



Advocating for Kids with Complex
Medical Needs & Disabilities

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Know Your Rights: The Community Integration Mandate

(by Jeneva Stone)



Image description: A young Black boy with a tracheostomy and a big smile wears a Little Lobbyists t-shirt and sits in a meeting room chair in front of a large banner that reads “Disability Integration Makes Our Lives and Communities Whole.”

Did you know that the Civil Rights Act of 1964 does not ensure civil rights for people with disabilities? The Act “[outlaws discrimination based on race, color, religion, sex and national origin.](#)” The Civil Rights Act does not outlaw discrimination based on disability.

So how then are people with disabilities protected from discrimination and ensured civil rights? It’s complicated, consisting of a set of regulations, a law, and a court decision:

- [Section 504 of the Rehabilitation Act of 1973](#) protects disabled people from discrimination in any program that receives federal funding, which includes Medicaid, other health services, public education, housing, transportation, and the workforce;
- [The Americans with Disabilities Act of 1990](#) protects disabled people from discrimination more broadly, including public settings and situations outside federally funded programs; and
- The Supreme Court’s 1999 decision in [Olmstead v. Lois Curtis](#) upholds the right of people with disabilities to receive Medicaid services in their communities, if a set of conditions are met.

Disabled people face discrimination on many fronts: jobs, education, housing, physical accessibility, and a variety of health services, among others. However, the key right, the one that unlocks all the others, is *the right to community integration*. Without the right to live in the community of your choice, people with disabilities would still be locked away in institutions.

What Is the Community Integration Mandate?

The Integration Mandate is the key to civil rights for disabled people. First appearing in the Section 504 regulations, it is codified (established in law) in the ADA. The Olmstead decision upholds it. You can find it in [the ADA under Title II](#), which is based on the 504 regulations that apply to the Department of Health and Human Services. This is [the key sentence](#) in the 504 regulations: “**A recipient [of federal funds] shall administer a program or activity in the most integrated setting appropriate to the needs of a qualified person with a disability.**”



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Note that the word “needs” is not restricted; it may apply to medical, social and/or other needs. You can read the entire Integration section of the 504 regulations [here](#).

The Integration Mandate protects the right of people with disabilities to receive their Medicaid benefits in their community of choice. These Medicaid benefits include [Home and Community-Based Services](#) (HCBS), which may include medical and rehabilitative services, assistance with activities of daily living (ADLs) from home care workers, private duty nursing services (PDN), transportation services, home modifications, and much more.

Why Are Disabled People Still Fighting to Live in Their Communities?



Photo Credit: [Rah Studios](#). Image: Just some of our nationwide Little Lobbyists family at the Care Coalition’s Community Integration Summit in Washington DC! Image description: A couple dozen children of various ages and their parents pose in front of a tan and black paneled wall at the Martin Luther King, Jr. Library in downtown Washington, DC. Most of the group members wear t-shirts with the Little Lobbyists logo.

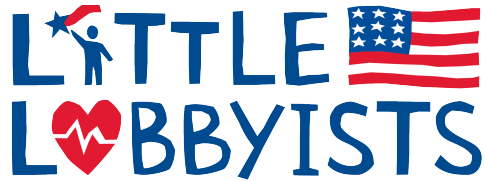
[When Medicaid was established in the Social Security Act of 1965](#), it guaranteed (or entitled) health care services for low-income persons and people with disabilities. However, people with disabilities were only entitled to receive the care many needed in an institutional setting. Nursing homes and Intermediate Care Facilities are institutional settings where disabled people receive care but are kept segregated from the community.

Disability advocates fought long and hard to require Medicaid to provide services in the community. The result is HCBS waivers. The problem with these waivers is that they are still “optional” for states—Medicaid’s “institutional

bias” is *still* part of federal law.

As a result of ongoing advocacy by the disability community, all 50 states now have HCBS waivers that serve both children and adults, although the terms of each state’s waivers vary tremendously. That’s because Medicaid is a federal/state matching program, and [each state is allowed to develop its own terms and conditions](#):

- Type of disability or disabilities served;
- Age of the person with disabilities;
- Number of slots available for services;



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- Length of waiting lists for services;
- Benefits offered from the allowable list of services maintained by the federal government's Center for Medicare and Medicaid Services.

As a result, just because you or your loved one receives HCBS benefits in Massachusetts, it doesn't mean you understand what others receive in California or why. The sad reality is that what constitutes appropriate "community integration" is still a matter of legal interpretation.



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Know Your Rights: The Olmstead Decision

(by Jeneva Stone & Laura LeBrun Hatcher)



Little Lobbyist James McLelland (c) and his mom Jeni (r) seated at a table with a royal blue cover on a stage in the Great Hall of the U.S. Department of Justice. Behind them is an American flag, a Justice Department flag & a Health and Human Services flag.

The U.S. Supreme Court’s Olmstead Decision, a landmark civil rights case for people with disabilities, marks its 25th anniversary this year! In 1999, the Court upheld the right to community integration in the Americans with Disabilities Act (ADA) of 1990. Our disabled loved ones have the right to live and thrive in their homes and communities, where they belong. [Home care is a human right.](#)

Little Lobbyists James, age 13, from California says: “I’m proud to be disabled. It’s part of who I am. ... Olmstead means I have a nurse who goes to school with me to make sure I keep breathing while I’m in class ... who comes to my house at night to manage the ventilator to keep me breathing. Being disabled means that I have to rely on other people – it’s okay to rely on other people for care. I’m here today because I’m an Olmstead success story – I’m getting the care I need to live my life the way I want to live it. I want to make sure that other disabled people have the same access to the community that I do.”

What was the Olmstead Case About?

[*Olmstead vs. L.C. & E.W.*](#) was brought by two disabled women, Lois Curtis and Elaine Wilson, against the State of Georgia and its commissioner of the Department of Human Resources, Tommy Olmstead. Lois and Elaine had been repeatedly institutionalized, and their suit argued that this was unjustified segregation and discrimination under Title II of the ADA. Lois was the driving force behind the case, repeatedly contacting the Atlanta Legal Aid Society to ask for their help, and in 1995, it agreed.

In 1999, the [Supreme Court sided with Lois](#), agreeing that “people with disabilities [...] have the right to receive the treatment they need in an integrated setting if that is what they want, if their doctors agree, and if it doesn’t fundamentally change how the state provides services to people



Photo Credit: Official White House photo by Pete Souza. [image description: Lois Curtis (c) presents President Barak Obama (r) with one of her paintings. They are in the Oval Office.]



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with disabilities.” According to all accounts of her life, Lois Curtis thrived outside of the institutions that had once oppressed her. She became a [well-known artist](#) with a talent for portraiture.

What is the “right to community integration”?

Disabled people have been fighting for their community living rights throughout U.S. history, for the right to stay out of institutions, facilities, and asylums. Medicaid itself did not allow in-home care until 1983 when [Katie Beckett’s](#) situation caused Congress to finally establish the first HCBS waiver. [The ADA of 1990 established community living rights](#) under Title II: “The ADA bans the unnecessary segregation of people with disabilities in a regulation called ‘the integration mandate.’ As a result, State and local governments that provide services to people with disabilities must offer those services in people’s homes and communities—not just in institutions.”

What does this mean for my family?

Under federal law, Medicaid’s HCBS waivers are still considered “optional” services for states, and states continue to make it difficult for disabled people to live in their communities, but progress is on our side. Given the high costs of institutionalization, states are expanding their offerings and beginning to reduce long waiting lists. [The American Rescue Plan of 2021](#) provided additional funding for HCBS, and, as of last year, states have committed approximately [\\$37 billion](#) to such programs. All 50 states now have Katie Beckett waivers for minor children to live at home.

Many families, though, first qualify for HCBS as their disabled loved ones transition from high school to adult services. While this transition can be emotional and difficult, remember that you or your disabled loved one have the right to live in your community in the most integrated setting appropriate to your needs. If transition coordinators propose something that isn’t right for you or your dependent adult, ask hard questions. Often, school systems will present transition as if entitlements end with high school graduation; however, civil rights are also an entitlement. Remind them of that. Ask about HCBS [“self-directed services,”](#) a good option for many people.

There are 56 [State Councils on Developmental Disabilities](#). Reach out to yours with questions and concerns. The National Association of Councils on Developmental Disabilities ([NACDD](#)) has many resources, including tips for advocacy.



Little Lobbyist Rob Stone, seated in his wheelchair and wearing his trademark Clark Kent glasses, smiles at the Olmstead White House event. He poses in a doorway with the blue oval seal of the White House and an American flag behind him on a yellow wall.



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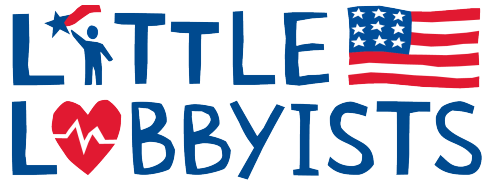
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And never give up. As former congressman Tony Coelho—the principal author of the ADA, and a person with a disability—said at the White House, “My philosophy in life is this: give me the right to fail. But in order to do that, give me the opportunity to succeed. And that’s what we all want—nothing more, nothing less. But we want that opportunity to succeed. And we only get that opportunity if all of you in this room work to make it happen. We did not get Olmstead, we did not get the ADA on our own. We got the ADA because of all of you and the rest of us all over the country who have disabilities.”

What’s Being Done to Ensure My Rights?

Olmstead marks the beginning of enforcement of community living rights for disabled people and the expansion of Medicaid’s [Home and Community-Based Services \(HCBS\)](#) waivers. Since 1999, states have made progress on HCBS: These supports include aides and other staff, job assistance and coaching, medical care, housing options, and funds for equipment and activities. But we have a long way to go.



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What Is “Section 504”? Disability Rights 101

(by Jeneva Stone)



Little Lobbyists pose in a row with the U.S. Capitol Building in the background. It's a beautiful day, and they wear colorful clothing. The children are very young. Some use adaptive strollers, and some stand.

The [Rehabilitation Act of 1973](#) opened doors to jobs, education, independent living, and much more for people with disabilities. The Act also established standards for accessible communication and information technology.

The Rehab Act (as it's often called) is the foundation for civil rights for people with disabilities in the U.S., and at its heart is [Section 504](#), which prohibits discrimination on the basis of disability “under any program or activity receiving Federal financial assistance.” Disability rights

activist [Judy Heumann](#), who was instrumental in the fight for the Rehab Act, [reacted this way](#), “I read the sentence over again, took my glasses off, rubbed my eyes, and read the sentence one more time ... This sentence acknowledged that the way we were being treated was actually discrimination.”

Until the Rehab Act passed in 1973, people with disabilities had been excluded from the protections of the Civil Rights Act of 1964. No one knows who inserted civil rights language into a bill that had been primarily focused on disability employment, but it changed history without amending the Civil Rights Act. Nonetheless, it would take four more years and [a famous 26-day sit-in](#) by disabled activists in the U.S. Health, Education and Welfare offices in San Francisco before Section 504 was finally implemented.

What's the Difference Between Section 504 & the ADA?

While most people think of the [Americans with Disabilities Act of 1990](#) (ADA) as the first law that established civil rights for people with disabilities, Section 504 predates it and lays the groundwork for the ADA.

The basic difference between the two laws lies in how each law guarantees rights. Section 504 prohibits discrimination against people with disabilities who participate in programs funded by the federal government—among these are Medicaid and Medicare, public schools, federal employment, federal buildings and public housing. The ADA builds on 504, extending civil rights for disabled people to everyday life in both the public and private sectors, such as businesses and other parts of government.



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In addition to launching the Americans with Disabilities Act, 504 further impacts the lives of disabled people through the [Individuals with Disability Education Act \(IDEA\)](#) that grants disabled students the right to inclusion, and the [U.S. Supreme Court's Olmstead Decision](#) which determines that disabled people have the right to choose where they live.

What Does This Mean for Our Families Today?

The fight to have the 504 regulations made into federal law was long and bruising—at the time, the very idea of considering people with disabilities citizens with equal rights was tremendously controversial. Businesses and others tried to get rid of Section 504 after the Rehab Act was passed, claiming it would be too expensive and difficult to adhere to. Although disability rights prevailed and 504 remains law, even today, we are still fighting for the rights of people with disabilities to live where they choose, receive basic medical care, and prove that disabled lives have equal value.

In the 50 years since it passed, Section 504 had never been revisited or revised. Since 1973, though, our society has changed dramatically: the personal computer has become an essential part of everyday life; the internet is available to the public; health care has become far more complex and sophisticated; our disabled children are included in public school; progress has been made in closing institutions; and more and more disabled people live, work, and play in their communities.

That's why the Biden Administration revised and strengthened the 504 regulations for the U.S. Department of Health and Human Services in July 2025. Because it's about time, and care can't wait! The legal and social changes of the last 50 years need to be aligned with Section 504.



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Using Our Words: Being a Better Disability Ally

(by Jeneva Stone)



Image: A young white man with curly dark hair poses in his wheelchair, his support vest covered in political buttons. His head rest supports a sign that says, "Little Lobbyists: Please Save Our Health Care."

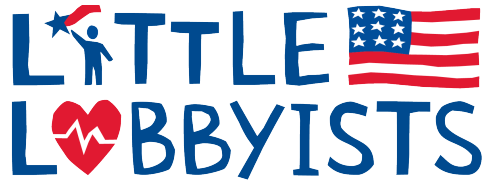
As parents of children and young adults with disabilities, we should always work to be better allies. Being an ally means empowering our kids and asking ourselves some challenging questions: Are we letting our children speak for themselves? Are we giving them the means and the platform to become their own advocates? As we advocate, are we centering our own experience as caregivers, or their experience as disabled people?

As a writer, I know that how we use our words matters. We, ourselves, may have heard certain terms used in a medical setting that we think are ok to use, or heard slurs directed at our kids that we know not to use. But have we listened enough to people with disabilities themselves and how they would like us to use language? Soon enough, our own children will be grown. Listening to the disability community and using appropriate language helps us raise them with a sense of dignity and awareness, with the understanding that they are allowed and encouraged to challenge the words used to describe them, and that their lives are their own.

So let's talk about a few terms in use by nondisabled people that are not preferred! These terms can be infantilizing, misleading, or derogatory. The best way to unlearn them is to understand why they are harmful and what we can say instead.

Special Needs: We should say our children have **needs**, just like anyone else! They need to eat, dress, go to school, breathe, and thrive. They might access these activities with medical interventions or social accommodations, but their **needs** are still the same. Disabled people feel that referring to their needs as "special" perpetuates the idea that disabled people are not like their peers when inclusion is really a matter of access and accommodation for everyone, disabled and nondisabled.

Wheelchair-bound: This phrase suggests that the person using the wheelchair is stuck or imprisoned in their chair, when, in fact, many wheelchair users see their chair as their freedom and means of accessing their world. This phrasing also suggests that the wheelchair user cannot make their own choices, or spends all their time in one seated position. **Wheelchair users** have dignity. They decide where they want to go (and when), and when they want to use other physical supports (bean bag chairs, beds, walkers, other chairs). A wheelchair is a means of being independent.



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~~[Insert disability or medical condition]~~ **Mom/Dad/Parent:** As parents, we provide a lot of support to our children, but that doesn't mean we share their disabilities. When a family caregiver uses this label, they are centering their own experience as caregivers, instead of our child's experience as a disabled person. We need to let our children have their own identities, and we, as family caregivers, need to develop identities of our own. Try saying, "**I'm the parent of an autistic child**," instead.

Nonverbal: Many disabled people rely on gestures, sounds, and facial expressions, and/or assistive technology, such as tablets, symbol and letter boards, or other computerized devices in order to communicate. This does not mean they don't understand language; they simply may not use their mouths and vocal chords to generate words, i.e., "speak." Try saying that someone is **nonspeaking** instead.

Medically Fragile: By referring to our children using this phrase, we're perpetuating an image that they are less capable than they really are. Referring to someone as "fragile" gives others the impression they need to be sheltered and kept apart from their communities. Disabled people with all sorts of medical needs (tracheostomies, ventilators, tube-feeding) are present in their communities every day! By referring to your child as **medically complex**, you're not shying away from their high medical needs, but you're emphasizing their capability.

High/Low Functioning: Drawing distinctions among people based on assumptions about their capabilities, whether cognitive or physical, isn't the way nondisabled people would refer to other nondisabled people. So why use these terms with disabled people? Your friends are good at some things, not so great at others. Instead, describe the supports your child might need to participate, such as, "**My child needs instructions in plain language**," or "**My child can play baseball, but must hit the ball from a tee, and needs help swinging the bat**."

~~SpEd Kids/Special Education:~~ As with "special needs," we must emphasize that our children's need for an education isn't "special"; it's as universal a need as anything else. While school systems refer to "special education" for the time being, as parents we can avoid using that phrase in our conversations with friends and family, as well as the phrase, "SpEd kids." Try just saying, "**My child attends elementary school**." If you need to explain anything else, try saying, "**My child receives learning accommodations, just as "gifted" children and other groups do**."

Crazy/Insane/Nuts: Mental health should never be treated lightly, nor turned into a joke. But the use of words like "crazy" or "insane" to describe feelings, events, or actions is everywhere. It can be challenging to stop using these words, but we all need to try. Instead, you could substitute "**wild**," "**amazing**," for stuff we enjoy, or "**uncalled for**," "**inappropriate**" for actions or encounters we can't understand or condone, or "**unsettled**," "**scattered**," "**that annoys me**," for feelings.



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Dumb/Idiot/Moron: These words were used along with “mental retardation” in medical diagnostic manuals during the 19th and 20th centuries to define levels of cognitive ability. They’ve since migrated into casual conversation, but it isn’t right to judge anyone’s intelligence, even if you think you’re just kidding. Try substituting “**insensitive**” or “**mean**” or be more descriptive and say, “**My boss is a really bad boss.**” Or just don’t use them at all.

R-word (some people STILL don’t know): Just don’t use this slur. It conjures up everything ugly about *you*. People use “r*tard” because they think it’s the only acceptable slur left after racial and ethnic slurs have become unconscionable to use. It’s not a joke, either, nor a term of “endearment.”

The R-word is an unconscionable word because it implies that disabled people are completely other and different from everyone else. And that’s really the issue, disabled people are not different, they’re just like everyone else. Their needs, to be listened to and respected, are also the same as everyone else’s. As parents and caregivers, fulfilling that need starts with us.