capacities of adults living in residential and community settings. The PIDA[31] was developed to assess the driving skills of individuals living in long-term care and includes 30 skills – 28 specific driving skills and Two scored 'global' skills, which are assessed through observation. The PCDA,[32] on the other hand, is a comprehensive community driving assessment which identifies areas of driving which may be problematic to allow clinicians to focus on these specific skills to enhance safety and performance. The PCDA[32] assesses driving skills in the areas of general driving, wheelchair accessible transit, driving with controls (driving method) in different positions and on varied surfaces, and accessing public spaces. These assessments provide guidance as to the kinds of skills an individual needs in order to drive safely and competently in their environment.[31,32]

The Wheelchair Skills Confidence for Powered Wheelchair Use Measure (WheelCon-P)[33] uniquely assesses an adult's confidence in performing power mobility skills. Reduced confidence can negatively impact an individual's participation when using a power wheelchair.[33] Confidence issues may relate to actual performance of the power mobility skill, to the physical environment, or to individual resources and coping skills.[33] The WheelCon-P[33] measures wheelchair confidence in

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negotiating the physical environment, activities performed in the wheelchair, knowledge and problem solving, advocacy, managing social situations, and managing emotions.

We urge you to consider assessment as the first step in training as a way to improve the efficiency of the training process and to focus on those skills and abilities which most need to be addressed. Refer to Table 2 (see page 39) for clinical insights related to each of these outcome measures.

GENERAL TRAINING TIPS AND PRINCIPLES FOR PROVIDING POWER MOBILITY TRAINING TO INDIVIDUALS WITH COGNITIVE IMPAIRMENTS

TIPS AND PRINCIPLES FOR PEDIATRIC CLIENTS

1. All children require age appropriate adult supervision during power mobility training and use. You would not allow a typically developing 2 year old to wander around unsupervised, and you certainly would not allow a typically developing 6 year old to wander around the mall or the grocery store by himself. In our experience, children who have both mobility restrictions and cognitive limitations may in fact require more adult supervision and support to ensure safety.

2. Children may benefit from the use of process-based, rather than skills-based, power mobility training methods. Such process-based methods are clearly outlined in the ALP[5] but are also reflected in the use of the PMTT[24] to establish goals and set up the environment to encourage the emergence of power mobility skills.

TABLE 1: COMMON PEDIATRIC POWER MOBILITY TRAINING APPROACHES USED IN RESEARCH STUDIES[16]

APPROACH	DEFINITION OF THE APPROACH
1. Goal-directed Mobility	Positioning a toy, object, or person to encourage the child to functionally use power mobility.
2. Incorporating Play	Use of play to provide opportunities for moving the power mobility device to enable the child's play.
3. Natural Environments	Providing opportunities for children to practice and use power mobility in home, school, daycare and community settings.
4. Self-exploration	Purposefully allowing the child to use power mobility to explore the environment.
5. Skills-based Programs	Practicing specific power mobility skills through a formal program.
6.Technology-augmented Power Mobility Devices	Using power mobility devices equipped with sensors or guidance systems to lessen the demands of power mobility use.
7. Virtual Reality and Computer-based Gaming	Using computer games or virtual reality to allow children to practice power mobility skills.

3. As with many rehabilitation processes, power mobility training methods should be individualized to meet the needs of a specific child. As suggested in a recent qualitative study exploring the experiences of children who were learning to use power mobility, there is not a cookbook that provides the single, best recipe for success for every child.[34]

4. When children have both mobility limitations and cognitive impairments, longer periods of time may be required to learn power mobility skills.[7,8,35,36] Several studies focused on power mobility training for children with cognitive limitations provided power mobility training over extended periods of time (several years)[7,8]; however, other studies involving children in this population have noted improvements in power mobility skills (although not competent power mobility use) following training periods of eight to fifteen weeks.[9-11]

5. When providing power mobility training to children, consider using alternative power mobility devices such as modified battery-operated toy cars[37] (especially for younger children) or specialized motorized platforms (such as the Play and Mobility Device[9] or the Power Wheelchair Trainer[10,11]).

TIPS AND PRINCIPLES FOR ADULT CLIENTS

1. Power wheelchair training should be provided for all adults who receive a new powered mobility device regardless of whether they have driven before. This is particularly true for new drivers, regardless of their cognition, and for individuals who are changing their driving method or drive wheel configuration. There is evidence to suggest that training wheelchair skills remains relevant even for

individuals who have been using power wheelchairs for longer periods of time.[22]

2. Adults with cognitive impairments may need power mobility training which is more tailored to their learning needs. Often individuals with age-related cognitive decline or short-term memory loss may have difficulty with trial and error learning and could benefit from approaches that promote successful experiences and graded learning opportunities. Breaking down skills into more manageable tasks and completing training in the natural environment may help to improve skill development in this population.

3. Some adults, especially those who have developmental disabilities, may benefit from the use of training programs designed for this population, including those described by Nilsson[5] in the ALP[5] and DrivingToLearn™ [7,8] program, depending on their cognitive level.

4. Although adults may be technically able to complete powered mobility skills, there is a relationship between their levels of confidence and their use of those skills in their day-to-day life. Consider using an assessment like WheelCon-P,[33] listed in Table 2, to determine where your clients may experience low levels of confidence that can then be addressed through power mobility training.[33]

CONCLUSION

This article has provided an overview of select power mobility training methods and outcome measures that have been used to promote power mobility use in individuals who have cognitive impairments. Although adequate supervision must be provided to ensure safety, individuals who have cognitive impairments as well as mobility limitations may benefit from power mobility use.

TABLE 2; OUTCOME MEASURES TO TRACK POWER MOBILITY SKILL PROGRESSION IN INDIVIDUALS WITH COGNITIVE IMPAIRMENTS

OUTCOME MEASURE	INTENDED POPULATION	CLINICAL INSIGHTS
The Assessment of Learning Powered mobility use (ALP)[5]	Children & Adults	A processed-based measure. Provides strategies to facilitate learning to use power mobility based on where an individual is positioned along the continuum of learning.
Power Mobility Community Driving Assessment (PCDA)[32]	Adults	Designed for use with adults living in community settings. Flexible to accommodate different environments of use.
The Power Mobility Indoor Driving Assessment (PIDA)[31]	Adults	Developed for use with adults in long-term care. Includes global scores for speed selection and sharing public space.
The Pediatric Powered Mobility Program (PMP)[26]	Children	May be helpful for children who are operational or functional power mobility learners.4
Power Mobility Training Tool (PMTT)[24]	Children	Can be used with children who use a switch(es) or alternative joystick placements. Designed to assist in developing power mobility training programs for children who have multiple, severe impairments.
The Wheelchair Skills Confidence for Powered Wheelchair Use Measure (WheelCon-P)	Adults	Available in French and English for both power wheelchair users and caregivers.
The Wheelchair Skills Checklist (WSC)[27]	Children	Several items require power wheelchair skills to be performed on command.
The Wheelchair Skills Test (WST)[18]	Adults	A direct observation measure available in French and English for both power wheelchair and power scooter users, as well as caregivers.
The Wheelchair Skills Test Questionnaire (WST-Q)[18]	Adults	A self-rated questionnaire available in French and English for both power wheelchair and power scooter users, as well as caregivers.

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Emma Smith is an occupational therapist and PhD candidate studying the use of shared control for powered mobility training in older adults with cognitive impairments. She has presented on this topic nationally and internationally, including at RESNA, ESS, ISS, ISPO and the CREATe Conference.

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CASE STUDY HIGHLIGHTING A PEDIATRIC CLIENT RECEIVING MOBILITY TRAINING TO OPTIMIZE USE OF A POWER WHEELCHAIR

Written by: **KIHM HYMORE,** MOT, OTR/L, ATP

Movement and mobility are inherent for all of us, nearly from the time of birth. However, when a child has multiple complex diagnoses, mobility becomes less inherent, requiring the need for more strategic, guided and optimized training to increase his or her ability for independent mobility.

SAWYER

Meet Sawyer (see Figure 1), an 18-month-old male with the diagnosis of cerebral palsy, a disability resulting from damage to the brain before, during or shortly after birth and outwardly manifested by various levels of processing delays, muscular incoordination, speech disturbances and visual processing impairment. Other diagnoses include: ROP (retinopathy of prematurity), cerebral ventriculomegaly, impaired mobility and muscle weakness. Sawyer's family wanted to increase his independent mobility though power mobility. Several factors impact a person's ability to safely and effectively use power mobility; for Sawyer we identified three main factors: technology features (seating, positioning and access), sensory processing and motor ability.

TECHNOLOGY FEATURES

Sawyer was not able to sit independently and required moderate external supports to maintain an upright sitting position for extended periods of time. A seating system that included a contoured head support, lateral trunk supports, pelvic positioning belt, contoured cushion and back, medial knee support and footrest was used to ensure that Sawyer would be stable when moving (see Figure 2). In this seating system, he was fairly comfortable and supported.

With positioning figured out, determining an access method was the next step. Sawyer was able to reach to midline with both upper extremities, demonstrated a targeted reach to touch objects and could initiate and sustain a grasp on an object. In addition, Sawyer was observed during his initial assessment holding onto and drinking from his sippy cup, grabbing snacks from mom's hand, and playing with and manipulating his favorite toys. Given his upper extremity function, it was obvious that alternative controls would not be needed. He had demonstrated appropriate strength and motor control to use a standard joystick. It was decided to center mount the joystick, so that Sawyer would have optimal access to the joystick with either of his hands.

SENSORY PROCESSING

The evaluation power wheelchair was set-up with the appropriate positioning and a center mount joystick. The next factor to consider was sensory processing, which includes visual processing. Sawyer demonstrated poor visual attention and recognition of new objects and environments, two characteristics of cortical visual impairment (CVI). CVI is a form of visual impairment that is caused by a brain problem rather than an eye problem (the latter is sometimes termed "ocular visual impairment" when discussed in contrast to CVI). Some people have both CVI and a form of ocular visual impairment. CVI does not refer to whether you can see something but rather how your brain interprets what you are seeing. With the list of diagnoses Sawyer did have, the possibility of CVI was high.

Since Sawyer did not reach for, explore, or even seem to know there was a joystick in front of him, strategies were used to increase his visual attention and awareness to the

CHILDREN WITH CVI ARE EASILY OVERSTIMULATED BY NEW AND UNFAMILIAR VISUAL, AUDITORY AND PHYSICAL STIMULUS. TO CONTROL THE AMOUNT OF AUDITORY STIMULI SAWYER WOULD HAVE TO MANAGE, HE WAS REMOVED FROM THE BUSY, CONGESTED, LOUD HALLWAY AND TAKEN INTO A QUIETER MOBILITY ROOM WHERE STIMULI COULD BE BETTER CONTROLLED AND MANAGED.

FIGURE 1

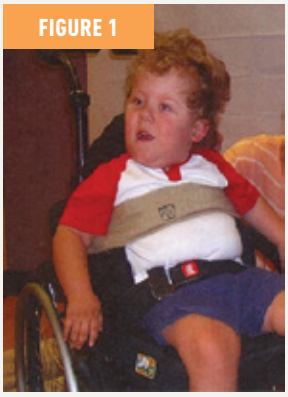

Figure 1: Sawyer

Figure 2: Seating system used to support Sawyer during power mobility training

Figure 3: Joystick moved to center and traditional handle replaced with a big red ball to make it more visually attractive.

Figure 4: On the left, lots of light and increased clutter in the background, more difficult to see visual target. On right, lights lowered and background clutter removed.

FIGURE 2

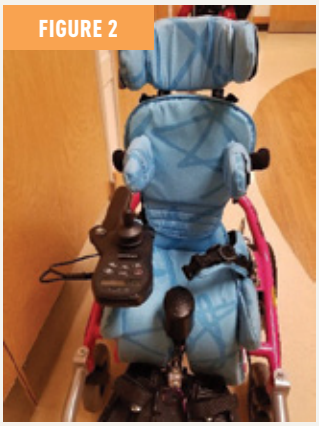

FIGURE 3

FIGURE 4A

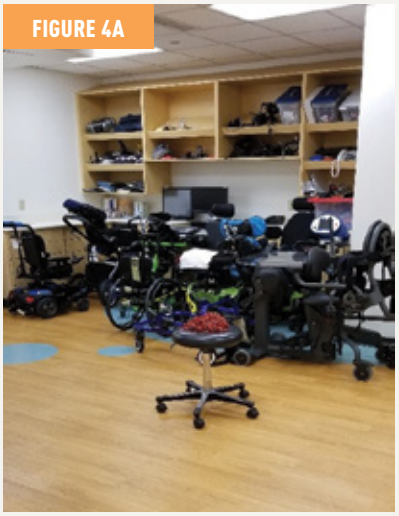

FIGURE 4B

joystick, as well as improve his ability to process this new environment and activity. Red reflective tape was placed on the joystick handle to draw Sawyer's visual attention to the joystick. Red reflective material is more visually stimulating and alerting. Sawyer could see the joystick better when it was covered with the red tape and he began to reach for, play with and move around the joystick during this training session. However, he still was not moving the chair around his environment and hand-over-hand assistance was needed to initiate chair movement. Providing the correct level of stimulus was the next step. Children with CVI are easily overstimulated by new and unfamiliar visual, auditory and physical stimulus. To control the amount of auditory stimuli Sawyer would have to manage, he was removed from the busy, congested, loud hallway and taken into a quieter mobility room where stimuli could be better controlled and managed. When in the mobility lab, the doors were closed to reduce auditory stimuli and visually stimulating targets were used such as red and orange brightly colored objects, or his favorite toys. This step helped greatly, but we continued to make modifications to optimize his ability to successfully use the power wheelchair.

In session two, the small joystick handle with red tape was replaced with a large, soft, red ball resulting in Sawyer touching and playing with the joystick even more (see Figure 3). All of the clutter was removed from the mobility room and visually stimulating targets were again utilized (see Figures 4A and 4B). Sawyer demonstrated increased independent interaction with the joystick and movement of the chair with the joystick. Another visual modification used in this

CONTINUED ON PAGE 44

CASE STUDY HIGHLIGHTING ...
(CONTINUED FROM PAGE 43)

session was to turn off many of the bright overhead fluorescent lights in the mobility room. Bright overhead light can distort a visual target for those with CVI, causing them to misinterpret what they are looking at and stop moving because they are not able to interpret where they are moving. Once much of the bright overhead light was reduced, we could use focused light and/or reflection to guide visual attention. For this, mom's smartphone playing one of Sawyer's favorite videos was used. We had his mom hold her smartphone about 5 feet away from Sawyer to encourage him to move toward the video while in the power wheelchair. Independence in our controlled environment was great, but not "functional." In the next sessions, we would continue to use the same visually stimulating objects while working on transitioning Sawyer to a more functional environment.

FOR THE TRANSITION FROM MOBILITY ROOM OUT INTO THE HALLWAY, WE HAD TO IMPLEMENT SOME OF THE STRATEGIES WE HAD USED TO GET SAWYER TO USE THE JOYSTICK TO MOVE IN THE CHAIR IN THE MOBILITY LAB.

In the third session, we began transitioning Sawyer out of the mobility lab into a more functional environment. Due to his visual impairment, we knew we would need to take baby steps and continue to keep a routine while trying to push him a bit further each session. We began this session in the mobility lab and used the big red ball as the joystick handle. We again reduced the overhead light in the mobility room, but not as much as the time before, and kept the doors to the room open, letting in greater amounts of noise and auditory distractions. Now that Sawyer was familiar with the activity and the process, he continued independently driving the power wheelchair in this familiar environment. With each session, Sawyer needed fewer and fewer modifications; however, our goal was to get him to be independently mobile in all situations and currently he was still only independent in the mobility room itself.

For the transition from mobility room out into the hallway, we had to implement some of the strategies we had used to get Sawyer to use the joystick to move in the chair in the mobility lab. We started by clearing away any additional and unneeded clutter in the hallway, we dimmed about half of the bright overhead lights in the hall, and had mom use her smartphone to play one of Sawyer's favorite videos to entice him to move out into the hall. Starting in the mobility room was necessary for Sawyer to recall the activity and draw on his familiarity and memory of the activity. Routines and familiarity are a big help when working with those who have CVI. So for the next few sessions, Sawyer would continue to start in our mobility room for a bit before going out in the hallway. Keeping consistency with his training throughout the sessions allowed Sawyer to learn, retain what he had learned and become familiar with the activity all while continuing to progress a bit further each session. Now that he had made it into the hallway with environmental modifications, the next goal was reducing modifications needed in the hallway.

The next session we were able to turn on more lights in the hallway and he required fewer videos to motivate him, but we continued to use his favorite toys as visual targets. Each time we pushed Sawyer to go further, we had to either modify the environment or use familiar visual targets, but with repetition the new became old and what was unfamiliar became familiar to him.

By the final session, Sawyer was able to drive the power chair in a fully lit hallway with people walking around him. He required no modification to the visual environment and was actively exploring in the power wheelchair.

MOTOR ABILITY

The third factor we considered with Sawyer was his motor ability; the predetermined characteristics that affect movement performance such as agility, coordination, strength, and flexibility. He had demonstrated motivation for mobility by rolling to prone and supine from a side lying position, but he had not progressed from that. It can be difficult to determine motor ability when a client's diagnoses are as complex as Sawyer's because his motor ability can be significantly influenced by his sensory processing, specifically visual processing. Once the environment was more visually appropriate, Sawyer's motor ability was revealed. We developed his motor ability by compensating for his decreased visual processing, at first. As time and trials continued, we determined that his motor ability was sufficient because it took no environmental modifications to get him to drive the chair, and Sawyer would go further in the chair each trial.

In conclusion, we know that visual processing can be a major barrier for reducing independent mobility. Mobility is a very visually driven task. Most of us see something and want to go toward it. A child may not see anything close or familiar enough to encourage movement toward it. This may have little or nothing to do with their positioning or motor ability, but rather their sensory processing of their visual environment. Keep in mind when dealing with a client who has complex disabilities and difficulty processing the visual environment, that often the most meaningful change needed to impact mobility has nothing to do with the equipment being used, but the environment and activity set-up. As was the case with my fiend Sawyer.

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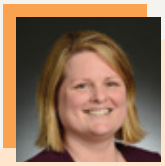
Kihmberly Hymore, MOT, OTR/L, ATP, Hymore is a graduate of Xavier University with a master's in occupational therapy. She is a lead occupational therapist at the Perlman Center at Cincinnati Children's Hospital Medical Center. The Perlman Center is a specialty center designed to address the complex therapy, developmental, assistive technology and care coordination needs of children, youth and adults with cerebral palsy and other complex conditions. Hymore has experience and training in sensory integration, assistive technology, adaptive equipment, and cortical visual impairment (CVI). She has become well-versed in the CVI range, educating families, other team members and co-workers about the CVI functional vision assessment and best-practice approaches for interventions to promote access and mobility.



Why Should

We Care

What Medicare Does with Pediatric Wheelchair Codes?

Written by: **CLAUDIA AMORTEGUI,** PRESIDENT,
THE ORION CONSULTING GROUP, INC.

It's not rare for people to ask me why Medicare has codes for pediatric products. Understandably it does not make much sense, since Medicare is known to cover the over 65 population. However, everyone must first remember that being over 65 is not the only qualifier when it comes to Medicare. More importantly, people need to understand that Medicare is seen as the "ruler" of HCPC codes. Sadly, this title tends to hurt those with other insurance, especially when it comes to Medicaid and the pediatric population.

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(CONTINUED FROM PAGE 47)

When we look at mobility equipment, the pediatric coding for manual wheelchairs exists; however, its use does not make much sense. For manual wheelchairs, Medicare does not look at age, they look at size. At the beginning of the year, I wrote an article for DIRECTIONS that focused on manual wheelchair coding for pediatrics. Simply put, the key in the policy is 14 inches or less – seat width or depth. This means that the wheelchair for my very petite grandmother, would have been billed as a pediatric code; even though the same wheelchair in a more standard size would have been billed with an adult code (i.e. K0005). To make matters worse, Medicare has designated the pediatric manual wheelchair codes as capped rentals – meaning, a provider has to rent these codes for 13 months prior to them being converted to a purchase. Medicare's belief that the majority of children with a mobility disability (requiring a wheelchair) is temporary, is beyond me.

Coding for pediatric power wheelchairs is determined by the product provided to the client. So again, this is not necessarily based on age; the code is determined by the product choice. As you know, Medicare requires all power mobility devices to be code verified by the PDAC (Medicare Pricing, Data Analysis, and Coding contractor). Therefore, if a client is placed in a specific power wheelchair, the designated code must be billed.

All these rules tie to Medicare, but most pediatric clients do not have Medicare coverage, so why does this matter? As much as most would think that the Medicare policies would not affect our younger clients, unfortunately they do. Most other funding sources, including state Medicaid programs, look to Medicare as the lead in developing policy. Since Medicare is also responsible for maintaining the HCPC codes, this all ties together. Due to Medicare's involvement, several issues are created for non-Medicare clients.

Let's look at an obvious error ... In Medicare's eyes, a handrim is a handrim. Many years ago, they changed the code definitions of the handrim with or without projections (E0967 or E2205) to include the wording "Any Type, Replacement Only."

Time and again it has been found where other funding sources will take Medicare policy and implement it within their own policies. The problem becomes not only that they may become more restrictive than what the what is intended (i.e. in-the-home need), but also even worse is when they misinterpret a policy. I can't count the times I have had to attempt to explain to a funding source what the policy really says. On the flip side, Medicare does not take into account that their policies are adopted by many others. I understand, that they cannot write their own policy to meet the needs of varying funding sources; however, Medicare needs to understand that certain changes trickle down to everyone. What's even worse is when the Medicare allowables are adopted by other insurers and then they decide that their allowable is 20 percent lower than Medicare.

State by state, and even within certain states, Medicaid policies vary for the kids needing wheelchairs. Thankfully, the Medicaid programs do consider needs outside the home. Where everyone still tends to get stuck is within the coding, not just for the wheelchair bases but the options too.

As stated above, the coding for the wheelchair base is established by either size (manual) or PDAC coding (power). As for the options/accessories, this part becomes even more of an obstacle not only with Medicare claims but also with Medicaid and other funding sources. For a good many years now, it has seemed as if Medicare is trying to eliminate the K0108, wheelchair miscellaneous code. What it feels like is that they are trying to shove a lot of square pegs in round holes. This has left the Complex Rehab Technology (CRT) world with their hands tied behind their backs for many orders. Sadly, the real losers are the end users as access has been limited to certain items. At times, the providers lose as they end up "eating" the cost just to take care of their clients. In my eyes this is all wrong.

However, we cannot all just sit back and let things continue to happen. We need to continue to fight for new and updated coding. We need to continue our battle for the recognition of a separate benefit category for CRT.

Let's look at an obvious error … In Medicare's eyes, a handrim is a handrim. Many years ago, they changed the code definitions of the handrim with or without projections (E0967 or E2205) to include the wording "Any Type, Replacement Only." The code definition even goes as far as stating "includes ergonomic or contoured." Medicare also included theses codes as items that could not be billed separately with the initial issue of a manual wheelchair. In my simplistic brain, I completely understand why a standard aluminum handrim would be considered part of the base of the wheelchair, but how would a handrim that is not needed by most (plastic-coated or projections), nor wanted by most (why make your wheelchair wider and less functional) be included in the base allowable? Why would any manufacturer include such an item as a standard option?

Other examples are headrests, positioning belts, and trays (upper extremity supports). We can all admit that there are basic products within each one of these categories. However, we also all know that there are very complex items within each category. Some may argue the definition of complex, but we at least can agree that many items are nowhere close to standard. As

Be a "consultant" to your other funding sources. Show them the differences.

Medicare forces "all types" within a generic code, the other funding sources are doing the same in many cases. Again, the losers in these scenarios are the clients; access to the proper products are limited or eliminated.

What to do … I understand that funding sources want to keep claims processing as streamlined as possible. I understand they do not want to use the miscellaneous code very often, as it slows down the process. However, we cannot all just sit back and let things continue to happen. We need to continue to fight for new and updated coding. We need to continue our battle for the recognition of a separate benefit category for CRT. Even more importantly, you need to assist in the education process. Be a "consultant" to your other funding sources. Show them the differences. Have them understand how much of the Medicare policy is not written for CRT and how it definitely does not consider pediatrics. It is their responsibility to meet their beneficiaries needs, but it is your responsibility to be involved.

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Claudia Amortegui has a Master of Business Administration and more than 20 years of experience in the DMEPOS industry. Her experience comes from having worked on all sides of the industry, including as DMEPOS Medicare contractor, supplier, manufacturer and consultant. For many of these years, Amortegui has focused on the rehab side of the industry. Her work has allowed her to understand the different nuances of complex rehab versus standard durable medical equipment. This rare combination of industry experiences enables Amortegui and her team at The Orion Group to assist ATPs, referrals, reimbursement staff and funding sources in understanding the reimbursement process as it relates to complex rehab.

THE JOURNAL OF HUMANITIES IN REHABILITATION

Written by: **WEESIE WALKER,** ATP/SMS

Every supplier and clinician have a story (or several) about a customer who touched them. I believe that the key to successful outcomes is seeing the person, the human, who requires our services. If we lose sight of the real purpose of rehab, we have lost our way. It is not about reaching our goal but the specific and unique goal of the person who puts their trust in our skills and knowledge.

As I looked at the many offerings from the Journal of Humanities in Rehabilitation,, the common thread is seeing the positive in a negative situation.

It is easy to get wrapped up in all the challenges we face as suppliers and clinicians to provide the necessary products. But, we should never forget the humanity of those we serve.

The following poem is reprinted from the Journal of Humanities in Rehabilitation. To see all the journal content, go to www.journalofhumanitiesinrehab.org

IF WE LOSE SIGHT OF THE REAL PURPOSE OF REHAB, WE HAVE LOST OUR WAY. IT IS NOT ABOUT REACHING OUR GOAL BUT THE SPECIFIC AND UNIQUE GOAL OF THE PERSON WHO PUTS THEIR TRUST IN OUR SKILLS AND KNOWLEDGE.

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See Me

By Amanda LaLonde, PT, DPT, GCS

I'm here. I have a name.
I still dance, I cook, and laugh.
I'm known and I'm loved.
I'm here, your patient, looking at the space we share.
The waiting room, an ICU, a therapy gym.

I need trust, respect, and a healing touch.
Do you know me? Do you see me?

I'm here. I'm more than what your paper says.
I'm not cancer.
I'm not diabetes, not hypertension.
I've lost a leg, but I'm not some amputee.
I'm not a stroke, not Parkinson's; I'm not an ACL, not a total hip.

I'm here. I have a name.
I'm open, honest, seeking your care.
I'm here and present on this journey we share.
Through training and instruction, from cues to independence.
See me, know me, look beyond.

I'm here and I'm more than what your paper says.
I'm no diagnosis.
My wheels carry me; I'm not confined.
I'm not cerebral palsy.
I'm not depressed, not a fracture.
I've struggled with pain, but I'm not defined by suffering.
I'm not Alzheimer's, not spina bifida, or tendonitis, or anxiety.

How do you define me? What do you see?
See me, see all of me.

I'm your patient, complex, sum parts to a whole.
See me, see all of me.
Don't call me a condition.
I'm here and I'm more.
I have a name.

Healthcare is desensitizing. Suffering becomes commonplace in our workplace, and rarities—truly new cases—are few and far between. Humanity is easily lost in the day-to-day healthcare routine, and perhaps understandably so. Best intentions are stretched thin after long daily hours and years of study.

As professionals, our own sacrifices abound. We are informed, dedicated, and ambitious. An early end-point may have been connection; but after years on the job, silos are formed. Time spent with a patient, the one who needs you, the ultimate goal, becomes swallowed by tasks and necessities. Our focus on

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productivity, although important and necessary, only serves to perpetuate our tendency to disconnect. Challenged are many to balance demand with limited emotional supply. Is this trade-off worth the price?

I often wonder: How did we get here? When did we stop thinking about the human being in front of us and start categorizing individuals by their diagnoses? Bad enough to categorize, we rarely use names and are unfit to emote. This trend of desensitization and disconnection doesn't discriminate among providers. Physicians, therapists, nurses, and aides all tend to label patients. Educators often set bad examples as well.

Disengagement

So healthcare remains, understandably, disengaged. Media even joins in on the name-calling as reporters refer to people by their diagnoses and impairments rather than noting the individual strength of characters. An easy oversight, you could say, when the language of providers referencing clients solely by room number, or some self-deprecating patients so-naming themselves crippled or worthless is not called into question.

That stroke in room 202 has therapy today; the total hip needs a walker; the amputee is waiting for a prosthesis. He's confined to a wheelchair and my 4:00 is cancer-stricken. She is too anxious, and the traumatic brain injury keeps acting inappropriately. The ACL repair is too eager to return to sport. Dementia patients always need more time. MS patients are all the same.

Restoring Humanity

Who will shift this conversation and its vast generalizations? We all have a responsibility to restore and value humanity in healthcare. Small, attainable changes are waiting at our fingertips. Simple shifts in language and awareness, being fully present with the other. Humanity is not a lofty goal; rather, a requisite along a journey to healing. If you seek to have an impact on others, then respect must be a part of your conversation.

Let's Challenge Ourselves

Humility, humanity, and empathy: essential elements lost in the hustle of each day. How do we reset and infuse these necessary components into healthcare? What will you ask of yourself, how will you rise to the call? To be the one, to take the time, to invest in those in front of you requires dedication and a necessary awareness. Tomorrow, will Adam know you speak to him and not his diagnosis? Will Sarah be reassured by your warm smile, your gentle touch? Challenge yourself and others. Be the one to see.

About the Author

Amanda LaLonde, PT, DPT, GCS, received a Bachelor of Arts in Dance from the University of Wisconsin- Stevens Point in 2003, and is a 2008 graduate of the University of Wisconsin-Madison Program in Physical Therapy. In 2014, she earned her Transitional Doctor of Physical Therapy degree through The College of St. Scholastica. She is a Board Certified Geriatric Clinical Specialist through the American Board of Physical Therapy Specialists. Amanda is the Director of Clinical Education and an Assistant Professor in the Program in Physical Therapy at the University of Minnesota. Shaped by her own experiences as a clinician, Amanda strives to ensure students reflect on the complex role of clinical practice; seeing beyond a diagnosis or treatment plan to truly engage with their clients. Amanda notes that value in interaction and appreciation of the human side of healthcare is as important as new technology and treatment approaches.

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Congratulations to the newest NRRTS Registrants. NAMES INCLUDED ARE FROM SEPT 5 THROUGH NOV 2, 2018.

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Fax: 678-392-4212
Registration Date: 10/16/2018

Bryan Clever, COTA, ATP, RRTS®
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6350 Regency Pkwy
Norcross, GA 30071
Telephone: 470-235-0105
Fax: 678-206-2185
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Matthew Corley, RRTS®
Brookstone Home Medical
123 Hugh Rd
Leesburg, GA 31763-5202
Telephone: 229-496-6963
Registration Date: 10/5/2018

Anna Davis, MPA, RRTS®
National Seating & Mobility, Inc.
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Centennial, CO 80111-6400
Telephone: 720-389-5212
Registration Date: 11/1/2018

Steve Ebert, ATP, CRTS®
Norco Medical
150 Shannon Dr
Nampa, ID 83687-8207
Telephone: 208-467-3070 x.110160
Fax: 208-467-3317
Registration Date: 10/30/2018

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University of Michigan
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Telephone: 734-971-8286
Fax: 734-232-2277
Registration Date: 10/15/2018

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Rehabilitation Equipment Professionals, Inc.
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Telephone: 703-370-2100
Fax: 703-370-7985
Registration Date: 9/26/2018

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Anaheim, CA 92807
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The NRRTS Board determined RRTS® and CRTS® should know who has maintained his/her registration in NRRTS, and who has not.
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