Creating an Inclusive Environment for Patients with Disabilities
Patients in our Cerebral Palsy clinic are just one example of the care we provide to those with diverse abilities.

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27 In Recognition
For me, the impending fall months feel like times of possibility and potential. This outlook leads me to think of what you make possible at Nationwide Children's Hospital. You heal, you nurture and you help our patients grow. As an organization, we try to accomplish those same actions by nurturing staff, helping them grow and creating a culture where all people feel valued and welcome. That culture, our One Team culture, is built on the individual strengths and abilities of each member of our One Team. Diversity, equity and inclusion are cornerstone values at Nationwide Children’s. We have a strong track record of promoting inclusion and supporting all employees, the communities we serve and all children and families regardless of who they are, where they’re from or their ability to pay.

To achieve our mission to Lead the Journey To Best Outcomes for Children, we seek out the best people to build the best programs. Our vision is an inclusive and diverse culture that fosters mutual respect, where our staff are valued and provided opportunities to achieve their full potential. We recognize an inclusive and diverse culture is grounded in a firm commitment to attract and retain talent, reflective of the communities we serve. The Institute of Medicine (IOM) Future of Nursing Report emphasized the need to make diversity of the nursing workforce a priority. Additionally, the Health Resources and Services Administration (HRSA), the primary federal agency responsible for improving access to health care services for the uninsured and medically vulnerable, funds grant programs to enhance the understanding of barriers to achieve a diverse health care workforce. We must all embrace and advance this work to eliminate health disparities and achieve health equity!

More than halfway through 2023, our organization is energized and focused on building our workforce across many disciplines. We are partnering with local, regional and state schools to build a talent pipeline for the future, with a focus on increasing the diversity of our team. We are excited to have our health care career students back to in-person, on-site experiences where they can see and experience our culture firsthand.

At Nationwide Children’s, not only does everything matter, but everyone matters!
Initially, they would likely be reliant on others for care including decreased ability to breathe effectively and forcefully cough. They could have some wrist function but minimal active finger movement nor some ability to flex their elbow but not extend it. They may have likely have intact facial, neck and shoulder movements and movement at specific area of the body.

With this classification of C6 AIS A in mind, Taylor would likely have intact facial, neck and shoulder movements and some ability to flex their elbow but not extend it. They may have some wrist function but minimal active finger movement nor movement or feeling below their upper chest. They could have decreased ability to breathe effectively and forcefully cough. Initially, they would likely be reliant on others for care including turning in bed, eating, getting dressed and getting out of bed to a wheelchair. Their spinal cord injury would also alter their bowel and bladder control, requiring assistance for bowel and bladder elimination.

Place yourself in their shoes - the drastic change in independence and unexpected change in degree of medical care needed can be devastating and overwhelming. As a final stop in hospitalization before going home, Taylor begins their stay in inpatient rehabilitation. While the team is large, it is clear each member plays a unique role in teaching them and supporting their journey home.

At Nationwide Children’s Hospital, the aim of our inpatient rehabilitation program is to help patients and families safely transition back into their home, school and community where recovery will continue.
complete pressure mapping and positioning changes to ensure surfaces such as wheelchairs, toileting and bathing equipment provide adequate pressure offloading. In Physical Therapy (PT), Taylor and their family will receive guidance on strategies to assist with mobility in bed and transfers out of bed to a wheelchair. There is a focus on body mechanics, endurance and strengthening of the muscles that are still intimated while transitioning to build comfort and independence with their “new” body. Taylor may also be seen by the Speech Language Pathologist (SLP) to assess safe eating and swallowing skills as well as be coached in breath support, tolerating speaking devices and assess for adaptive communication devices.

Getting Taylor back to school and into their community is a large focus of our program. The collaboration to support Taylor’s reintegration back into the school setting is key. Our schoolteacher works alongside the family, team and home school facilitating communication and providing recommendations as reintegration is discussed. We provide assessment by our neuropsychologists, as needed, to identify recommendations for additional support in the academic setting. With the Recreation Therapist (TR), Taylor explores leisure activities used to improve or maintain physical, mental, and emotional health. TR may provide information about adaptive activities and sports to meet Taylor’s interest as well as connect Taylor and their family to resources in their community. TR may incorporate Animal Assisted Therapy (AAT), utilizing a specially trained facility dog to work on rehabilitation-related goals that may not be achievable through human intervention alone. The Massage Therapist (MT) provides Taylor with various techniques to enhance relaxation, relieve muscle tension, increase circulation and flexibility. These interventions often help reduce anxiety, enhance self-esteem, and assist in pain management for improved patient function. Music Therapy can work with Taylor using music to target the motor, sensory, emotional and social needs to support their rehab goals.

The psychosocial team communicates information that is pertinent to supporting Taylor and their family to other members of the care team. Psychologists will assist Taylor and family in adapting to functional life changes. A Child Life Specialist (CCLLS) utilizes specialized training to help Taylor cope and adjust to health care experiences. They may also work with Taylor’s siblings and peers to help them better understand the injury or diagnosis. The Social Worker (SW) will advocate for Taylor and their family as well as evaluate how the injury and hospitalization has affected family life. They provide support and assistance with resources in the community when necessary. There is also a focus on preparing patients for socialization outside of the hospital. To help, our team offers peer mentorship opportunities for Taylor and their family from past patients with a similar diagnosis. Group activities are also used to encourage socialization and peer interaction between patients on the unit.

After four to eight weeks on rehab, it will be time for Taylor to go home. The team celebrates this monumental landmark with a graduation send-off, highlighting the hard work put forth by Taylor and their family. Their hospital stay may be over but there are still needs that require management across their lifespan. Taylor will continue outpatient therapies to support strengthening and functional skills that promote further independence. When Taylor is ready, there are opportunities to explore activities including adapted sports such as wheelchair rugby, seated boccia, adapted skiing and more. Pursuing driving with adapted hand controls, traveling on an airplane, attending vocational rehabilitation or higher education are just a few opportunities available in the future. While life with a spinal cord injury may look different than what Taylor imagined, the opportunities are still there to live a fulfilling and active life!

For patients with limb deformities, limb lengthening surgeries offered through Nationwide Children’s Hospital provide children the ability to correct their deformities and improve pain, physical appearance and quality of life. While limb lengthening can certainly sound like a daunting procedure, the Center for Limb Lengthening and Reconstruction (CLLR) incorporates a comprehensive approach to patient care by collaborating with different specialties to make the process as smooth and comfortable as possible – this includes working closely with the Acute Pain Service and Pain Psychology to optimize pain management after surgery.

The use of peripheral nerve catheters (PNCs) and pain education are key components of post-operative pain control after limb-lengthening surgeries at Nationwide Children’s. The Acute Pain Service (Pain Team) is a team of anesthesiologists and nurse practitioners who oversee the management of PNCs, a technology used to deliver a continuous infusion of local anesthetic around a nerve that innervates the area of surgery on the limb. By providing medication directly to the affected area, PNCs can provide pain relief without impacting motor function. During surgery, anesthesiologists utilize ultrasound to place one or two PNCs, and when in place, patients can participate in physical therapy prior to being discharged home. Patients are sent home with their PNCs in place for up to five days after surgery, and families often remark on how satisfied they are with the pain control provided. In addition, the utilization of PNCs significantly reduces opioid requirements after limb-lengthening surgeries.

As part of the standard of care in the CLLR, a pediatric psychologist meets with all patients and families prior to surgery to provide pain education. The psychologist emphasizes nonpharmacological strategies used to assist and augment pharmacological pain management. The psychologist also assesses for factors that can sometimes exacerbate pain after a surgery, including anxiety, depression, sleep problems, history of prior pain concerns and previous traumatic experiences with surgery/hospitalization. Psychology then briefly provides education on how pain works in the brain, and how certain factors (such as stress level, attention, expectations, inactivity, etc.) can make pain better or worse. The psychologist reviews the connection between stress and pain, and demonstrates strategies for reducing physiological stress (e.g., belly breathing/paced breathing, muscle relaxation, mindfulness, etc.). They also emphasize the benefits of other nonpharmacological pain coping skills, including distraction strategies, positive self-talk, elevation and icing. Lastly, the psychologist meets with patients in the hospital and follows up with the patient in clinic during their scheduled post-operative visits. This service helps reduce stress related to the limb-lengthening surgical experience and provides patients with alternative methods for pain management in addition to pharmacological agents.

Together, the Center for Limb Lengthening and Reconstruction, Acute Pain Service and Pain Psychology act as One Team to provide optimal pain management and care for patients undergoing limb-lengthening surgeries.

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**Comprehensive Pain Management for Limb-Lengthening Surgeries**

Jessica Hoehn, PhD, Licensed Pediatric Psychologist, Department of Psychology/Neuropsychology

Kanda Strohl, MS, APN, CPNP-PC, Pain Management
What if you were born with one leg shorter than the other and needed to wear a shoe lift? What if you had leg bowing or knock knees that made it difficult for you to run and play? What if you broke a bone and it didn’t heal properly? Now, what if you learned about surgical options to correct these issues? Patients of the Center for Limb Lengthening and Reconstruction (CCLR) at Nationwide Children’s Hospital experience this type of life-changing transformation every day.

The Center for Limb Lengthening and Reconstruction is a multidisciplinary specialty center within the Department of Orthopedic Surgery at Nationwide Children’s. Under the direction of Christopher Iobst, MD, the center focuses on the management of limb length discrepancies and limb deformities in children and adults. Along with Dr. Iobst, the team includes a pediatric nurse practitioner and a registered nurse dedicated to the care of these patients and families. Each clinic has two physical therapists who provide patients with specialized therapies at each visit. A pediatric psychologist assists patients with issues that may arise before and after surgery, including anxiety/fears, pain management, school concerns, sleep problems and coping with changes in routine. An administrative assistant, social worker and child life specialist help ensure that each patient’s unique needs are met. In the future, the center hopes to add a dedicated clinical dietitian to focus on bone health and healing for all our patients.

Innovations in Orthopedic Care at the Center for Limb Lengthening and Reconstruction

Christopher Iobst, MD, MD, FAOA, Director, Center for Limb Lengthening and Reconstruction, Director, Limb Lengthening and Reconstruction Fellowship, Clinical Associate Professor, Orthopaedic Surgery and Danielle Hattfield, MS, APRN, PNP-PC, Nurse Practitioner, Orthopedics

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As its name implies, there are two primary patient populations managed by the CCLR: patients with one limb longer than the other (limb lengthening) and patients with a limb deformity requiring realignment (reconstruction), although it is common for patients to present with a combination of both issues simultaneously. While deformity or leg length discrepancies usually involve the lower extremities, the center also treats patients with upper extremity, hand, foot or joint concerns. In some instances, these conditions are present and noticeable at birth, but for many other patients, these issues develop later in life as the result of injury or infection. Although it may be surprising, limb lengthening of two extremities can be performed simultaneously for patients requiring increased height. The center evaluates patients of any age with limb abnormalities and, in many cases, adult patients can have their surgery and receive comprehensive care by our team at Nationwide Children’s.

In addition to nearly eliminating the need for opioids in our patients, the center has also worked on improving the patient experience during clinic visits. One strategy is the use of virtual reality headsets during physical therapy and routine dressing changes after surgery.

The CCLR is innovative. The team is always looking for new ways to improve patient care and outcomes. For example, improving pain control in our post-operative patients is a major initiative at the center. In collaboration with the Acute and Regional Pain Service at Nationwide Children’s, we employ peripheral nerve catheters to assist in the management of post-operative pain. Peripheral nerve catheters work by delivering pain medication directly to the affected limb, thus greatly reducing surgical patients’ need for opioids. For the vast majority of patients, only an overnight stay in the hospital is necessary after surgery due in large part to the comfort provided by the nerve catheters.

In addition to nearly eliminating the need for opioids in our patients, the center has also worked on improving the patient experience during clinic visits. One strategy is the use of virtual reality headsets during physical therapy and routine dressing changes after surgery. The distraction provided by these popular headsets enable our providers to conduct treatments better and more efficiently. These two examples are just a few of the ways that the Center works to provide ground-breaking and exceptional care for our patients.

With more than 60 publications in the first five years of its existence as well as national and international award-winning research, the center has demonstrated its commitment to exploring new and innovative ways to improve the patient limb reconstruction experience. In just five short years, the center has become one of the premier limb lengthening and reconstruction leaders in the world. Over the next five years, we plan to expand our clinical and academic activities and continue the search for the safest and most reliable outcomes possible for our patients.
Nurse-Driven Clinical Inquiry

Cathleen Opperman, DNP, RN, NPD-BC, EBP-C, NEA-BC, CPN, EBP Nurse Specialist, The Center For Nursing Excellence

Clinical Inquiry is the overarching term used to describe quality improvement (QI), evidence-based practice (EBP), research and innovation. Nurses are involved in all forms of clinical inquiry, however few of these practice changes are driven by nurse-led teams.

This article focuses on nurse driven evidence-based practice initiatives: definition, recent examples, resources available and who should contact the team. EBP is a systematic exploration of the most relevant research (external evidence) and organizational outcomes (internal evidence) to answer a burning practice question. The EBP process requires using this evidence in combination with the organizational knowledge/clinical expertise of the team AND the patient preferences and values to decide a course of action. This means that an EBP initiative is more than simply finding a few articles that support a change, it is a detailed implementation process which:

1. Considers organization timing, resources and training
2. Measures the impact of the practice change
3. Provides a sustainability plan

Numerous resources are available to facilitate more nurse driven EBP changes. Consultation with the EBP nurse specialist, learning modules, library support and infrastructure like job descriptions, policy and procedures and a clearinghouse for all nurse-driven initiatives are some of the resources available at Nationwide Children’s Hospital.

Whether you are a nurse passionate about wanting to improve practice or a graduate student completing a requirement, every nurse leading a practice change based on evidence should have a consultation with the EBP nurse specialist.

Using an EBP consultant model helps facilitate individuals or teams inexperienced with the steps of EBP by having someone to coach them through the process. If your team is interested in exploring the concept of clinical inquiry, numerous modules are currently available and being developed to offer the initial education on topics. For example, “What is Clinical Inquiry?” is a module comparing QI, EBP, research and innovation. It is available in The Learning Center.

The Nationwide Children’s Hospital Library resources are invaluable to the success of embedding EBP in all aspects of our work. The extensive collection of journals we have access to, the experience of our medical librarians in searching topics and the ease of access to search engines on the Library ANCHOR page have evolved, simplifying the process for the clinician.

**RECENT EBP PROJECTS AT NATIONWIDE CHILDREN’S HOSPITAL**

<table>
<thead>
<tr>
<th>CLINICAL INQUIRY</th>
<th>INTERVENTION</th>
<th>NURSE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduce time to D/C for children with head lacerations</td>
<td>Change communication pattern for triage team and providers</td>
<td>Scott Oman</td>
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<tr>
<td>Increase lipid screening during well child visits</td>
<td>Staff education, patient teaching tool and provider reminders</td>
<td>Lindsay Shaw</td>
</tr>
<tr>
<td>Reduce frequency of routine vital signs over night</td>
<td>Employee education regarding criteria for “VS while awake” orders</td>
<td>Karmyn Schneider</td>
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<tr>
<td>Find ways to keep bedside nurses engaged and involved by integrating support of nurse driven clinical inquiry</td>
<td>Develop an interactive module on clinical inquiry</td>
<td>Rebecca Conatser</td>
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<tr>
<td>Streamline surgeon, APRN and nursing communication to reduce LOS and increase staff satisfaction</td>
<td>Interprofessional handoff sheet in EHR to include a dotphrase to limit frequency of contacts for clarifications</td>
<td>Jennifer Weiner</td>
</tr>
<tr>
<td>Increase knowledge and comfort levels of nurses working with patients having seizures</td>
<td>Neurology team complete a series of self-paced modules and a multi-disciplinary simulation with Epilepsy Monitoring Unit training team</td>
<td>Shivani Bhartnagar, Allison Nelsen</td>
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<tr>
<td>Increase teamwork, address staffing challenges post-pandemic</td>
<td>Implement TeamSTEPPS to improve teamwork and communication</td>
<td>Ashley Humphrey</td>
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<tr>
<td>Incivility (knowledge of behaviors, recognition when it occurs, mechanisms to address)</td>
<td>Interactive module and four-hour workshop</td>
<td>Andrea Manning</td>
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<tr>
<td>Disruptions to patients’ sleep due to environment and low team care clustering behaviors</td>
<td>Designated Quiet Times; Rest Warriors; Interactive learning module; Weekly email reminders</td>
<td>Caitlin McGee, Nikki Hernandez, Cathleen Opperman</td>
</tr>
<tr>
<td>Support more moms in NICU to provide human milk to their baby</td>
<td>Designated lactation consultant role for rounding and teaching mothers</td>
<td>Leslie Biggers</td>
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Cheering fans and screaming athletes are familiar sounds in gymnasiums and fields across the country. From little league baseball to track and field, more than 56% percent of children 6 to 17 years old participated in an organized sport in 2019. As part of the “Healthy People 2030” project, the U.S. Department of Health and Human Services has set a goal to increase access and opportunities so that 63.3% of students are playing by the end of this decade.

There are countless physical, social and emotional benefits of athletic participation and the physical activity reaped by young athletes who are involved in an organized sport. Unfortunately, many students who have the most to gain are among the lowest participants. Children and adolescents with disabilities generally participate in substantially less physical activity than their peers.

While physical activity benefits all children, those with disabilities often have lower levels of cardiovascular fitness and muscular endurance along with higher levels of deconditioning and obesity. Regular physical activity has been shown to help control or slow the progression of chronic diseases, increase physical fitness, decrease body fat, and improve overall health and function in this population. Regular activity is crucial for individuals with physical disabilities to maintain muscle strength and flexibility and can help slow many functional declines associated with disabling conditions.

The benefits of sports participation extend far beyond physical health. Organized sport participation improves individual self-esteem, promotes inclusion and supports relationship development. Lessons learned in athletic participation include teamwork, dedication, time management and sportsmanship. Individuals with physical disabilities involved in sports report higher levels of confidence, independence and quality of life. Within the social circles of adolescence, adaptive sports participation can enhance peer acceptance and support, along with a venue for sharing experiences among friends, family and communities. Research conducted at Nationwide Children’s Hospital and The Ohio State University Adapted Sports Institute demonstrated a positive correlation between life satisfaction and minutes of participation adaptive sports amongst surveyed youth with disabilities; the more they participated the greater their satisfaction.

Each of these lessons and benefits of physical activity have the potential to carry over beyond adolescence into adulthood as well. Individuals involved in adaptive sports maintain higher quality of life, higher employment rates and better overall emotional health. Perhaps most importantly, participation in regular physical activity at a young age has been shown to increase the likelihood of continued physical activity later in life and contribute to maintaining overall health.

The benefits of physical activity in organized sport are universal for all children, including those with disabilities. Fortunately, opportunities to participate in competitive sports for athletes with physical disabilities have grown rapidly in recent decades. The “Paralympic movement” has taken the world by storm with unprecedented coverage and interest on the international stage has stimulated the development of para and adaptive sports opportunities at the state level and local communities. Ohio is one of 30 states whose state high school athletic association has dedicated adaptive programming for the last 10 years. In 2019, the Ohio High School Athletic Association opened the doors for students with disabilities to compete in swimming as well. Outside of schools, community organizations such as The Adaptive Sports Connection, Columbus Recreation and Parks Adaptive Sports Club and Ohio Sled Hockey provide a variety of adaptive opportunities of engagement and participation for individuals with physical and cognitive disabilities as well as visual and other sensory impairments.

To increase performance and reduce the risk of injuries, all athletes need to prepare and train for their sport. Athletes with disabilities should follow a program designed especially for them. Nationwide Children’s Adaptive Sports Medicine Program has been developing specialized plans for these athletes since 2018. Although there are countless benefits of physical activity, it is important to understand the potential risks of overuse, pain and injury associated with participation. Due to the functional impairments associated with congenital or acquired neurological/neuromuscular diagnoses, adolescents may be more prone to developing pain from overuse and/or
measures and improves confidence to engage in a variety of physical activities with friends and peers.

With increases in physical activity, there are higher risks of acute and/or overuse injuries as these individuals adjust to their prosthetics or assistive devices. They need to use new adaptations to be able to return to or to begin a new sport. Depending on the severity of the injury, they may require therapy to improve strength, flexibility, range of motion, balance and coordination when returning to physical activity. Adaptive Functional Rehabilitation is a program managed by licensed athletic trainers at Nationwide Children’s and it is tailored for those athletes and patients with adaptive needs when they are returning to activity from an injury. Gait analysis is used to determine biomechanical issues leading to overuse injuries in a patient learning how to run properly with the use of a lower extremity prosthesis or orthotic brace. Based on the findings of the analysis, corrective exercises are provided to help prevent continuation of overuse injuries in the future. Similar concepts can be applied to an athlete who uses a wheelchair, where an analysis of their wheelchair stroke can be helpful to identify and correct any imbalances that may have contributed to their overuse or injury. This analysis can then determine proper postural changes and movements and corrective exercises to provide a safer active lifestyle for these patients.

Significant improvements in technology and a better awareness and understanding of how to best prepare this unique population of athletes have contributed to new and emerging opportunities. However, the greatest growth in this field has come with a much greater understanding of the benefits of inclusion and participation. Together these concepts have opened a whole new horizon for children with disabilities. “Play Ball” can now be a strategic goal for patients, families and clinicians through successful partnerships with Nationwide Children’s Hospital Adaptive Sports Medicine Program.

### Recognizing Nurses

Nurses Month 2023 was a blanket of recognition, self-care, professional development and community service, with plenty of fun for all who participated in the activities. Historically, Nurses Week was designated as the week of Florence Nightingale’s birthday (May 12), however during the pandemic the American Nurses’ Association (ANA) called for expansion of celebration for nurses to a month to better capture the impact nurses have on health care.

The Nationwide Children’s Hospital Nurses’ Week committee used the ANA themes to plan activities to celebrate nearly 4,300 nurses in inpatient, ambulatory, off-site, leased and traveler roles. The following are highlights of the celebrations organized by theme.

#### Recognition

On May 5, we kicked off the Nurses’ Month celebration with a Fun Day on day and night shifts.

Approximately 500 nurses participated in the Operation GetAWave, Selfie Station, Pizz Wheel, Head and Neck Massages, and hotdog/smoothie/popcorn/cookie giveaways. The festival atmosphere was a great break for nurses mid-shift.

Our Chief Nursing Officer (CNO), Lee Ann Wallace, presented stories of initiatives led by nurses in “Lemonade with Lee Ann.” She recognized the efforts of many nurses who made a difference for our patients, families, employees and community. Participants left feeling a sense of pride for the work done by nurses at Nationwide Children’s and inspired to be a part of projects like these in the future.

The Senior Leader Walk-abouts were appreciated by all employees who had the opportunity to talk with Tim Robinson, CEO, Lee Ann Wallace or Rustin Mone, MD, CMO. During eight different dates and times (including evenings), our senior leaders met hundreds of employees while passing out small gifts. After introductions, many said it was so good to meet the leader and realize that the leader recognized the challenge of the work being done. The leaders enjoyed talking with so many dedicated employees, many of whom shared stories from their daily work.

### Self-Care: Doing Something for You

Self-care can come in many forms. Visiting with and cuddling a therapy dog was arranged different times throughout the month with many nurses walking away reporting, “I needed that” or “What a fun thing to do in the middle of the day.”

Our chaplains provided a small ceremony with a Blessing of the Hands for nurses. Nurses partaking remarked on the feeling of renewal and how they wished every nurse could experience it. The YOU Matter program gave our warm lemongrass towels during various events like “Lemonade with Lee Ann.” The aromatic towels were both relaxing and refreshing. Taking part in small gestures like these contribute to self-care.

Another form of self-care is having fun. Brutus Buckeye, Blue Jacket’s Steinger and the mascots Krash and LouSeal from the Clappers were here for mascot photo fun. Nurses came from all over campus to have pictures with the mascots. Families and patients jumped in whenever the mascot was walking the halls.

### Additional Recognition

Additional recognition included lots of treats and prizes! Panera generously provided a gift card to all 4,500 nurses including our travelers and leased nurses. At all events snacks and beverages were provided, along with a chance for a massage from The NOW Boutique, compression socks from Pacas, McDonald’s drinks and grab bags of logo goodies. It is heartening to know so many organizations showed support for our nurses.

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At Nationwide Children's Hospital, we serve patients and families with many different types of disabilities. When we think about persons with disabilities, it is important we reflect on legislation, history and advancements. This history has brought us forward to today’s appropriate etiquette in interacting with persons with a disability.

Although the Americans with Disabilities Act (ADA) has been in effect since July 26, 1990, history shows the movement to advocate for better opportunities for persons with disabilities started years before. Thousands of people worked on the disability rights movement. There were volunteers working to distribute information, politicians lobbying for rights and parents of children with disabilities speaking to community groups. These people wanted to show the American public that disabled Americans were being discriminated against and they deserved to have a more fulfilled life.

A historic push for the disability public policy occurred in 1973, when the passage of Section 504 of the 1973 Rehabilitation Act was passed. Section 504 aligned the discrimination of people with disabilities to those discriminated against for race, ethnic origin and sexual orientation. The section 504 recognized all the many disabilities that people faced and how these disabilities affected their employment, their education and simply access to society. At one point Section 504 was nearly deregulated, but this resulted in a huge uproar among groups with disabilities and was eventually kept.

BASICS OF DISABILITY ETIQUETTE

The goal of sharing and becoming more aware of the proper etiquette when interacting with someone with a disability increases the comfort and effectiveness for everyone. Those with disabilities are individuals, complete with emotional, physical and psychologic needs like any other individual. There are general guidelines that may help to make any communication more effective.
• Put the person first. A disability does not define a person, although it may be a significant part of their life. It is important to address the person first. In most cases you should say “a person with a disability” rather than “a disabled person.” It is OK to ask an individual, including children, their preference about how they would like to be addressed.

• Ask before helping. Children and people who have disabilities are often independent. It is important to always ask permission before helping. Don’t make assumptions about what a person may or may not be able to do.

• Think before you speak. Be considerate of asking a person or child too many questions about their disability. As health care providers it is important to know this information and many people are open to sharing, but the focus should be them as a person first and foremost. Talk to a person with a disability just as you would talk to anyone else. Talk directly to the person and not just to their caregiver or support person.

• Respond graciously to requests. Be open to accommodations or specific requests from a child, person or family of a child with a disability. Our goal is to create an environment where their specific needs are addressed regardless of the disability they have.

**PHYSICAL DISABILITIES**

Working at Nationwide Children’s we may encounter children, families and/or colleagues that have a variety of physical disabilities. These disabilities are often identified by using an assistive device such as wheelchairs, walkers, crutches, canes and service animals.

Physical disabilities are typically easier to identify. When interacting with a person with a physical disability there is general etiquette to follow.

• Always talk directly to the person, with good eye contact.
• Do not touch their equipment without asking.
• When at all possible, put yourself at their eye level.
• It is important to respect one’s personal space, and their wheelchair or assistive device should be seen as a part of their personal space.
• Be sensitive about physical contact both to the person and to their assistive device. Be aware that physical contact could cause balance issues or even pain.
• Service dogs are working and should not be touched or talked to without permission.

**HIDDEN DISABILITIES**

There are also patients, families and/or colleagues we may encounter that have a disability that we cannot see or obviously identify. Some of these hidden disabilities may include individuals who are blind or have low vision, deaf/hearing loss, speech disabilities, epilepsy or seizure disorders, autism spectrum disorder, developmental disabilities, psychiatric disabilities, mental illness, learning disabilities, intellectual disabilities or traumatic brain injuries.

It is helpful to keep in mind this etiquette when interacting or communicating with colleagues, patients and families with a hidden or not easily identifiable disability.

• Treat each person as an individual.
• Give your full attention, actively listen and don’t interrupt. It is OK to ask clarifying questions or an individual to repeat information if you do not understand.
• Don’t make assumptions.
• Ask what needs or preferences each person has and what would make them feel most comfortable whether you are aware if they have a disability or not. Respect their needs or requests.
• Be open to different accommodations such as providing information written or using pictures or adapting the environment to be less over stimulating or loud.

The opportunity to care for persons with a disability is unique. Knowing the proper way to communicate is the key to building strong relationships and trust. This knowledge encourages best practice for our patients, families and staff.

**Physical Disabilities**

During the pandemic, the rates of communication disorder diagnoses in children ages 0-12 more than doubled, putting pediatric communication professionals in the spotlight as they support the growing needs of our community. We often think of these professionals - speech-language pathologists and audiologists - as social and behavioral clinicians that use their diagnostic and therapeutic skills to support families as they improve hearing and communication. But, did you know, our speech-language pathologists and audiologists at Nationwide Children’s Hospital are also scientists using cutting-edge technologies to diagnose, intervene and facilitate new applications that use technology to enhance and build on the current communication abilities of each child.

Some children who use AAC devices to communicate also develop the need to use additional assistive technologies (AT) to use their AAC devices or to navigate their daily environments. Eye gaze used with a device equipped with eye tracking is an example of an assistive technology that is utilized by children for communication and other needs. If eye movements are the most reliable source of movement for a child, as could be the case for a child with Retts syndrome, a speech-language pathologist or an occupational therapist can support a child and family in using their eyes to identify the words they want to communicate or the function on a device that they want to activate. With this programming a child can utilize their AAC device, maneuver their wheelchair, manipulate the controls to a television or adjust environmental controls to turn lights on/off through the use of simple eye movements.

Together with these cutting-edge technologies, our speech-language pathologists and audiologists are helping each child enhance their own abilities to become more effective communicators with the people that matter most to them.
Cerebral palsy (CP) is the most common motor disability in childhood, affecting approximately one in 345 children in the United States. CP is an injury or abnormality of the developing brain that affects movement. The injury to the brain will not get worse over time, however a child's ability to function may change. The Comprehensive Cerebral Palsy Program at Nationwide Children's Hospital provides holistic, lifelong care to these patients and families.

Provider collaboration is an essential component when caring for patients with complex needs. CP is a chronic health condition and research has shown that early identification and care coordination improves outcomes. The CP Program uses the International Classification of Functioning, Health & Disability (ICF) framework along with the F-words of Childhood Development: function, family, fitness, fun, friends and future to develop goals in a functional and family centered manner. When thinking about childhood disability the health care providers, patients and families are encouraged to shift away from the mindset of "fixing" and focus on these F-words. Assistive devices can play an important role by improving independence with mobility, activities of daily living and communication, and can significantly impact the F-words.

One of the most frequently asked questions from parents is “Will my child be able to walk?” This question cannot always be clearly answered, but clinicians can be guided in their response by using the Gross Motor Function Classification System (GMFCS). The GMFCS categorizes gross motor skills of children with CP into five different levels. It looks at a child's ability to self-initiate movements and their need for assistive devices. This tool can help both families and clinicians have a clear description of a child's current motor function as well as an idea of what assistive devices a child may need in the future. For example, a child with a GMFCS level I is typically independent with their mobility without an assistive device, whereas a child classified as GMFCS level V may be dependent for their mobility using a wheelchair with a caregiver pushing.

There is a wide range of assistive devices that an individual with CP can use to achieve a greater level of independence with mobility. Equipment such as forearm crutches, reverse walkers and gait trainers can help support a child with their walking. Other children will use medical strollers, manual wheelchairs, or power wheelchairs to assist with mobility. Assistive devices also exist to improve independence with activities of daily living such as bath chairs and adaptive toiler seats that provide additional support. Button hooks, zipper pulls, reachers and shoehorns can all assist with dressing. Adaptive feeding supplies such as built-up handle utensils, curved utensils, high sided bowls and dishes and weighted utensils can all allow a child with CP to have greater success with self-feeding.

CP can also affect a child's ability to verbally communicate. Augmentative and Alternative Communication (AAC) can play a significant role in developing effective communication, academic and literacy skills. AAC includes no or low-tech switches, picture communication boards or books and high-tech Speech Generating Devices (SGD). Many SGDs offer alternative access methods such as eye gaze or switch scanning to help the child independently communicate when they are unable to directly access the device with their hands. AAC can start and be successful from a very young age.

With the use of assistive devices children with CP can increase their independence, participate in fitness related activities, play with friends, be included in family events and have fun. An event that encourages this activity is the CP Program sponsored annual Family Fun Day at Recreation Unlimited. By incorporating the F-words, ICF framework and GMFCS levels in developing a plan to improve function and to assess the need for assistive devices, the CP Team facilitates improved quality of care and outcomes that are meaningful to the family and patient, which is the ultimate goal!
Promoting Inclusion at Nationwide Children’s Hospital: Project SEARCH

Cara Inglis, PsyD, BCBA – Psychology Supervisor
Nichele Mather, LISW-S – Transition Specialist, Center for Autism Spectrum Disorders, Adolescent Transition Program, Nationwide Children’s Project SEARCH

Over the past several years, Nationwide Children’s Hospital has created dedicated efforts to have a diverse and inclusive culture where Everyone Matters. Our Inclusion and Culture programs have expanded, Employee Resource Groups (ERGs) have received greater support, and we have begun programs to help serve and support a more diverse range of individuals – including our employees. At Nationwide Children’s, we recognize that representation matters to our patients. They are thrilled to see someone like them working at our hospital, and this is especially true for our disabled population. As a hospital, we are beginning to recognize that individuals with disabilities represent an amazing group of untapped talent when it comes to having committed, capable employees. Nationwide Children’s is committed to diversifying our workforce.

One example of this commitment is the Project SEARCH program. Project SEARCH was started at Cincinnati Children’s Hospital in 1996 and there are currently more than 600 programs in the U.S. and internationally. It is a transition-to-work program for individuals with developmental disabilities, with an end goal of competitive employment. Project SEARCH is specifically targeted toward high school students who are on an Individual Education Program (IEP) and in their last year of high school eligibility. Project SEARCH student interns participate in daily group instruction and gain hands-on work experiences by rotating among three 10-week unpaid internships at Nationwide Children’s throughout the school year. Department managers at each internship site work together with the Project SEARCH instructor and skills trainers to support each student intern.

Project SEARCH was approved to begin at Nationwide Children’s in August 2020, and was housed off-site during the 2020-2021 academic year. The program officially launched at Nationwide Children’s in the fall of 2021 and moved to a space on the eighth floor of the Big Lots Behavioral Health Pavilion. During the 2021-2022 academic year the program had five interns, and Nationwide Children’s has successfully hired four of them. Interns have been employed in departments such as Clinical Research, Nutrition Services, Laboratory Services and Central Distribution. Other past interns have successfully found employment outside of our hospital. The Nationwide Children’s Project SEARCH program continues to expand, and there are six student interns starting in August 2023 with hopes to recruit new departments to be a part of the program.
The Project SEARCH program at Nationwide Children’s is unique in that we can provide an additional layer of Behavioral Health services not typically found in traditional models. In our program, all student interns, skills trainers and departments have access to additional support through Nationwide Children’s Center for Autism Spectrum Disorders (C ASD). CASD clinicians provide mental health support, behavioral consultation to support the development of job skills, as well as services outside of the Project SEARCH program to help our interns gain independence as they transition to adulthood. We also team with department staff to develop strategies to best support our interns in learning skills, and in partnership with our disability ERG, CapABLE, we offer departmental trainings on inclusive employment.

The goal of a Project SEARCH internship is not to take away from existing positions. Instead, interns can help with tasks staff might be too busy to complete, or that would allow staff to focus more on their clinical responsibilities.
Daisy Award

Taylor Ormond, RN

The quarterly Nationwide Children’s Hospital Daisy Award was presented to Taylor Ormond, RN, of H09A. The Daisy Award is given in appreciation of the important difference our nurses make in the lives of our patients and families at Nationwide Children’s.

Taylor provided extraordinary care to a mother of a patient who needed additional education for how to use her child’s nasogastric (NG) tube and feeding pump.

Says Taylor’s nominator: “Taylor was patient and found creative ways to educate a parent who was overwhelmed and wanting to do the best thing for their child. Her dedication to collaborating with and educating this mother helped ensure the patient received her necessary feeds and care. Taylor went above and beyond in her role as a compassionate, patient and understanding nurse, and she made a significant difference in the care of this patient by providing extraordinary family-centered care.”

To learn more about our Daisy winners, and read their full nomination, visit NationwideChildrens.org/Daisy-Award