

**Independence**

**For**

**Adults**

With Developmental Disabilities

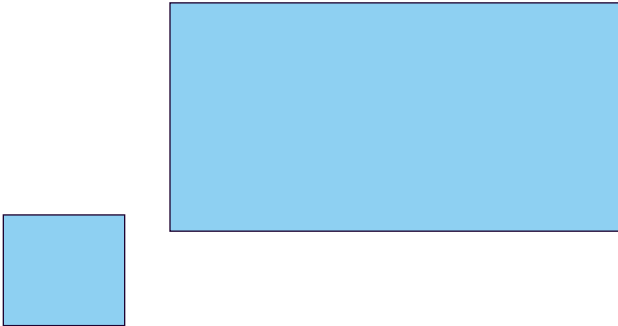


## Introduction

According to the 2010 Census, roughly 1.2 million adults in the United States (0.5 percent) had an intellectual disability, and 944,000 (0.4 percent) had other developmental disabilities.<sup>1</sup> Many adults with developmental disabilities rely on Medicaid Home and Community Based Services (HCBS) waivers to remain living independently in the community. Some of these adults live with their parents or other relatives and rely heavily on their caregivers for support. Others live in group homes or their own apartments, with or without a roommate. Some of these adults have previously lived in Intermediate Care Facilities (ICFs) and have moved into community living, while others have never lived in an ICF and do not want to do so.

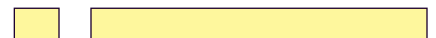
There are three Medicaid HCBS waiver programs administered by the Ohio Department of Developmental Disabilities (DODD): Level One, Self Empowered Life Funding (SELF), and Individual Options (IO). The Level One waiver is the lowest level of funding, and the IO waiver is the highest level of funding. Many individuals with developmental disabilities would like to live independently in the community, like a person with no disability. Parents and guardians of individuals with developmental disabilities also desire independence for their loved ones to ensure that they can lead full and productive lives, particularly after their caretakers' passing. For some adults, the Level One waiver is enough to meet their needs. Still, others may require more intensive supports and services to live independently, and therefore, more funding.





## Adults with Severe Needs

There is a wide range of skills, abilities, needs, and challenges among adults with developmental disabilities. Some adults have such severe needs that a Level One waiver cannot meet those needs. These adults require many services and supports to remain in the community and avoid institutionalization. Services can range from case management, home health aide services, adult day programs, respite care, transportation, and homemaker and personal care (HPC) services, which support an individual in developing skills and assistance in the home and community. Although family members may provide “natural supports,” or unpaid assistance, these supports must be voluntary to help their family member with their daily needs. According to DODD, “when family members express the need for additional supports in order for them to continue providing natural supports, a frank and specific conversation should take place to discuss and plan what care they will provide and what additional support/waiver service is required to maintain the family unit.”<sup>2</sup> In some cases, like the example below, a family member is willing to provide extensive support, but cannot do so without compensation because they cannot work outside the home and care for their loved one.



## Coco's Story

Coco and her aunt, Bianca, moved to Ohio from a western state. Coco is 30 years old and has been living with her aunt, who is also her legal guardian, for most of her life. Coco has been diagnosed with Cerebral Palsy, Autism Spectrum Disorder, Obsessive Compulsive Disorder, Pica, Developmental Delay, and a severe intellectual disability. Coco is non-verbal and can become very upset when she cannot communicate her needs. Coco can walk on her own, but she relies on Bianca to bathe her, dress her, and change her diapers. Coco requires 24-hour care due to her disabilities.



Coco cannot be left alone because she poses a risk to herself and others. Coco's behaviors include harming herself and others, picking at her skin, running away, and eating inedible or dangerous items. Coco also has insomnia and only sleeps two hours a night.

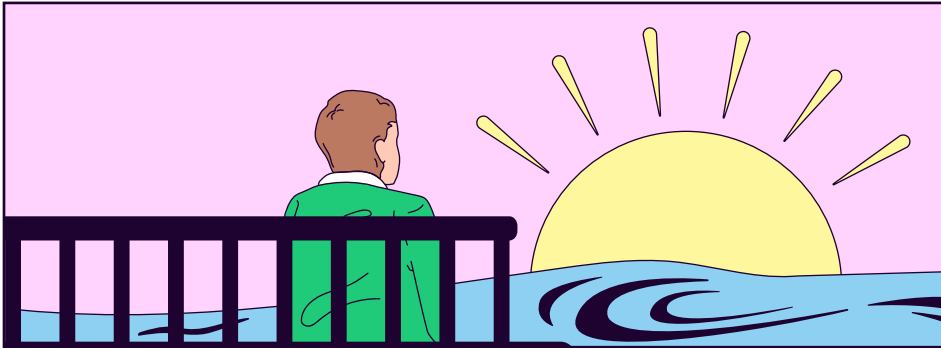
Bianca is not only Coco's sole caregiver; she is also the legal guardian to four nieces and nephews, ages 7-16, who also live in her home. Due to Coco's intensive needs, Bianca is unable to work outside the home. Bianca's adult son will sometimes watch Coco for short periods so that Bianca can sleep or run errands. Still, overall, Bianca has little support in caring for Coco.

When Coco moved to Ohio, her County Board of Developmental Disabilities evaluated her and found her eligible for their services. The County Board also chose to place her on a Level One waiver, the lowest level of funding and support of the three waiver programs. Coco began using her waiver to pay for an adult day program, which provided Bianca some relief. However, Bianca felt that she was the best person to provide most of Coco's care. Bianca became a certified independent provider for homemaker and personal care (HPC) services, which allowed her to receive some compensation for the extensive care she provides to Coco. This allowed Bianca to remain at home and care for Coco, rather than needing to find an outside job and hire a skilled service provider, which would likely cost more than she could make working outside the home. Because of Coco's extensive needs, funding for her Level One waiver ran out six months into her waiver span. Coco was then granted some temporary emergency funding.

When they first moved to Ohio, Bianca told the County Board that she did not think the Level One waiver would be enough to meet Coco's needs. Bianca asked the County Board to conduct a Waiting List Assessment to assess whether Coco had unmet needs and could be placed on a higher-level waiver. The County Board found that Coco had current unmet needs (needs that would not be met within 12 months) and placed her on the waiting list. However, Bianca strongly felt that Coco had immediate needs (needs that would not be met within 30 days), and appealed the decision through her ABLE attorneys. At the hearing, Bianca and her attorneys argued that Coco posed a substantial risk of harm to others by showing incident reports from the day program where staff were unable to de-escalate Coco's behaviors, resulting in her hitting other attendees in the face. Bianca and her attorneys also argued that Coco posed a substantial risk of harm to herself, due to self-injury and eating inedible items. The hearing officer found that Coco had an immediate need and ordered the Board to put Coco on a higher-level waiver. The County Board then put Coco on an Individual Options (IO) Waiver.

Under the IO Waiver, Bianca could be compensated for more of her time caring for Coco through a service called shared living. As a shared living participant, Bianca gets paid a daily rate for her assistance on days when Coco does not use other services like respite, adult day programs, or homemaker and personal care services.

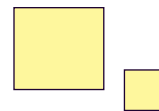


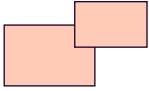


## Adults Who Wish to Increase their Independence

Some adults with developmental disabilities are highly skilled and adept at living in the community but need support to increase their independence. For example, a person may be currently living with family members but desire to live in a group home or an apartment with a roommate. Also, a person may now be in an ideal living situation but desire to work part-time or full-time in the community. For people with developmental disabilities, changes in their daily routines can be challenging and adjustments require time and support.

According to DODD, “increasing a person’s independence and community participation are appropriate goals.”<sup>3</sup> Further, “when confronted with appropriate desired changes, such as a family wanting a person to move into his or her own apartment, the assessor should discuss the feasibility of the desired change happening within the next 12 months.”<sup>4</sup> Yet, people with disabilities often face rejection when they apply for assistance in increasing their independence and community participation. Cassidy’s story is just one example.





## Cassidy's Story

Cassidy is a friendly and highly ambitious woman in her 20's. Cassidy has Autism Spectrum Disorder, a vision impairment, and Post Traumatic Stress Disorder. She splits her time living with her mother, Sandra and her father, Julian. Cassidy works as a classroom assistant at a specialized school for children with Autism Spectrum Disorder. She also books speaking engagements all over the country as an advocate for disability rights. Cassidy was receiving a Level One waiver, the lowest level of funding and support of the three developmental disability waiver programs. Cassidy came to ABLE after going through the new Waiting List Assessment (WLA) process and being denied placement on the Waiting List for a higher-level waiver. Cassidy, through her ABLE attorneys, appealed the WLA decision.

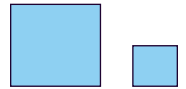
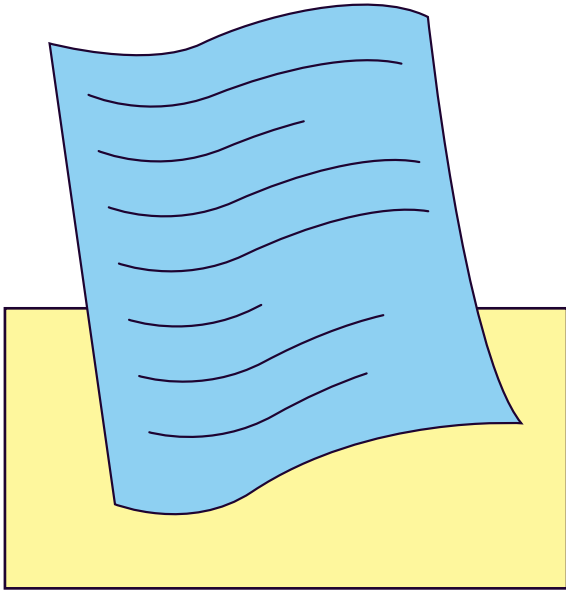
Cassidy and her parents told the County Board about her desire to live more independently, to live in her own apartment with roommates or alone eventually, and to rely less on her parents and friends for support. Sandra discussed how she was exhausted from the emotional support she provides Cassidy daily. She was spending more and more time caring for her elderly mother, and she had a financial need to find work but could not do so while spending so much time caring for Cassidy. Julian explained that he was spending over \$1000 out of pocket a month on expenses related to Cassidy's therapies, social activities, transportation, private caregivers, and other needs and could no longer afford it. Julian explained that he needs to also devote attention to his other children and an aging mother-in-law that he cares for while also working full-time. Cassidy spoke about her desire to start her own business but needed career planning support.

The County Board argued that alternative community-based resources could meet Cassidy's needs. Yet those resources were either not available to Cassidy because she did not qualify or were resources she had already tried in the past with no success. Cassidy and her attorneys spent over a year and a half in an extensive appeals process, including appealing to the common pleas court and obtaining new Waiting List Assessments (WLA).

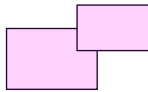
After 20 months, Cassidy, her family, psychiatrist, and attorneys participated in a fifth WLA. At this time, the COVID-19 pandemic had changed everything for Cassidy and her family. Cassidy was going without needed services and was also no longer able to work, attend in-person medical appointments, or socialize in the community. Cassidy was finally determined to have a current need (an unmet need for home and community-based services within 12 months) and was placed on the waiver waiting list for her county. Cassidy was finally granted a SELF waiver in October 2020.

Many people do not have access to legal help to engage in multiple appeals to finally obtain the services they need to remain or increase independence and live in their communities. There are policy solutions that would greatly improve access to much needed services and economic stability.





**Recommendations – These policy changes and funding mechanisms would provide immediate solutions to the issues discussed in this brief.**



1. Technical assistance and financial grants through federal agencies to encourage states to implement technology solutions in long-term services and supports, such as remote monitoring, sensors, robotics, and smart homes, to create efficiencies, reduce costs, reduce injuries, and support community living for people with intellectual disabilities.<sup>5</sup>
2. The Ohio Department of Developmental Disabilities could deliver immediate relief with these policy changes:
  - Allow parents or family members to act as paid providers in all waiver programs.
  - Allow Homemaker and Personal Care services to be conducted virtually to help address the shortage of providers, especially in rural areas.<sup>6</sup>
  - Allow more than one household member to serve as a paid provider under the IO waiver’s shared living service to help reduce the need for outside providers.
3. Allow for additional hours of HPC services to allow people with developmental disabilities to develop independent living skills.



## Citations

<sup>1</sup> <https://www.census.gov/prod/2012pubs/p70-131.pdf>

<sup>2</sup> <https://dodd.ohio.gov/wps/portal/gov/dodd/about-us/communication/Memos/memo-waiting-list-guidance>

<sup>3</sup> <https://dodd.ohio.gov/wps/portal/gov/dodd/about-us/communication/Memos/memo-waiting-list-guidance>

<sup>4</sup> Id.

<sup>5</sup> Id.

<sup>6</sup> Homemaker and personal care services (HPC) help a person to become more independent while meeting their daily living needs. HPC services can include assistance with household chores and personal care, money management, and any other kind of support that improves a person's ability to express their opinions and choices. While some HPC services would be difficult to provide virtually, other services could be provided remotely. For example, you can teach someone to balance a checkbook or fold laundry virtually. Where possible and appropriate, an individual should be able to request that HPC services be delivered remotely.





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