

BY MEGAN
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PHOTOS BY
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Elena Walke is like so many second grade girls. She enjoys math and reading, plays games in gym and attends school with all the neighbors on her block.

Yet what Elena does in her everyday life is even more impressive considering she has cerebral palsy that affects all four of her limbs. She is non-verbal, non-ambulatory and cannot purposefully use her hands.

Elena was clinically diagnosed around nine months old with cerebral palsy, which was confirmed six months later with an MRI.

“There was certainly a period of grief and anger as we mourned the child that we thought we were going to have, but we knew that we had to get through that in order to be a parent for our young child,” says dad Bernhard Walke.

“Elena has always been an upbeat and happy child, so it’s hard to be sad about her disability when she wakes up with a smile every single day,” he says. “Elena just let us know that she was on her own timeline and own path of doing things”

From her diagnosis until she was 3, Elena received physical therapy, occupational therapy and speech therapy at home. Then from ages 3-5, she was in the Early Childhood program in her school district in Oak Park where she thrived.

“She loved the social interaction, the teachers, her aides and of course, her friends,” he says. “Early Childhood gave her the chance to show off to the world all that she could do and how she did it.”



Charting her own course

How one girl's disability is celebrated and embraced

Sheri Lenzo has worked with Elena since Early Childhood as her assistive technology specialist and physical therapist and saw firsthand how well Elena has

adapted to school life.

“I don’t really see Elena as someone with a disability,” she says. “I see a very determined young girl who’s smart, social,

eager, and playful like other girls her age. She’s a very special, and amazing little girl, and she’s given me far more than I’ll ever be able to give her.”



“She has taught me to be patient, adaptive, innovative and serve as an advocate not only for Elena but also for those who live on the margins.”

Ready for more

Both of Elena’s parents are educators, so they knew the ultimate goal of a student with special needs is to put them in the least restrictive environment with appropriate support.

“In all honesty, Elena advocated for herself to be in a mainstream school setting,” Walke says. “She demonstrated to all her teachers and aides what she could do and they advocated for her as well.”

Rosa and Bernhard decided to send Elena to her local school, Horace Mann Elementary.

“For her social-emotional development, we wanted Elena to go to her local school with everyone in the neighborhood, so that she was more included and plugged in to her community,” he says. “We wanted her to be known as ‘Elena’ rather than the girl in the chair who gets shipped away every day to a different school. Normally, Elena rolls down the alley with all the neighborhood kids on the way to school and it’s truly no big deal.”

Lenzo says she believes it’s important for all children to have the opportunity to learn and play together, regardless of ability or disability.

“A direct discussion about a child’s disability, and about the things he or she needs that are different, yields understanding and is beneficial to everyone,” she says.

Three years into grade school, Elena is flourishing and progressing each day. She communicates using her eyes and her facial expressions. For simpler tasks, she looks up to say “yes” or to the side or down to say “no.”

For academic or more complex work, she uses a computer that recognizes her eye movement and allows her to select what she would like to communicate.

According to Sarah Kiolbasa, Elena’s resource teacher and case manager at Mann, she is on par with her peers.

“While Elena benefits from being at Mann, I think the rest of the students and staff benefit even more,” Kiolbasa says. “Elena brings out the best

in all her fellow students. Her peers jump at the opportunity to hold the door for her, open her locker or assist in other daily living tasks. Students develop empathy, compassion, patience and an appreciation for all types of diversity when they learn alongside Elena.

“Elena’s perseverance and grit is inspiring to her teachers.”

Celebrating disability

The Walke family made the conscious decision for Elena’s disability to be celebrated rather than tolerated and to be more thankful for what they have rather than what they lost.

“When I was in the classroom teaching English, one of my students told me ‘Mr. Walke, we should never be judged by the situation that we are born into, but rather how we respond to it.’ I’ll never forget those wise words and I’d like to think that Elena has taught us to properly respond to her disability,” he says.

While mainstreaming was appropriate for Elena, Walke advises parents to find a setting that is best for their own child.

“There is so much diversity in the disability community and there’s seldom a one-size-fits-all solution,” he says. “Also never be apologetic for your child’s disability. Nothing ‘happened’ to your child; it’s part of their identity and it doesn’t need to be fixed or cured.”

Elena is just one of the kids at Mann and on the block.

“Our hope is that one day Elena is able to live, move and communicate independently with assistance,” Walke says. “Early on, her therapists mentioned that they pictured Elena in college and we share that aspiration as well. She has taught me to be patient, adaptive, innovative and serve as an advocate not only for Elena but also for those who live on the margins.”

Megan Murray Elsener is a Chicago Parent contributor, freelance writer and mother of three.