

WHAT MATTERS?

Community

Born in Baltimore City with lissencephaly, a brain disorder, **Paz**, 24, can't speak or use her arms and legs. She needs assistance to get around in her wheelchair, and with all activities of daily living. Yet from birth she has been included in her community with her peers without disabilities, communicating her preferences by squirming or going to sleep when bored or unhappy, and smiling alertly when life feels good.

Paz's services are self-directed and overseen by her parents, Leslie and Russ, who interviewed several people before choosing Nahkita to be Paz's support person. For additional hours of support in the home, Leslie and Russ brought in Pearl, Paz's former elementary school aide. With Nahkita and Pearl's support, Paz has thrived. Her days out in the community with Nahkita are spent awake, engaged, calm, and smiling. Her mother reports that she makes up for it by sleeping a lot at home on weekends.

One of Leslie's operating principles is the concept of "dignity of risk." She explains: "People with disabilities have the same right to risk as the rest of us. The same right to smell the roses and maybe get scratched by a thorn. With lissencephaly, Paz's health could be considered fragile. But I'm not going to keep Paz in a bubble."

So Paz's weekdays with Nahkita are busy. They might go to Belvedere Square for music and lunch, or to the movies, or roll through a breezy park or down city sidewalks teaming with life. They've been to Annapolis to advocate, to music events and museums, and to Dave & Buster's because Paz enjoys the arcade lights and sounds. They participate in



Paz hands out cupcakes to the children at the recreation center where she volunteers.

Athletes Serving Athletes and go rollerskating. Sometimes, they visit the principal, teachers, and students at Paz's old school, or attend a sporting event. Often, she is included at one of Nahkita's large family gatherings, or watches Nahkita's son at one of his basketball games. Paz is so embraced by the family that Nahkita's grandmother fills in if Nahkita needs a day off.

Paz and Nahkita volunteer regularly at the recreation center in Sandtown-Winchester, handing out snacks to kids after watching them race around the gym. The children appreciate Paz, hugging her and laughing with her, their hands covered with cupcake crumbs. She smiles and turns her head toward them, tracking them quietly with her eyes. Her presence impacts them, too.

"Paz draws people to her," says Leslie. "It's been that way since she was a baby. The more you get to know her, the more you get from her."

What matters? That our days be spent with purpose. Services are changing to help people with disabilities lead the lives they want. Ensuring they have opportunities to work and spend their days in other meaningful ways, alongside people without disabilities, is one of the ways change is happening. Learn more at: www.md-council.org