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Close-knit: Seeing a need, she picked up her needles

By Gillian R. Swart/ newburyport@cnc.com

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If someone had told Anita Perkins that one day she would be the unpaid CEO of a non-profit organization - funding activities by knitting - she would not have believed it. Even now, at home on Plum Island, running payroll in her bathrobe, she sometimes still can't believe it.

The one-time reporter gave up her old life nearly two years ago to provide a better life for her autistic daughter Katie.

Katie was living in a group home, but a cut in funding meant then end of Katie's prized paper route.

Perkins knew what the job meant to her daughter and that something had to be done.

"Nothing is more energizing than the parent of a handicapped person's rage," someone from the Association for Retarded Citizens once said to Perkins. In Perkins' case, her anger led to a novel solution in January 2004.

The idea was for Katie to have her own home, a plan that required a lot more money. Esther Njugi, the manager of the group home where Katie had been living, suggested they buy a house together and set up a care program for the young woman. Perkins quickly set up the Katydid Foundation, and in early July, Katie and her friend from the group home moved into a 14-room house in Haverhill.

Today, the foundation is helping other families with adult autistic children find a place their children can call home and receive the attention they need.

State funding only covers the basics, so Perkins needed another source of funds. Into the mix came the Plum Island Knitters. Perkins was already teaching a knitting class out of her home when she left her job and decided to ramp up the knitting classes, holding them in both Newburyport and Haverhill, with a portion of students' fees going to the foundation.

"The knitting classes became the funding mechanism [for the foundation]," she says, "You could say we really knitted the two together!"

Perkins says that although services for children and adolescents with autism are becoming more plentiful, resources for adults with autism are scarce. Perkins found that once Katie turned 22, she only had two options for her daughter: Put her in a group home or bring her into the family home. The latter was not an option for the single mother, so she placed Katie in the group home although she does not think it is the best place for a person with autism.

"They have to be familiar with their own routine and see the same people," Perkins says. "They need a lot of consistency."

Katie and her friend Bobby now live on one side of the house with a live-in staff, and Njugi, who is the on-site manager of the program, and her daughter live on the other side.

"The state Department of Mental Retardation allowed us to start this [home]," Perkins says. "It took a lot of calling." She is quick to add that the agency is very supportive of the program now. Perkins also had the burden of filling out a mountain of paperwork to set up a 501(C)(3) tax-exempt public charity, which is necessary to receive state funds.

Buddy Bostick, Katie and Bobby's Department of Mental Retardation caseworker, says, "It's a wonderful success. She and everyone involved should be applauded."

Bostick says that the relationships and interactions both Katie and Bobby have experienced in their new environment have allowed them to flourish.

Perkins compares the process of setting up the house to crocheting squares on a granny quilt, joking that she didn't sleep for a year and a half. But when she goes to the house in Haverhill and finds that Katie is out, it makes it all worthwhile.

"When she was younger, it was difficult to get her to go out into the community," says Perkins.

Now 29-year-old Katie has a paper route again, runs errands and goes shopping.

"Going out is what keeps her going," says Perkins.



Tuesday evenings Anita Perkins' knitting group, Plum Island Knitters, gather in her home on the island. (Photo by Ulrika G. Gerth)

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The Autism Society of America defines autism as "a complex developmental disability that typically appears during the first three years of life and is the result of a neurological disorder that affects the normal functioning of the brain, impacting development in the areas of social interaction and communication skills."

Autism is a spectrum disorder, meaning that it affects each individual differently and in different degrees. It is the most common of the Pervasive Developmental Disorders, affecting an estimated 1 in 166 births according to the Centers for Disease Control Prevention.

ASA estimates that as many as 1.5 million Americans may have some form of autism today, and the number is rising. Although the overall incidence of autism is consistent throughout the world, it is four times more prevalent in boys than in girls, according to ASA.

Perkins says they are working with families who have set up their own houses or apartments through Katydid Foundation. Some are just getting started, others simply need information and/or support. She has a staff of eight to 12 working at the house in Haverhill, which usually includes three that live on site. Retention of staff is one of her biggest challenges, as Katie needs to see the same faces consistently.

Another big challenge is raising money. Perkins says she hopes to hire a grant writer somewhere down the line.

Her Plum Island Knitters are some of her staunchest supporters; she says many of them have been with her all along the way, and many of them donated money to help her out in the beginning.

"I can't say how much we all admire Anita," says Andrea Tymann, one of the knitters. Tymann was taking a class with Perkins when she began her big adventure. "It was very scary, but it all worked out."


The foundation also has "five incredible volunteers" on its board, Perkins says, all of whom help out in varying capacities.

"They all bring something special to the board," she says. On the board are a 70-year-old mental-health nurse, a business coach, a CPA and Perkins' other adult daughter.

"The foundation helps [families] to at least deal with problems, if not solve them," says board member Brenda Smith, Perkins' longtime friend. The board has big plans for the future of the Katydid Foundation, including hopefully receiving grants that will allow them to offer financial assistance to other families.

For more information about the Katydid Foundation, go to www.katydidfoundation.org. If you are a parent of an autistic adult or an adolescent approaching adulthood and would like to investigate how to go about setting up a house or an apartment, the Foundation's phone number is 978-465-2335.

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