

Stories from Home

Self-Direction during the COVID-19 Pandemic

John, a 22-year-old who has epilepsy and an intellectual/developmental disability, “aged out” of his public high school in January 2020. At that time, John and his parents sought to replace the exceptional services he had received at school, including support in the event of a seizure.



The solution was a combination of self-direction and traditional programs. Mondays and Wednesdays included time at a small MassHealth-funded Day Habilitation program. Fridays provided group supported employment at a Department of Developmental Services (DDS)-funded redemption center. Tuesdays and Thursdays were engaged at 3LPlace, a program focused on life-long learning and community participation paid for through John's DDS self-directed budget. DDS self-directed funding was also used for therapeutic horsemanship lessons and some 1:1 staff support in the community. The MassHealth Adult Family Care program helped provide funding for supports in the family home. John operated his own ice cream cart called “John's Dream Ice Cream” that he used to promote epilepsy awareness and raise funds for Epilepsy Foundation New England.

In March 2020, the COVID-19 pandemic changed everything for John. All three programs that John attended during weekdays shut their physical doors. Other community activities and supports abruptly ceased. Even “John's Dream Ice Cream” was put on ice. After just getting accustomed to his new routine, it was unclear how John would continue accessing needed supports.



Fortunately, **John self-directs some of his services, which means that he has more choice and control** over how his Massachusetts DDS and MassHealth funding is utilized. This gave John the flexibility to quickly adjust to the pandemic.

One of John's programs, 3LPlace, was able to immediately and very effectively shift their dedicated staff and robust curriculum to online live delivery through Zoom. John's control over his self-directed budget allowed him to increase his time with 3LPlace from two to four days per week. This helped to fill the void left by the other programs closing. **Self-direction empowered John to re-allocate the portion of his self-directed budget that was not being used** for other purposes during the pandemic.

June of 2020 brought another change. John received a Housing Choice Voucher that provided self-directed funding for an apartment of his choice, including a second bedroom as a reasonable accommodation for a live-in aide. While this was a huge opportunity, it also created some challenges. **Self-direction came to the rescue again.** John changed from the MassHealth AFC program to MassHealth's Personal Care Attendant (PCA) program to provide self-directed funding for a live-in aide.

John was able to hire his brother as his live-in PCA. This has had many advantages. John's brother had shifted to remote college classes, so in addition to already knowing and trusting each other in general, they were also on the same-page relative to pandemic precautions. Pulling together several aspects of self-direction has provided a more appropriate and safer residential arrangement for John than an institutional setting or group home may have.



While he looks forward to returning to his in-person community programs and activities when safe to do so, **self-direction has given John the flexibility to adapt his services and supports to meet his needs**, especially during the unique challenges of the pandemic. Without self-direction, it is hard to say if or how John would still be receiving safe and impactful services, what his living situation would look like, or who would be providing the 1:1 supports he needs. While COVID-19 has caused worry and uncertainty for many, those like John who self-direct are able to receive the help they need in their own homes without sacrificing health or safety.