

THE STATE OF MAINE, OFFICE OF
AGING AND DISABILITY SERVICES
IS PROUD TO SHARE

SELF-DIRECTION IN ACTION

Maria's Story

ON A CRISP SPRING MORNING IN RURAL MAINE,

a few hardy residents brace themselves against the stiff breeze outside Maria's apartment building to soak in the abundant sunshine. It is much warmer in the lobby, where a basket of root vegetables, free for the taking, sits on the counter and residents settled in rocking chairs wave guests cheerfully toward the elevators. Perched on an island in the Kennebec River in Fairfield, this residence has the feeling of a close-knit community. Everyone knows Maria, and everyone eagerly asks why we are here to visit her.

When Maria opens the door to her cozy one-bedroom apartment, the brightness only amplifies. There are comfortable stacks of books and folded clothes piled about, colorful artwork on all the walls, and all the window blinds are pulled up to let the light pour in. Maria, a small woman with physical disabilities, moves adeptly through the tight spaces between rooms and objects with her walker to guide us into the living room that adjoins the kitchen.

This is her space, suffused with her wise and winning personality, and she is delighted to welcome guests.

With her long brown hair pulled back in a ponytail, light flashing across her glasses and in her eyes, and proudly sporting a Disability Rights Maine t-shirt, Maria radiates happiness and eagerness to share her experiences with self-direction. Her significant speech impediment



makes clear communication a challenge, but only at first. Her measured, deliberate approach to conversation quickly falls into an easy-to-understand rhythm, opening up plenty of space for honest disclosures, insight, understanding, and laughter. (Maria has a wicked sense of humor and a natural performer's instinct for comedic timing.)

Maria decided to take the plunge into self-direction after a brief period of living outside of Maine. "I kept my funding with the move but lost my agency," she explains, "and that left me without services for a year. I had heard about self-direction but was leery of being my own boss. I have a lot of mental health issues and I'm not good at setting boundaries. But the alternatives were limiting, so I called my Care Manager and asked them to find me a care coordinator."

Self-direction has a learning curve and getting the ball rolling meant stepping outside her comfort zone almost immediately. "It's very intimidating, interviewing people," she remembers. "The list of potential hires they give you—there are good people but there are some people who aren't great fits. And at first, I hired anyone who would call me back."

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more independence.”**



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It took Maria more time than she had hoped to find her ideal caregivers, in part because she needed to gain the confidence to let go of providers who were not meeting her needs. It took time for her to find her footing, take charge of the process, and advocate for herself. “I wish I had let certain people go sooner, instead of waiting for them to quit,” she reflects. “Because then I found a really good worker named Jill, and she’s been with me ever since.”

Even with her early struggles with hiring, self-direction offered immediate and tangible benefits. “It allowed me to gain more independence,” she said. “Before beginning self-direction, I had started looking at group homes because I was so depressed. I was not doing my activities of daily living and I had stepped away from activities outside of home. Jill motivates me—to get into the shower, to fold my laundry—silly stuff, but important stuff. Sometimes when I am having a really bad day it is tempting to let Jill do everything for me, but she is really good at reminding me that isn’t her job,” she adds with a laugh.

Bringing Jill on board not only made it possible for Maria to continue to live independently, it accelerated her personal growth and progress in other meaningful ways. “Jill also encourages me to participate in things outside of my house,” she explains. “I had stepped away from a local theater company I really love, the Recycled Shakespeare Company in Fairfield. Our focus is on making Shakespeare accessible to everybody, and using recycled materials in our costumes and props. Now I am right back in it, assistant directing our production of *A Comedy of Errors*, and I’m also in the play.” Sure enough, there’s a well-read copy of the play sitting right by her chair.

Self-direction also gave Maria a foundation to share her life with someone else. “I got healthy enough to ask out a guy!” she says, eyes shining. “We’ve been together for a year and a half now, and we are doing *great*.”

As Maria gained strength and resources, the self-direction program in Maine did, too. “When I started, there was no goods and services piece,” she explains, pointing out several time- or energy-saving devices in her kitchen she was able to purchase with her goods and services budget. One of the expansions she appreciates most is the addition of caregiver mileage to that budget, a key factor for remote areas in Maine where qualified caregivers are harder to find. “I love that I am now able to reimburse Jill for mileage,” she confirms. “That’s a really big thing. I loved being able to give her a raise, too, but the mileage was a big thing.”

Maria continues to optimize her self-direction experience. “I am working on checking my budget during the month and setting aside part of my budget to save for bigger purchases,” she explains.

She is also a knowledgeable advocate for self-direction in Maine. “I served on the committee that advised the State of Maine on compliance with the new HCBS settings rule, and that was fun! I know a little bit more than the average consumer,” she says with pride.

When asked how self-direction can be improved, she immediately goes back to those early days of learning how to self-direct in the moment. “Self-direction is very different than working with an agency, and having an independent support broker who is familiar with self-direction would definitely help. So would training with the waiver. If you have a client that is timid they might not ask questions.”

She also believes self-direction is well worth it and more people facing similar challenges should try it. “I have so much more confidence in my ability to be a boss,” she says. “I think I’m doing better than at any point in my life.”



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