



Maedi Tanham Carney

The Founder's Story



“Ellie was beautiful, and being born with OFDS type 1, I had a baby that was truly special. Her life roadmap and our journey did not have a manual, and as it turned out, we created one which was unique and only written for my daughter.”

My name is Maedi, and I am Ellie and Emily's mother. The birth of my oldest daughter Ellie changed the course of my life.

When Ellie was born, I was still numb from the anesthesia when the doctor stated, "There's something wrong with the baby." All I wanted to do was pull Ellie to my chest and hold her; instead, the medical team hovered over Ellie, and a nurse wheeled me out to wait in an empty hallway.

Later that day, a young geneticist named Dr. Cynthia Tift helped me begin my journey as a parent of a child with special needs. She diagnosed Ellie as having a rare neurodevelopmental disorder, Oral-Facial-Digital Syndrome Type I (OFD1). Ellie is intellectually disabled. She was born with a cleft palate and a bifid tongue, and abnormal fingers and toes. She received two kidney transplants as a teenager and faces innumerable health challenges.

As Ellie grew up, I dedicated myself to her success by finding early interventions, therapies, and educational programs that believed in Ellie's abilities to learn. Along the way, Ellie had the necessary supports to succeed.

I loved being a mother and wanted another child. When my second daughter Emily entered the world 23 months after Ellie, the first thing I did was inspect

her fingers. Unlike Ellie's, they were long and straight like a spider's legs. She was perfectly healthy. Three weeks after Emily was born, my then-husband decided he did not want this life and left us.

While being a single mother of two children was challenging, Ellie, Emily and I became a content family of three. We lived in Washington, DC and loved walking our dogs along the river, hiking, playing sports, making friends, and spending time with loving aunts, uncles and cousins.

As the girls grew up, I grew keenly aware of my own mortality, especially having lost both my parents at an early age. I was afraid, but not alone in that fear; when my friends and I who had children with disabilities got together, we asked one another what would happen to our kids when we died.



In 2009, I launched “M&L Special Needs Planning,” with the M representing “Emily” and the L representing “Ellie.” I harnessed my certified financial planner (CFP®) background and the years of financial experience I gained while managing Ellie’s life to share those lessons with other parents whose children have special needs. I held workshops on special needs planning and invited speakers. I taught every aspect of special needs financial planning, estate planning, government benefits, transition planning and how to plan for a child’s life from day-one all the way past the parents’ inevitable deaths.

While Ellie was at her post-secondary school in Massachusetts, I began to research independent living programs for adults with special needs. In DC, I found nothing but sub-par group homes. I realized the definitions of “independent living” and qualities of service were radically inconsistent.

I wanted to know my options, and I knew that families like mine needed to know, too. I hired a graduate student from American University to research independent living programs nationwide and tailor the findings to speak to the concerns and struggles of families like ours. The study provided a treasure-trove of information.

One of the gems we found was the Center for Independent Futures® (CIF®) in Evanston, IL. CIF was “building communities” for adults with disabilities and I was fascinated by the concept. I interviewed Jane Doyle, the founder of CIF®, and she told me how they ran their programs without state funding. She told me about employing life coaches, community builders and supports, and how to help adults with special needs build peer-to-peer relationships.

The concept of independent living and building communities energized me. In October 2013, I invited CIF®’s Jane Doyle and Ann Sickon to educate interested families on building community using the “Full Life Model™.” Sixty people showed up that Saturday morning. Everyone was intrigued by what CIF® offered. I asked whether any families wanted to fly to CIF® in Evanston, IL to take the training. Several families answered with a resounding “Yes!”

In February 2014, those families and I traveled to Evanston, IL to complete two days of CIF®’s four-day training. We were amazed when we visited one of CIF®’s three-story brownstones populated by adults with special needs who lived independently. We were determined to make this a reality for our own young adults. My excitement swept up the founding families and we began meeting monthly to study CIF®’s training manual. We developed the concept of community “pods” based on geographic location and decided to have 6–12 young people with disabilities, whom we called self-advocates, in one community pod. In May 2014, the facilitators of the CIF® training came to DC to complete the last two days of their four-day training. They recommended that I establish a nonprofit to make this training sustainable. Integrated Living Opportunities (ILO) was born!

Jane Doyle, CIF’s founder, said to me, “You’re going to be busier than you’ve ever been in your life.” And she was right. For the first five years, I did not take a salary from ILO. I spoke to over 1,000 families as a guest speaker and presenter, a panelist, and an advisor to families and medical professionals. I networked with partner organizations, reached out to commercial real estate developers, and did everything I could to serve as a helpful, knowledgeable resource for ILO staff and participating families. Building ILO consumed me.

ILO would not be what it is without the dedication of the founding families: Debbie Fickenscher and her daughter Elaine, Janie and Glenn Griffin and their son¹, the Katz and Goodman family², Brian and Carole Somers and their daughter Clare; and Andrea Kline and Harvey Kabaker, and their son Ben Kabaker. The founding families passionately believed in ILO’s mission and the vision for their young adults with disabilities. For years, they would come to my home each month to discuss how to implement, improve, and grow ILO. These families understood that if we came together, we could create new opportunities for our loved ones to live independently.

When Debbie Fickenscher joined ILO in 2014, she was a 69-year-old single parent of Elaine, who had been born with Down syndrome. Debbie feared for her daughter’s long-term care. She knew Elaine wanted to live life on her own, but Debbie felt stuck

¹ We are not naming every adult child in this document, only those whose names are authorized by their parents.

² This family no longer participates with ILO.

about how to make it happen. Debbie understood that finding a place for Elaine meant finding the right community. After nine months in ILO, Debbie felt confident to transition Elaine into independent living, where she has been living successfully for 9 years. Debbie was a member of ILO's Board for several years, administered the Skills Inventory and trained five others to give the inventory. Debbie is now 78 and has peace of mind about Elaine's future.

Janie and Glenn Griffin and their son came to ILO to create the community for him that they had not found anywhere else. Their son worked with ILO community supports to help adjust to living on his own and to build meaningful relationships with people outside of his family. Janie Griffin was integral to organizing the documentation we needed to move her son and three other ILO self-advocates into our very first pod in Gaithersburg, MD. Their son has happily been living independently since 2016.

Carole and Brian Somers and their daughter Clare joined ILO because they wanted to be part of a progressive community of parents to share issues, concerns, and wins regarding life cycle issues and care of young adults with special needs. Clare and the other young adults benefited from the peer groups that ILO staff created to share social activities and friendships.

Andrea Kline and Harvey Kabaker's son Ben is an adult with autism and severe anxiety. As Andrea and Harvey grew older, they worried about Ben being able to live independently and to support himself with work. The family joined ILO in 2014 when Andrea was 60, Harvey was 71, and Ben was 28. After several years in ILO, Ben moved into the Gaithersburg, MD pod. Ben lives on his own and works from home as a full-time medical coder (many thanks to Phil Lartigue from The ARC of DC for helping Ben find employment).

Amazing individuals stepped up to help when I had no idea where to start. In the earliest days, my

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friend Tina Campanella, past ED of Quality Trust for Individuals with Disabilities, came over with a bottle of wine and said, "Tonight we're building a business plan." And we did. Doug Baldrige, the father of my daughter Emily's friend and a prominent lawyer at Venable in Washington, DC, engaged the pro-bono wing of the firm to secure our non-profit status and develop policies and by-laws.

ILO became even stronger when we created our board of participating family members and friends that helped steer us in the right direction. For years, our board met at my house for dinner. I am immensely grateful to Matt Hoffman who worked at Enterprise Community Partners in the affordable housing space and joined ILO's board from the very beginning. Matt stayed on the board for five years to help form ILO into what it is today.

Our fundraising grew organically as participating families cycled and volunteered their way into fundraising with successful "Hike, Bike, & Barbecue," "Bike to the Beach," and "ILO Family 50" events.

As ILO grew, I had trouble managing ILO by myself. Jan Brown joined ILO in 2019 as the Director of Member Services. Jan decisively and patiently helped me delegate responsibilities to her and others. I am intensely grateful for Jan and the way she made ILO more effective. Maria Morel joined the team in 2020 as an administrative assistant, and she made us endlessly more efficient.

ILO's community builders are crucial to helping our self-advocates create peer-to-peer relationships, teamwork and real friendships. When Sherita Mason began as ILO's first community builder in 2016, she mandated Wednesday night meetings with her pod of young men. For months, the young men would not socialize or connect. Sherita persisted. She modeled behavior, respected each self-advocate's individuality, openly talked about issues, planned engaging events, and fostered a safe space. Then, something clicked. I remember calling Sherita to check in on the pod. She sounded

ILO TODAY

As of March 2023, ILO comprises five pods: Washington, DC; Bethesda, MD; Rockville, MD; Germantown, MD; and Gaithersburg, MD.

Soon, we expect ILO will expand into a new Washington, DC location called City Ridge. I began planting the seeds for this opportunity in 2019. Four years later, the developer told me they want to dedicate affordable units to ILO self-advocates.

ILO serves 37 families, and 33 self-advocates live independently. ILO serves an additional 62 families annually through the ILO Community Group of families that are considering joining ILO.

exhausted as she explained that she had stayed up until 1:00 am playing video games with the guys, and that they were now best friends! Sherita made such an impact that she is now our Director of Programming and coaches our growing team to positively impact our self-advocates' lives.

Our life coaches and administrators of the Full-Life Process™ Skills Inventory make it possible for ILO to address each self-advocate's individual needs and desires and improve their life skills. One of our life coaches taught two roommates, Jack and Griffin, to improve the way they clean their apartment and maintain their laundry schedule. One Friday night when I was visiting Ellie in the building, I saw Jack carrying his laundry basket in the building's hallway. I asked him how he was, and Jack declared, "I'm doing my laundry on a Friday night. This is what independence looks like!"

There is one more ILO program that is integral to my vision for ILO: long-term facilitation (LTF). ILO launched the long-term facilitation (LTF) program in 2022. LTF is the advocacy piece for the self-advocate when the parents have passed on or are still alive but no longer capable of managing the care of their loved one. Through the LTF program, families are entrusting their self-advocates to ILO and partners so that the self-advocates can continue to live independently with the supports, and live a full life integrated in the community.

My daughter Ellie has been living independently since 2017. While this sounds wonderful given the obstacles we faced initially, it is important to know that the entire first year Ellie was homesick and begged me to let her come home. But during that time, Ellie grew into an independent young woman. Ellie learned to navigate the DC-area subway and bus system, volunteers at a dog daycare company, and takes pride in her Special Olympics bowling

and swimming medals. Ellie loves taking her chocolate Labrador Olive on walks and Olive loves sunbathing on Ellie's terrace.



A day came when Ellie visited me at our family home, glanced at her watch and said, "Mom, it's time for me to go home." Go home. To her own home. Ellie is living her own life, and so am I.

At first, my reason for building ILO was to help Ellie and to ease my fears. When I began working with our founding families, my reason grew larger to encompass them. The love that our community generated for one another buoyed us all. As new families join the ILO community, I am eager for parents and their children to dream their personal dreams, without feeling selfish or fearful, and be filled with hope for the future.

As I step back and assess what ILO has accomplished, I need not look any further than the ILO self-advocates around me laughing, having serious discussions about current events, grocery shopping together, going to ball games together, and most importantly, reaching out and helping one another. I am no longer afraid for their futures. They are prepared with the life skills they need, they have the support they need, and they are thriving.

ILO - Building Supportive Communities Helping Young Adults with Disabilities Transition to Independent Living

