

STORIES FROM HOME

Pamela is a Support Brokerage Coordinator in Pennsylvania, and the mother of Robert, a 34-year-old man with disabilities. When Robert was born, Pamela chose to raise her son in an inclusive environment as opposed to an institutional setting and became a disability advocate.

While Robert originally received only agency-based services, he began self-directing as a teenager. Pamela only became aware of self-direction after extensive research into federal regulations and waivers and her proactive outreach to state agency officials. Pamela and Robert have been educating others about the option to self-direct ever since.

● Robert has complex needs, both physical and cognitive, and requires 24/7 support. He has tried multiple service models, including day services and living in a group home, before determining self-direction was by far the best fit.

● When it became clear in 2015 that a group home was not the appropriate setting for Robert, he and Pamela began discussing **what a good life would look like for him**, and a large part of this was increased **CHOICE and CONTROL** over his services.

"They are more than just employees. They are family."

Robert now lives with Pamela and receives round-the-clock support from six workers, most of whom have been with him since he began self-directing. Robert recruited and hired his employees, determined their rate of pay, trained them, and manages them. With self-direction, Robert can be flexible with his workers' hours and accommodate their lives and schedules. He is able to create a work environment that helps maintain employees long-term.

Support brokers have been invaluable to Robert and Pamela while self-directing.

As a parent, Pamela is all too familiar with the challenges of navigating the system, noting that "you have to support the person and their family because it is not easy." Self-direction can present challenges, particularly finding and retaining staff. The assistance of qualified and knowledgeable support brokers can make all the difference for families just starting out.



With self-direction, Robert "truly lives an everyday life". He is frequently out of the house engaging with his community, without a rigid structure of needing to leave and return at a specific time. Robert is able to dictate his schedule and make adjustments when necessary. He watches the news, pays attention to social media, and can pivot if something comes up that means he can't follow the original plan.

When the COVID-19 pandemic began, Robert's life remained surprisingly consistent.

While there was some initial reorganization of staff, all six workers were able to continue supporting Robert because they were able to adjust their schedules to accommodate changes brought on by the pandemic. Robert was able to continue both his employment and his self-advocacy at Self Advocates United as One remotely. Robert and Pamela also have weekly video chats with friends in a nearby town. "We already had the technology," Pamela recalled, "we just got better at using it." There was some initial fear regarding the virus itself, but Robert's staff has been able to safely navigate the pandemic and to date no one supporting Robert has gotten sick. He has continued to be connected to his family and community, which unfortunately has not been the case for most individuals with disabilities.

During the spring of 2021, Robert and Pamela ran into the parents of a friend from Robert's childhood. This individual lives in a group home and because of the home's COVID precautions, his parents have only been able to see him twice over the past year. It has been incredibly upsetting and stressful for the family and sadly not uncommon for many individuals with disabilities and their families. While self-directing during this pandemic, Robert has the choice and control to safely see his family and friends.

When reflecting on the value of self-direction, Pamela considers both cost savings and improved quality of life.

When Robert lived in the group home, he went to the emergency room 12 times and had one serious hospital visit.

There were multiple incidents at the group home such as minor injuries, theft of personal property, neglect, medication errors, and verbal abuse.

Once he began self-directing at home, Robert went to the emergency room twice during the first six months, and hasn't been back in 4 ½ years.

With self-direction, Robert is happier, healthier, and living a life that he has full control over.

With help from his staff and through online learning opportunities, he's learned the importance of healthy eating habits so he can maintain his physical and emotional well-being. "Everyone should have the option to self-direct," Pamela reported, "When my son is happy and healthy, I am happy and healthy."