

## PEOPLE Building a Better World Together



Wendy Ross, MD

*Dyan was at the football game with her autistic son. He started to get overwhelmed. She walked around the stadium to find the sensory room while his agitation grew. She was wondering if they should just leave. At last, the sensory room was in sight.*

*Inside, it was dim, it was calm. It was a relief to him—and to her. They spend the rest of their time here. Occasionally, they can hear the faint roar of the crowd. It reminds her of how much they're missing. She initially thought this outing would be a touchdown, but it feels like only a first down instead. Good, but not good enough to win the game...*

Community participation can be an issue across all areas of life. What about when it applies to medical care? The numbers of those with autism began steeply climbing in 2003, meaning that over the next decade, over half a million individuals with autism will be reaching adulthood and require adult medical care.

Studies show that most individuals affected by autism do not obtain medical care after aging out of pediatrics<sup>(1,2)</sup>. When admitted to the hospital, they are significantly more likely to die than neurotypical individuals<sup>(3)</sup>. Neurodiversity encompasses autism and includes anyone with thinking or communication differences, such as those with psychological issues, intellectual challenges, impacts of aging, learning disabilities, and the like. In reality, accommodations made for those with challenges have historically benefited everyone. As a powerful example, ramps were designed for wheelchairs but support those with walkers, strollers, and delivery dollies. By accommodating those with autism and neurodiversity, we simultaneously provide the care that some need and that all deserve.

Jefferson Center for Autism and Neurodiversity has been reaching out across Jefferson University and Jefferson Health



*It is all about Perspective; this young lady with autism is providing us with the solutions to communication and conversation.*

to bring individuals with neurodiversity and clinicians and scientists from diverse backgrounds with unique talents together to share ideas, conceptualize, and build a better future. The importance of interdisciplinary and interpersonal collaboration cannot be overemphasized in the development of an accessible community. Key stakeholders drawing from their personal and professional perspectives enhance the outcome by layering experiences with expertise in multiple areas. No single viewpoint can embody the enrichment and learning experience as fully as a united effort can. To this end, we have designed the PEOPLE model:

### P.E.O.P.L.E.

1. **PERSPECTIVES:** Ask people what matters to them. Getting perspectives from all stakeholders creates a better outcome. While those affected by autism and neurodiversity are a priority, networking with experts in occupational therapy, speech and language pathology, architecture, design, nursing, medicine, and more provides innovative solutions to challenges facing all of us.

2. **EDUCATION:** Educating providers and patients alike reduces anxiety and prepares everyone for the path ahead. Resources and accommodations make all of us feel welcome.
3. **OUTCOMES:** Measuring outcomes is critical for determining best practices and moving the needle on policies that can extend opportunities to more people with clinical fidelity.
4. **PROCESS:** Developing processes to introduce new experiences facilitates opportunities. We do not become adept at new challenges by simply preparing materials or reading about them. Experience is an essential ingredient to success.
5. **LEARNING:** True learning happens when we meet people where they are and create meaningful stepping stones to where they want to go. For some, this will mean direct support for their treatment. For others, it will mean helping them to reach their goals more independently. Professionals will also enrich their own learning by partnering with each other, with the people they hope to serve, and by extrapolating strategies to other populations.

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*Creating new Processes and Environments that facilitate inclusive access is essential for individuals with autism*

6. **ENVIRONMENTS:** Environments are critical to the effective functioning of many, especially to those with sensory issues. Creating new built environments – where we can – will be valuable. Where we cannot, we must find adaptations that maximize accessibility.

We are applying this model internally to medical care at Jefferson, and externally to other community settings, like sporting events and more.

#### **PEOPLE in Action—Imagine This:**

**PERSPECTIVES:** Dyan is in a focus group with occupational therapists, individuals with autism, caregivers, speech and language pathologists, behavioral specialists and more, before taking her son to the game. She shares her perspective that she and her son could stay in the game if sensory-friendly seating was provided in the accessibility section of the stadium.

**EDUCATION:** The seating is provided along with visual stories, noise reduction headphones, fidgets, and other strategies pulled together by an interprofessional team

for Dyan, her family and others. The stadium personnel are educated so they understand autism and have the seating and sensory friendly room available.

**OUTCOMES:** Jefferson Center for Autism and Neurodiversity's interprofessional team conducts outcome studies to assess the efficacy of interventions.

**PROCESS:** Tickets are provided to Dyan, her family, and others. Interprofessional team members are assigned families to observe, help problem-solve, identify any other barriers to participation, and collect data.

**LEARNING:** After the experience, professionals and participants describe the lessons learned. Applications of the model, for example, to other settings like healthcare, are explored.

**ENVIRONMENT:** Aspects of the environment that worked and may not have worked are assessed by participants and discussed with designers and architects. Feedback is applied to future experiences to help drive progress for improved participation.

Fundamentally, connecting the neurodiverse population with the breadth of expertise across the Jefferson Enterprise will improve navigation, as well as the quality and safety of care for everyone. Thinking outside the box only happens when all kinds of minds come together. Our goal is to provide opportunities across the enterprise and across the population. Jeff CAN aspires to be a catalyst, empowering others to reach their potential in the world, not just in a room. When we all come together, everyone is in the game. And in this game, everyone wins.

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- Note: while some prefer a people first language model (i.e. 'person with autism'), many autistic individuals themselves are currently insisting on an autism-first moniker (i.e. autistic individual). With this in mind, this article has alternated in methodology of reference in order to accommodate both schools of thought.