

ACTNow

Advocacy, Collaboration, and Transformation

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ACTNow is a quarterly newsletter published by the TASH Early Career Research Network Policy HUB (Human Rights, Unlearning, and Belonging). This newsletter is a collaborative effort of all members of the Policy HUB and aims to provide information on advocacy at the local, state, and federal levels.

This newsletter will highlight collaborative efforts and resources for self-advocates, families, early-, mid-, and late-career professionals, and disability allies engaging in macro- (e.g., policy and systems change) and/or micro- (e.g., local and community action) advocacy.

Each newsletter will contain a relevant **Top Story** or stories on federal or state government policy updates that impact disability rights. In addition, the newsletter will spotlight advocacy stories or resources for agencies and individual efforts in support of disability rights.

The **Policy to Practice** section is aimed at supporting professionals, self-advocates, families, and disability allies by providing practical information, resources, and tips that support our ability to take action with federal legislators, as well as in our local communities.

This newsletter also contains additional resources to support a broader understanding of disability rights and disability history (i.e., Did you know?). You can also check out our **Action and Supports Center** sections for helpful links to federal and state organizations that support disability rights.

Please feel free to access all or some of the sections of this newsletter. If you have feedback, a story, or need more information, please reach out to us at ecrnpolicyhub@gmail.com.

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TOP STORY

Community Living: Potential Impact of Recent Developments in Federal Policy

Communities are often defined as spaces that provide a sense of belonging, connection, and mutual support for groups of people who are connected not only geographically but also by interests, values, and/or identities. For more than 50 years, self-advocates, families, and disability allies have fought for individuals with disabilities to live, learn, work, and fully engage in their communities, rather than being unnecessarily separated in an institutional setting ([Rehabilitation Act of 1973, 1973 \(linked here\)](#); [Americans with Disabilities Act of 1990, 1990 \(linked here\)](#); [Olmstead v. L.C. ex rel. Zimring, 1999 \(linked here\)](#)). Recent developments in federal policy (e.g.,

Department of Justice [DOJ] memorandum, Section 504 lawsuit, and proposed changes to Supplemental Security Income [SSI]) have raised red flags regarding longstanding disability rights legislation and how these critical laws may be interpreted and implemented in the days and years ahead (U.S. Department of Justice [DOJ], Office of Legal Counsel [OLC], 2026; Social Security Administration [SSA], 2025; *Texas v. Kennedy*, 2024). These developments have not changed binding legal precedent at this time. However, self-advocates, families, educators, service providers, and allies may find themselves asking important questions about the future of community living and the legal protections that support equitable participation, services, and access in homes and communities across the United States.

This article explains a brief history on the right to community living, recent federal policy developments, and discusses how these issues may intersect. It also clarifies current legal protections, distinguishing between current law and proposed policy changes, and identifies ways that self-advocates, families, disability allies, and communities can stay informed and engaged as these developments continue to evolve.

Recent Federal Developments

A brief history: Olmstead and the right to community living

Terminology Note: To help readers understand who is included in *Olmstead v. L.C. (1999)* and

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potentially affected by the Department of Justice (DOJ) memo discussed below, it is helpful to clarify the terminology used in these documents. Throughout both documents (i.e., *Olmstead*, DOJ memo), the term "mental disabilities" is used broadly to describe individuals with intellectual disability, developmental disabilities, mental illness, and other cognitive disabilities receiving institutional services.

The court case *Olmstead v. L.C. (1999)* centers around the experiences of two women, Lois Curtis and Elaine Wilson, who had "mental disabilities" [sic] and were voluntarily admitted for psychiatric treatment to the Georgia Regional Hospital in the early 1990s. Despite treatment professionals determining both women could receive supports and services in community-based programs, they remained institutionalized for extended periods. In *Olmstead v. L.C. (1999)*, the Supreme Court held that unjustified institutional isolation of persons with disabilities may constitute discrimination under Title II of the Americans with Disabilities Act (ADA).

These legal protections for community integration are established in both the ADA and Section 504. Title II of the ADA prohibits state governments from discriminating on the basis of disability, and Section 504 prohibits disability discrimination in any program or activity that receives federal financial assistance. Together with *Olmstead*, these laws establish the legal principle that individuals with disabilities should

be supported within their community settings rather than confined to institutions when professionals determine such placement is appropriate, the affected person does not oppose such treatment, and resources are available to meet the needs of the individual (i.e., integration mandate; *Olmstead v. L.C. ex rel. Zimring, 1999*). For many individuals, these community-based supports are provided through Medicaid Home- and Community-Based Services (HCBS). HCBS funds supports including personal assistance, employment supports, transportation, and other services that enable individuals with disabilities to live and thrive in their local communities. This history and legal foundation provides important context for the recent policy developments that have raised questions about these disability rights protections and their future interpretation.

The Department of Justice (DOJ) Memorandum

On June 18th 2026, the DOJ released a [memorandum \(linked here\)](#) opinion for the counsel to the President that argues for a much more narrow interpretation of the integration mandate currently recognized in *Olmstead v. L.C. (1999)*. The memo states that "neither section 504 of the Rehabilitation Act nor Title II of the Americans with Disabilities Act ("ADA") imposed an integration mandate on states in their treatment of mentally disabled individuals. Nor does either statute authorize the responsible Executive Branch agencies to impose such a mandate" (U.S. Department of

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Justice [DOJ], Office of Legal Counsel [OLC], 2026, para 1). While this memo does not overturn or repeal existing legislation (e.g., Olmstead, ADA, Section 504), it arguably appears to significantly narrow the Supreme Court's holdings in *Olmstead v. L.C.* (1999) and the way this decision has historically been interpreted and enforced over the past 25 years. Consequently, this document has stirred considerable fear, frustration, and concern among many individuals with disabilities, families, disability organizations (e.g., TASH), and legal scholars regarding the potential implications of this narrowed interpretation and how it might influence future enforcement and disability policy, potentially weakening current community integration protections.

The Section 504 Lawsuit

The DOJ memo is not the only recent federal development to raise questions or concerns about disability rights. At the same time, ongoing litigation challenging Section 504 has generated additional concern among individuals with disabilities and advocates. *State of Texas v. Kennedy et al.* is a pending, federal lawsuit initially filed by 17 states; as of July 2026 only three states remain as plaintiffs in this case (i.e., Alaska, Florida, and Texas; American Council of the Blind [ACB], 2026). According to the National Association of State Directors of Developmental Disabilities Services (NASDDDS, 2026), the remaining states have narrowed their complaint to the constitutionality of the integration mandate under Section 504.

Although this litigation does not directly challenge Olmstead or the ADA, NASDDDS (2026) stated that changes to Section 504 integration regulations could affect one or more of the legal frameworks that have historically supported community integration and influence how states interpret and implement their obligations under *Olmstead* and other disability law.

Proposed SSI Changes

So far, this article has considered legal protections that help individuals with disabilities remain in their homes and communities, but many also require financial support in the form of Supplemental Security Income (SSI), to live in and participate in those communities and cover basic living expenses. According to Urbanski Law, PLLC (2025), over 7 million people residing in the U.S. receive SSI. This includes individuals who are blind, have a disability, or are 65 years or older and have limited income and resources.

In 2024, the Social Security Administration (SSA) changed its rules to make it easier for some people with disabilities who live with family members to receive their full SSI benefit. Under that rule, if an SSI recipient lived in a household where another family member also received public assistance, such as Supplemental Nutrition Assistance Program (SNAP), the SSA generally did not reduce the person's SSI benefit because the person was receiving help from family members. There is currently a new proposal to reverse that change. If the proposal

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is finalized, some individuals living with family members could have their SSI benefits reduced again if SSA determines they are receiving free or reduced-cost housing from relatives.

Individuals with disabilities and allies have expressed concern that proposed changes will make it more difficult for people with disabilities to continue to afford living in their communities. In a ProPublica article, Hager (2026) stated that 400,000 individuals receiving SSI might be affected (e.g., receiving reduced SSI benefits). Further, authors emphasized that this may particularly impact those adults with disabilities who live with family members. Currently, the proposal remains under review and has not been finalized.

Why Are These Developments Being Discussed Together?

Individuals within the disability community, advocates, and legal scholars are concerned by this multi-pronged assault on systems that make community living possible. This article has explored separate federal actions (e.g., the DOJ memo, the Section 504 lawsuit, and proposed changes to SSI), but many individuals with disabilities and advocates are considering the overall implications for community living across these interconnected systems (i.e., legal and civil protections, financial/economic supports). When considering current civil rights protections, including ADA, Section 504, and *Olmstead v. L.C. (1999)*, these important pieces of legislation protect individuals with disabilities

from segregation and disability discrimination ensuring needed supports are provided so they can live, work, participate, and thrive in their communities. Through Medicaid Home- and Community-Based Services [HCBS]), as well as financial and economic supports (e.g., SSI, SNAP) and housing assistance, individuals with disabilities can afford to remain integrated in their communities.

Know what has not changed.

It is critical to remember that Olmstead, ADA, and Section 504 remain in full effect and existing legal protections have not changed. That said, keeping a pulse on these developments is imperative. With proposed cuts to Medicaid funding and services in a system that has consistently faced workforce shortages (e.g., direct service providers), waiting lists for services, and limited resources, disability organizations, such as TASH and the ECRN Policy HUB, encourage individuals with disabilities, families, educators, service providers, and allies to advocate for maintaining existing civil rights protections, to preserve access to imperative medicaid programs (HCBS), and to support adequate funding for programs and services that enable individuals with disabilities to live, work, and participate fully in their communities.

Frequently asked questions.

1. Has *Olmstead* been overturned?

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- a. No. *Olmstead* remains binding Supreme Court precedent.
2. Has the ADA or Section 504 been repealed?
 - a. No. Both laws remain in effect.
3. Have SSI rules changed?
 - a. No. The proposed changes have not been finalized.
4. Should I be concerned?
 - a. Many disability organizations encourage individuals and families to stay informed because these developments could influence future policy and litigation, even though current legal protections remain in place.

How You Can Get Involved

Stay informed and get involved. This is one of the most effective ways to protect disability rights. It takes a village! We are calling on all individuals with and without disabilities, families, educators, service providers, and allies. Everyone should seek out and follow updates from trusted disability organizations (See resource section below and check our website). Take time to learn about your legal rights and the rights of others. Participate in public comment opportunities, contact your elected officials, and support organizations that advocate for community living and equal access. Remaining informed and engaged helps ensure that the voices of people with disabilities continue to shape policies affecting their lives.

Remember that community living is a basic human right, and it depends on a network of individuals (e.g., self-advocates, disability allies), legal protections, public services, economic supports, and continued advocacy. Together, we can protect programs that support fully integrated community inclusion.



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ADVOCATE SPOTLIGHT

We Want Your Story

The TASH ECRN Policy HUB is seeking stories of advocacy from the perspective of self-advocates, families, and disability allies. Sharing stories can help others know what to do when facing similar situations. Advocacy stories can also educate others about the different types of resources available and how to access them.

If you are interested in sharing your story, please reach out to us. You can contact us via email at ecrnpolicyhub@gmail.com.

#disabilityrightsarehumanrights

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POLICY TO PRACTICE

Moving Special Education to Health and Human Services

Right now there are several different departments within the Department of Education (ED) that are being moved and shifted to other agencies through interagency agreements. As of June 16, 148 K-12 and higher education programs, including special education programs, were shifted through these agreements. Education Weekly, an online news organization dedicated to reporting educational news, created [a tracker](#) for the public to see which education programs were shifted to which agency. Using the tracker you can see that eight programs within the Office of Special Education (OSEP) related to IDEA Part B-D were shifted to Health and Human Services (HHS).

This is a way for the current administration to keep its promise to effectively close the ED without

congressional approval. They can't dissolve ED without congressional votes, therefore; in an effort to accomplish what they want without congressional approval they are doing interagency agreements.

All of these departments can not be shifted without impact. For students with disabilities, moving special education out of the ED and into HHS is particularly concerning as this is moving special education to a health model instead of an education model. Additionally, Secretary Kennedy who leads HHS has said made inaccurate and damaging remarks about people with autism angering disability advocates and calling into question the ability of the organization to view students with disabilities as valuable members of our community and schools.

IDEA is an education and civil rights law and belongs within an education agency. Moving IDEA into a health agency is not just a bureaucratic move but it changes the way we view students with disabilities. Instead of viewing them as students that need classroom access, a health model conveys that these students need to be diagnosed, treated, and managed. Students with disabilities in schools are students first and schools are responsible for their education and progress.

Before the passage of the Education for all Handicapped Children Act, now IDEA, in 1975 education was in the Health, Education, and Welfare department. Before 1975 students with disabilities were not adequately served within schools and many students with ESN did not even attend public school and instead attended institutions. The ED was specifically created because the health, welfare, and education department could not meet the educational needs of students, particularly students with disabilities.

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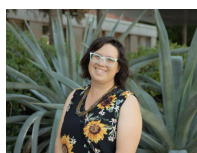
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We already know what happens when a health department takes control of educating students with disabilities. Students do not make progress and the most vulnerable students are removed from education altogether.

Additionally, the ED creates accountability if the accountability piece goes to each state we are losing a national view of what we are doing as a country. The accountability piece from the ED has been critical even to say we need to do better. If the data isn't there it doesn't mean we are doing better. Moving educational programs outside of education is making the ED less and less effective for what it is intended to do.



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DID YOU KNOW?

Acceptance is more than Awareness

July is Disability Pride Month, marking the passing of the Americans with Disabilities Act (ADA), and is a time to celebrate disability as a natural part of the human experience. What used to be called disability awareness has shifted to disability acceptance, and the impact of this idea is significant. First, we would like to emphasize that while July is a time to specifically celebrate milestones and systems change, the observation of Disability Acceptance Month should occur every day. Daily acceptance helps communities move past the idea of simply recognizing disability shifting in the direction of creating environments where people with disabilities belong, are respected, and valued.

While awareness is a critical first step, awareness alone cannot sufficiently change the experiences of people with and without disabilities in such a way to evoke change. Awareness means that we acknowledge that disability exists, but acceptance

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requires more. Acceptance requires a fundamental change in our beliefs, values, attitudes, and in our actions.

Disability is not rare. In fact, individuals with disabilities make up the largest minority population in the world (Shapiro, 2006). The World Health Organization (WHO, 2026) reported that 1.3 billion individuals worldwide and over 61 million (1:4) individuals in the U.S. identify with a disability.

So, what does acceptance look like?

Acceptance begins with presumed competence. Presumed competence means that ALL people are viewed as capable and intelligent without requiring someone to prove their abilities (Biklen, 2006; Jorgensen, 2005). This foundation is rooted in respect for all individuals. Additionally, acceptance means that we consider universal design across education, social settings, and the community, which means ALL individuals are considered at the outset of designing events, activities, and spaces, and individuals with disabilities' voices are included in the decisions.

Disability acceptance requires deep reflection on long held implicit (i.e., not aware) and explicit (i.e., aware) bias about disability. What are our assumptions about differences in the ways that people move through this world or communicate? ([Want to find out if you have bias: CLICK HERE](#))

Acceptance is making a real effort to eliminate ableist ideals and language. Landau (2021) defines ableism as "attitudes, actions, and circumstances that devalue people because they are disabled or perceived as having a disability" (p. 69). One way people can address language is to normalize the word disability (Ladau, 2021). Emily Ladau (2021)

asks that people don't "dance around disability" (p. 17).

To address blatant ableist language and actions, speak out. If you hear or see ableist or discriminatory language or actions, take action.

Acceptance requires asking questions and listening. For example, when referring to someone's disability, it is important to ask individuals how they identify in regard to their disability. Do they prefer person-first (i.e., individual with a disability) or identity-first (i.e., disabled person)? Ladau noted that there may not be easy solutions for all forms of ableism, but all individuals must be vigilant and consistent with both advocacy and action in the face of discrimination.

Acceptance is not a slogan or a catch phrase; it is a way of life and a basic human right for all people. Acceptance is born of connections and relationships. It is our hope that anyone reading this will reflect this month and hopefully every month on presuming competence, advocacy, accessibility, connection, inclusion, and belonging. Happy Disability Pride 2026!

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ACTION CENTRAL

Did you know that taking just 5 minutes per day can have a significant impact? Commit this time today to contact your legislators to discuss your concerns.

Do not know who to call or how to reach them? You can use supports like 5-Calls ([app version of 5-calls](#)) or [Call My Rep \(link\)](#) to locate your federal or local government representative. You can also locate your representative here: [CLICK ME](#)

SUPPORTS CENTER

1. State council on developmental disability: [FIND YOUR STATE \(link\)](#)
2. State protection/advocacy organization [National Disability Rights \(link\)](#)
3. [AFL-CIO \(link\)](#) organizations for your city/state
4. [The Arc Take Action Center \(link\)](#)
5. [TASH in Action \(link\)](#)
6. 5 calls app ([android link](#)) or ([apple link](#))
7. [Self-Advocates Becoming Empowered: SABE \(link\)](#)

8. [The American Association of People with Disabilities \(link\)](#)
 9. [Maryland Coalition for Inclusive Education \(link\)](#)
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[TASH.ORG](#) SUPPORTS

Please check out these additional [TASH.org](#) resources:

- [TASH Policy Priorities](#)
- [TASH Position Statements](#)
- [TASH Advocacy Tools and Resources](#)

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