

Unique Issues for Caretakers of Minors with Developmental Disabilities

Introduction

Developmental disabilities are a group of impairments in physical, language, learning, or behavior areas that begin anytime before age 22 and usually last throughout a person's lifetime. Developmental disabilities and intellectual disabilities often occur together. Intellectual disabilities are a group of impairments that begin before age 18 that significantly limit a person's ability to learn at an expected level and function in daily life. People with developmental and intellectual disabilities may struggle with major life activities such as language, mobility, learning, self-help, and independent living skills.

Developmental and intellectual disabilities affect people of all ages. The Department of Health and Human Services (HHS) estimates that about one in seven children (14 percent) between the ages of 3 and 17 have developmental disabilities.¹ Further, HHS estimates that the rate of autism spectrum disorder (ASD), a group of developmental disabilities often characterized by impairments in communication, has increased to about one in 68 children, and ASD commonly co-occurs with other developmental diagnoses.² The prevalence of severe cognitive impairments is estimated to be between 3 to 5 per 1,000 children.³ Additionally, the prevalence of developmental disabilities is on the rise. According to the Centers for Disease Control (CDC), between 1997 and 2008 the prevalence of ASD increased by 289.5 percent.⁴ During the same period, the prevalence of Attention Deficit Hyperactivity Disorder (ADHD) increased by 33 percent.⁵

Caring for children with developmental and intellectual disabilities has unique challenges. Children with developmental disabilities differ from their peers who do not have disabilities. Children with developmental disabilities may be delayed in reaching development milestones, such as talking, crawling, walking, toileting, and reading, or they may not reach these milestones at all. It can be difficult to find childcare for children with developmental and intellectual disabilities because they may have severe behavioral or medical needs. Further, some children with developmental or intellectual disabilities require around-the-clock care and cannot be left alone for even a brief amount of time.

¹ <https://www.hhs.gov/ash/oah/adolescent-development/physical-health-and-nutrition/chronic-conditions-and-disabilities/trends.html>

² *Id.*

³ <https://www.ncbi.nlm.nih.gov/books/NBK223473/#:~:text=In%20developed%20countries%2C%20the%20prevalence,to%205%20per%201%2C000%20children.>

⁴ <https://www.cdc.gov/ncbddd/developmentaldisabilities/features/birthdefects-dd-keyfindings.html>

⁵ *Id.*

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The Medicaid Home and Community Based Services (HCBS) waiver program can be crucial to safety and well-being for families of children with developmental disabilities. Medicaid HCBS waivers provide supports, services, and health coverage to people with disabilities. The HCBS waiver program is intended to keep people with disabilities living in the community instead of in an institution. Children with developmental disabilities and their families can access essential services such as respite care, homemaker and personal care or nursing services, home modifications, and other supports and services, without which they may not be able to remain in their home.

Why Are Adults More Likely to Receive Waivers?

All County Boards of Developmental Disabilities enroll more adults (18+ years-old) on waivers than children. This is to be expected for several reasons. First, parents and guardians have a legal obligation to care for minor children or to provide “natural supports.” They do not generally have an obligation to care for adult children, although they may do so voluntarily. This means that it is reasonable for a County Board to expect a family to provide more natural supports to a minor child than an adult.

Second, children and young adults have access to some supports and funding sources that older adults do not. For example, Medicaid-eligible children and adults under age 21 are eligible for Early and Periodic Screening, Diagnostic and Treatment (EPSDT). In Ohio, this program is also called Healthchek. Under Healthchek/EPSDT, children and adults under age 21 can receive any services, testing, or equipment that is considered “medically necessary” by a Medicaid provider.

However, some things require “prior authorization” to be approved. Under EPSDT, minor children can get more of a service or treatment than would be provided to an adult, or they may be able to receive services that are never available to an adult. Additionally, children and adults under age 22 may receive substantial supports and services through their public school under the Individuals with Disabilities Education Act (IDEA). They may therefore need fewer community services than someone who is out of school.

However, some minor children with developmental disabilities need a Medicaid waiver to remain in the community and not in a long-term care facility. For example, some children will not be eligible for Medicaid or EPSDT due to their family’s income unless they receive a Medicaid waiver. Access to Medicaid alone is not a reason to enroll a child in a waiver.

However, if a child has a demonstrated need for aide or nursing services in the home, and is not otherwise eligible for Medicaid, it is possible the child will require a waiver in order to receive those aide or nursing services.

Underserving Children

While it is expected that more adults than children will need waivers, it is not reasonable to conclude that no children will require a waiver. Again, 1 in 7 children has a developmental disability. Children make up the majority of the individuals served by County Boards of

Developmental Disabilities (DD). According to the Center for Community Solutions, children ages 0 to 21 represented 52 percent of those receiving services, and 21 percent of individuals served were under the age of 6 as of 2012.⁶ In some counties, like Shelby county, children make up nearly 70 percent of the people served by the County Board of DD.⁷ Yet, in that same county, only nine children receive waivers.⁸ Based on Shelby County’s population, we can estimate that the county has 1755 children with developmental disabilities. However, only .073 percent of Shelby County’s children receive waivers.⁹

Further, there are no children receiving waivers in Defiance, Meigs, and Wyandot counties, and only one child in Monroe county.¹⁰ These numbers likely indicate that children in many counties are underserved. Because of Ohio’s limited waiver capacity and use of the waiting list, some counties may be prioritizing adults over children in making difficult decisions about resource allocation.

Emily’s story

Emily lives with her parents, Cori and Mark, in a rural county in Ohio. At age 14, Emily is a bright and capable teenager. Still, she copes daily with sensory processing issues, communication problems, difficulty feeding herself caused by autism disorder, and general anxiety. Emily was on the waiting list for a Medicaid waiver for nine years. During that time, Cori and Mark sought alternative community-based services and other funding sources to try to meet Emily’s needs. The family applied for funding through the Multi-System Youth (MSY) program, a temporary funding source. The family had to reapply every three months, leaving Emily without respite care and therapy several times yearly. In the family’s small rural county, no children were receiving Medicaid waiver services. Despite Emily’s very severe situation, the county continued to determine that Emily did not have immediate needs and repeatedly denied her waiver services. The family waited nine years for waiver services for Emily. Feeling frustrated by the process and desperate for assistance, Cori and Mark contacted ABLE. ABLE advocated on their behalf with the County Board of Developmental Disabilities, and Emily was finally approved for a SELF waiver within four months. Emily’s story is not atypical based on 2020 numbers in Ohio’s counties.

Chart A: Numbers of Individuals Receiving Waivers by County as of August 7, 2020¹¹

County	Children	Adults	Total
Adams	6	73	79

⁶ https://www.communitysolutions.com/wp-content/uploads/2018/04/MajorReport_DD-System_032015_Frech_Honeck_Warren.pdf at 12

⁷ *Id.*

⁸ See Chart A

⁹ As of 2017, estimated population of Shelby County children was 12,291. See: <https://www.childrensdefense.org/wp-content/uploads/sites/6/2018/12/Shelby.pdf>. 1/7 of 12,291 is approximately 1755. 9/12,291 is approximately .00007.

¹⁰ See Chart A

¹¹ Data obtained via Public Records Request to the Ohio Department of Developmental Disabilities



Allen	16	402	418
Ashland	8	147	155
Ashtabula	7	248	255
Athens	5	200	205
Auglaize	6	144	150
Belmont	10	183	193
Brown	8	146	154
Butler	43	1027	1070
Carroll	4	120	124
Champaign	30	113	143
Clark	12	451	463
Clermont	37	443	480
Clinton	13	124	137
Columbiana	8	344	352
Coshocton	54	156	210
Crawford	3	115	118
Cuyahoga	121	4562	4683
Darke	9	164	173
Defiance	0	98	98
Delaware	393	516	909
Erie	5	177	182
Fairfield	43	458	501
Fayette	13	84	97
Franklin	811	4811	5622
Fulton	1	120	121
Gallia	11	92	103
Geauga	7	282	289
Greene	43	339	382
Guernsey	30	117	147
Hamilton	206	2716	2922
Hancock	24	265	289
Hardin	7	70	77
Harrison	3	31	34
Henry	2	129	131
Highland	9	125	134
Hocking	5	105	110
Holmes	9	80	89
Huron	4	155	159
Jackson	8	99	107
Jefferson	10	165	175
Knox	29	262	291
Lake	33	656	689
Lawrence	10	222	232
Licking	49	540	589

Logan	14	133	147
Lorain	21	601	622
Lucas	73	1763	1836
Madison	6	136	142
Mahoning	41	872	913
Marion	9	178	187
Medina	39	474	513
Meigs	0	51	51
Mercer	6	153	159
Miami	23	375	398
Monroe	1	46	47
Montgomery	62	1451	1513
Morgan	3	48	51
Morrow	11	74	85
Muskingum	22	186	208
Noble	7	23	30
Ottawa	1	142	143
Paulding	4	52	56
Perry	10	137	147
Pickaway	44	132	176
Pike	9	119	128
Portage	24	435	459
Preble	1	138	139
Putnam	8	100	108
Richland	11	510	521
Ross	54	294	348
Sandusky	7	239	246
Scioto	8	265	273
Seneca	10	110	120
Shelby	9	155	164
Stark	70	1677	1747
Summit	70	2170	2240
Trumbull	24	554	578
Tuscarawas	10	272	282
Union	49	199	248
Van Wert	4	114	118
Vinton	7	62	69
Warren	113	604	717
Washington	10	173	183
Wayne	15	347	362
Williams	2	77	79
Wood	46	440	486
Wyandot	0	60	60

Natural Supports for Minors vs. Extraordinary Care

Natural supports means help and care that someone gets from their friends, family, or community for free. Parents and guardians do have a legal obligation to care for their children. However, caring for a child with developmental disabilities can be a lot more intensive than caring for a child without a developmental disability of the same age.

According to Ohio Department of Developmental Disabilities (DODD) guidance issued in September of 2019¹², “the determination of where the parental obligations for minor children end and where needs created because of a person’s disability begin is challenging and should be determined case by case.” The Waiting List Assessment is supposed to take into account family dynamics and the child’s specific needs. DODD guidance further states, “waiver services should support parents’ efforts to care for their children, not relieve them of their reasonable responsibilities.” DODD’s guidance states that natural supports should be determined on a case by case basis, but does not include a standard definition or guidance when families should receive additional support through waivers or community-based alternative services.

One solution would be to use the Centers for Medicare and Medicaid Services’ (CMS) definition of “extraordinary care.” “Extraordinary care” is “care exceeding the range of activities that a [parent or other] legally responsible individual would ordinarily perform in the household on behalf of a person without a disability or chronic illness of the same age, and which are necessary to assure the health and welfare of the [child] and avoid institutionalization.”¹³ This standard is meant to compare the needs of a child with developmental disabilities to the needs of a child who is the same age but does not have disabilities. “Extraordinary care” would be outside the bounds of expectation for parents of children with developmental disabilities.

When determining eligibility for waiver services or other community-based alternative services, there should be an evaluation of the parent’s ability and readiness to provide care and support to the child. Some parents are expected to provide natural supports that are not reasonable given their situation. As DODD guidance states, these decisions must be made on a case by case basis. Some factors that should be considered are: the caregiver(s) physical and/or mental health and impairments; whether the caregiver is the only caregiver of the child; whether the caregiver(s) is/are employed and their schedule; whether there are other children in the home and what their needs are; and whether the caregiver(s) has/have the knowledge and training to perform certain tasks, such as medical care.

Kenan’s story

Ruby and Walter have two sons, a 13-year-old and an 11-year-old. Kenan requires 24-hour care due to the severity of his disabilities.

¹² <https://dodd.ohio.gov/wps/portal/gov/dodd/about-us/communication/Memos/memo-waiting-list-guidance>

¹³ 1915(C) TECHNICAL GUIDE, supra note 8, at 119

As an inquisitive boy, Kenan has issues with elopement, a behavior where he runs away from his caretakers without care for his safety. Kenan is nonverbal and can get very upset when he cannot express his needs and wants. Kenan has behavioral issues when he is stressed or upset such as throwing items, hitting others, and screaming. Kenan receives both occupational therapy and speech therapy at school and from a community provider.

A typical 11-year-old could be expected to stop and look both ways before crossing the street. Kenan, however, has no regard for his safety and will run into traffic. He cannot be left unsupervised for any amount of time, and his caregivers must be careful about locking doors.

This is an example of “extraordinary care” because a parent of an 11-year-old child without disabilities would not be expected to provide the same supervision level or physical care.

Preston’s story

Ellen is a single mother caring for two young children in a rural part of the state. Preston, Ellen’s older child, is nine years old and requires substantial, 24-hour care because of his physical and developmental impairments, which include cerebral palsy and a developmental delay. Ellen also cares for her 7-year-old daughter.

Ellen has significant knee problems that have required multiple surgeries. She may need a total knee replacement in the future. Ellen’s knee problems make it extremely difficult and unsafe for her to physically carry Preston up and down the stairs in her home or lift him in and out of a bathtub. Ellen came to ABLE because she was struggling with caring for Preston.

Ellen asked her County Board of DD for home modifications such as a wheelchair ramp to get Preston in the front door and bathroom modifications to her first-floor bath that would make it accessible for Preston and allow Ellen not to carry him upstairs for bathing. The County Board of DD initially denied her request.

A 7-year-old without disabilities could typically climb the stairs, get in and out of a tub, and bathe himself without much assistance from his parent. Preston’s case is an example of “extraordinary care” because his parent is expected to provide care that would not be required of a 7-year-old without disabilities. Further, Ellen’s physical impairment should be considered when determining what natural supports she can provide to Preston.

Alternative Community-Based Services

Alternative community-based services means the various programs, funding mechanisms, services, and supports, other than HCBS waiver services, that exist as part of the developmental disability service system and other service systems. For example, community-based services can include Medicaid State Plan services for those who are already eligible for Medicaid, services

and supports that the County Board of DD offers to all people it serves, services through the local school district for children, and services available through an intermediate care facility (ICF).

If potential alternative community-based services are identified and recommended in the Waiting List Assessment as options to meet a person's immediate or current needs, the county board should follow up to verify the resources are (1) actually available to the person and (2) successfully meeting the person's needs.¹⁴

If a county board identifies that nursing or aide services may be available through the Medicaid State Plan, they must consider whether the person will actually qualify for those services and whether those services will be enough to meet the person's needs, before denying waiver services. Another issue may be if supports and services are only available on a short-term basis. For example, if someone will receive funding for services through a grant, but the grant is time-limited, it likely cannot meet the person's long-term needs. Unfortunately, advocates see too many examples of people who are rejected based on alternative community-based services that are not available to the person requesting the waiver, not offering meaningful assistance to the person, or providing temporary assistance that does not meet the person's needs.

Emily's story

Cori and Mark received MSY funds to pay for Emily's occupational therapy, which was not covered under their employer-based insurance. MSY funds also paid for sensory equipment, home modifications, and for a portion of a trained service dog's cost. Emily needs consistent occupational therapy sessions to make progress on her feeding plan and other sensory issues. She is at risk of being institutionalized if she does not receive these services. Emily has been hospitalized in the past due to her inability to eat independently without therapeutic services.

Because Emily must frequently reapply for MSY funding, she can only be guaranteed services for three months at a time. This has led to periods where Emily gets no occupational therapy services and shows serious regression on her goals.

Because it is not a consistent funding source, the MSY program is an example of an alternative community-based service that does not meet Emily's needs. Emily has recently been approved for a SELF waiver. Once Emily is enrolled in the waiver, she will also receive full Medicaid benefits. This will allow her to access occupational therapy, physical therapy, and psychological care from any provider who accepts Medicaid insurance.

¹⁴ <https://dodd.ohio.gov/wps/portal/gov/dodd/about-us/communication/Memos/memo-waiting-list-guidance>

Preston's story

Ellen asked for a waiver to pay for home modifications and to be able to have an aide come in her home and help care for Preston. The County Board of DD conducted a Waiting List Assessment (WLA) and found that Preston did not have any current or immediate needs. They denied him placement on the waiver waiting list. During this assessment, Ellen's caseworker at the County Board of DD told her that if she could not care for Preston on her own, then the county's children's services agency would have to be notified. Ellen was terrified and worried she could lose custody of her child; therefore, Ellen downplayed the severity of Preston's needs and over-estimated her ability to care for Preston on her own.

At the hearing, Ellen's caseworker at the County Board stated that she was not threatening to report Ellen to children's services. Rather, she said the children's services agency was an alternative community-based service. Children's services is not a resource that can adequately meet Preston's needs because children's services should always be a last resort for parents or guardians struggling to care for their children. Additionally, children's services would not provide the aide or respite care that Ellen needed for Preston.

Challenges of Finding Providers

Many Ohioans with developmental disabilities currently find themselves unable to find reliable providers for the authorized services they are entitled to receive. It can be even more challenging to find providers who are willing to care for children with developmental disabilities, because not all providers are willing to serve children. Home health care services are one provider type that can be very difficult to find.

Home care occupations—which include home health aides and personal care aides—are among Ohio's fastest-growing professions.¹⁵ Despite this, approximately a quarter of home health aides leave their job within a year, while nearly half of all personal care aides quit their job within a year.¹⁶ Home health aides have demanding jobs that are physically and emotionally challenging. Additionally, home health aides receive low pay and frequently do not get benefits like employer-sponsored health insurance. According to some statistics, less than 40% of direct care workers have employer-sponsored health insurance.¹⁷

There can be additional barriers to finding a provider for parents and guardians living in the state's rural areas. There are not as many providers in rural areas, and many providers are unwilling to travel long distances to serve children or adults. Some agencies are willing to serve multiple counties, but they do not have staff in all counties. Hiring and retaining qualified individuals can be challenging.

¹⁵ See Paraprofessional Healthcare Institute (PHI), <http://phinational.org/policy/states/ohio>.

¹⁶ "Low wages, high turnover in Ohio's home-care industry," Policy Matters Ohio, Spring 2015, available at <https://www.policymattersohio.org/files/research/home-care-wages-4-20-153.pdf>.

¹⁷ See <https://phinational.org/policy-research/workforce-data-center/#var=Health+Insurance&states=39>

Another challenge is that services obtained through Early and Periodic Screening, Diagnostic and Treatment (EPSDT), a component of Medicaid that serves children, must be provided by a licensed Medicaid agency. EPSDT will not pay for services that are provided by an independent contractor. This limits the number of providers available to a parent.

Preston's story

Preston needs aide services in the home to help his mother, Ellen, care for him. Ellen applied for aide hours through Medicaid EPSDT, and Preston's aide hours were approved. However, Preston and Ellen live in a rural county. They could not find a Medicaid-approved agency willing to serve Preston. Ellen found an aide who was an independent contractor. After meeting with him, she determined he would be a good fit for Preston. However, EPSDT could not fund his services. After her ABLE attorney advocated for Preston, the county board of developmental disabilities agreed to use some of their funding to pay for Preston's aide services with the independent contractor. However, the limited number of aide hours received through the County Board funding was still insufficient to meet Preston's extensive needs. After months of appeals, the County Board of DD was ordered to reassess Preston's needs. They approved him for an Individual Options Waiver. Under the Individual Options Waiver, Ellen and Preston have more choices for providers and receive more hours of aide services.

Recommendations

The following policy changes would reduce hardships for families of children with developmental disabilities and make the waiver system work as intended:

1. Require the use of the "extraordinary care" standard from CMS in evaluating what level of natural supports parents and guardians must provide to their children
2. Consider the unique circumstances of families when evaluating natural supports
3. Provide more guidance to county boards of DD about when alternative community-based services are actually available and able to meet a person's needs
4. Require county boards of DD to submit documentation that confirms the availability of all alternative community-based services proposed
5. Increase the allowable mileage reimbursement and hourly pay rate of all providers to incentivize people to work in the field and retain valuable providers
6. Allow Homemaker and Personal Care services and other waiver services to be provided remotely, especially in rural counties¹⁸
7. Increase the number of HCBS waivers that the state requests from CMS to meet the demand within the state

¹⁸ 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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