Follow Your Passions

Simon is a passionate kid. He loves to be active, and he loves nature and the outdoors.

Last winter, when unable to go the YMCA because of COVID or to play outside because of the cold weather, Simon asked his mom for a treadmill. Marnie, Simon’s mom, was worried that the treadmill was, like it often happens with kids, a passing interest for Simon, but he persisted. Marnie checked with Simon’s pediatrician, who was in favor of the idea. Simon has autism and a lot of energy. He is happiest when he is active – a treadmill would enable him to do that even with the restrictions of COVID.

Marnie and Simon’s EPI Self-Direction team explored the options and were able to cover the cost of a treadmill in Simon’s Self-Direction budget. The Self-Direction budget also covered personal training classes to ensure Simon would use the treadmill safely. When the family went to the showroom to make the purchase, Simon was so excited that he tried out every single treadmill on display. Marnie had to redirect him to the treadmill that was in the Self-Direction budget! Simon now has his own treadmill in the basement, and he loves it. He uses it every day.

“I love Self-Direction,” said Marnie. “Other programs have lot of constraints. Self-Direction offers the flexibility to follow Simon’s interests. Instead of trying to fit Simon into a program, Self-Direction funds help develop his interests.”

Knowing how much Simon loves the outdoors, Tess – the family’s respite caregiver paid for via Simon’s Self-Direction budget – took him to her farm, and he was fascinated by her chicken incubator. He decided he wanted to be a chicken farmer. His parents got a special permit from the town of Brighton to get a backyard chicken coop and now Simon has six chickens!

Self-Direction not only provided Simon’s family with access to respite services, but also the ability to hire a staff person that fit the family and Simon best. Marnie was able to hire Tess and could not have higher praise: “Tess is phenomenal. She is like Mary Poppins.”

Self-Direction assists people with intellectual or developmental disabilities and their families to choose and manage their own budgets, services, and staff. Self-Direction not only offers greater choice and control over the supports they receive but it also expands their options beyond traditional programs to include services such as such art and music therapy, community classes or training, gym memberships, camps, and special equipment, such as a treadmill.

Self-Direction funds also covered swimming lessons for Simon. Knowing that Simon loves water, Marnie wanted to be sure Simon would be safe around the lake during their summer vacation in the Adirondacks. They signed up Simon for swimming lessons with a YMCA instructor and Simon was able to fully enjoy his vacation at the lake.

The benefits of allowing children to pursue their own passions are innumerable. Nurturing their interests helps children develop their self-esteem and their sense of self-determination. Self-Direction, for many families like Simon’s, makes this possible.

For more information about EPI’s Self-Direction services, please contact: info@epiyny.org or (585) 442-4430
And finally – a big thank you to the Pirate Toy Fund for providing lots of cabin activities such as games and arts-n-crafts that are very big deal for our campers. truly a home away from home for our campers – a place where their seizures and epilepsy are no big deal. And that is a very big deal for our campers.

To say that the staff at EPI were excited to hold in-person camp again this summer is an understatement and pales in comparison to the happiness and excitement we saw on our campers faces at check-in. Both of our camp programs are truly a home away from home for our campers – a place where their seizures and epilepsy are no big deal. And that is a very big deal for our campers.

Camp Coast for young adults with epilepsy and IDD and Camp EAGLE for kids with epilepsy and their siblings aged 8-17 would not be possible without the support of our volunteer counselors and especially our medical staff from UR Medicine! The presence of neurologists and nurse practitioners at camp provides our parents with much needed peace of mind and allows for camp to be a true respite for family members.

EPI would also like to extend a special thank you to our donors and especially UCB, Greenweich Biosciences, and the Glover-Craik Foundation, whose gift at our 2020 Chocolate Ball funded nearly 30 scholarships!

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I have always thought that opportunity can be found in chaos. These last couple of years have provided many challenges. They have also opened the door for EPI to be a more creative and effective service provider, a better employer, a bigger part of our communities, and a more impactful human services agency.

Outdoor fun, fellowship, and camp fires!

This summer, after 18 months of social distancing and zoom calls, camp was all about catching up with old friends and making new ones. Camp rang with laughter and silly camp songs again. The dining hall was full of lovely conversations and shouts across tables to talk with other cabins.

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From the President
Jeff Sinsebox

This year presented EPI with an opportunity for reflection, planning, and the implementation of several initiatives that will lead us for several years to come. The challenges of the pandemic and difficulties caused by a labor shortage required thoughtful and creative approaches for the agency’s success. In a follow-up to our rebranding, EPI has engaged in a thorough strategic planning process. Over the past several months, agency staff and board members have worked hard on a three-year plan that charts the path for the agency while allowing enough flexibility to address our uncertain environment. Look for updated Mission, Vision, and Values statements in the near future.

A strengthened effort is underway to address our workforce challenges. We realize that a high-quality, well-trained, diverse, and mission-driven workforce is the key to assisting the people we serve to live meaningful lives. This year, we committed to the Rochester Monroe Anti-Poverty Initiative pledge and raised our minimum hourly wage to $15. In addition to raising salaries, EPI is finding new ways to recruit and retain staff by overhauling our onboarding and training processes, engaging employees, and improving communication.

We are also excited to share that construction is underway and we will be able to unite EPI’s two Rochester offices this December in a single fully renovated space on South Avenue. This change will include an update of our technology and create a more enjoyable environment for all staff.

The turbulent times have had a strong impact on the people we serve. We recognize that business as usual won’t be enough to meet the needs of those we support. Striving to meet individual needs while impacting system changes, EPI has partnered with other local organizations to address service inequities amongst marginalized populations and improve the delivery of self-directed services with the generous support of the Golisano Foundation. We are also seeking to transform and modernize epilepsy services on a national level through our relationship with the Epilepsy Alliance America. And we are working to better address the needs of aging-out school children in the central New York area.

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