

Stable Leadership in
Unstable Times

NATIONAL
LEADERSHIP
CONSORTIUM



ON DEVELOPMENTAL DISABILITIES

National Leadership Consortium **Bulletin**

About the Bulletin

The National Leadership Consortium Bulletin is a free, web-based publication dedicated to providing relevant, trustworthy, and thought-provoking information to leaders, practitioners, and people with disabilities and their families involved in the field of developmental disabilities support services. The Bulletin will serve as a bridge between scientific journals and day-to-day leadership, exploring timely research and policy issues in the leadership and disabilities fields with the aim of promoting organizational change and assisting leaders to support people with disabilities to experience inclusive, valuable, and meaningful lives.

About the National Leadership Consortium

Leadership, Values and Vision: Transforming Lives and Organizations

The National Leadership Consortium was founded in 2006 to develop current and future generations of disability sector leaders to have the knowledge, skills, and values needed to transform services and systems to be responsive to the needs, wants, and rights of people with disabilities. Our mission is to provide quality training, technical assistance, and support aimed at the development of values-based leadership in disability sector leaders. The National Leadership Consortium is focused on promoting the rights of people with disabilities to direct their services and lives and to fully belong in their chosen communities. One way the National Leadership Consortium works to meet this mission is through a nationally recognized, intensive leadership development program, the Leadership Institute. These in-person or virtual trainings focus on knowledge, skills, and supports leaders need to transform systems and organizations in the disability service sector.



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Introduction: Stable Leadership in Unstable Times

Anyone else sick of the word "unprecedented"? It seems over the last several years, we've faced more unprecedented times than preceded. I, for one, wouldn't mind some predictability, mundane, or even optimistic times.

Of course, leaders in this field have never had a ton of predictability and stability. Yet, they have advanced services and supports for decades, often in times when resources and political or public investment were in decline. Disability field leaders created a system of supports from nothing; then they transformed a system founded on isolation and segregation to one that (albeit imperfectly) attempts to promote inclusion, connection, and self-determination. Before the [Americans with Disabilities Act](#) was passed, advocacy leaders crawled up the steps of the [Capital Building](#) to demonstrate why accessibility matters. Leaders in 19 U.S. states built the foundation for self-directed supports, now [utilized in all 50 states](#), from [grants](#) designed to enhance self-determination. Before the [Home and Community Based Services](#) regulations were even written, several leaders developed person-centered approaches and co-created supports that are meaningfully chosen and controlled by people with disabilities. The [UN Convention on the Rights for Persons with Disabilities](#), largely drafted by leaders with disabilities and lived experiences, established a global standard of human rights for people with disabilities. During COVID, leaders became substantially more tech savvy and built several service options that have outlasted stay at home orders, in order to maintain critical supports. And on and on.

So now, with the recent passage of an unprecedented (U.S.) [federal bill](#) that promises to cut Medicaid funding by almost a trillion dollars in the next 10 years, decimates the Supplemental Nutrition and Assistance Program, and increases taxes for many families with modest incomes, we know that leaders in all positions and roles in our field will continue to step up as they lead services, advocacy, policy, research, etc.

This issue of the National Leadership Consortium Bulletin provides readers/leaders with useful information about what upcoming changes mean and how they can lead in ways that continue to problem solve, pivot, transform, innovate, and enhance our field's commitment to the rights and dignity of people with disabilities.

Our 2025 summer issue starts with an article from our consulting editor, Amanda Rich, about how U.S. federal policy is made, offering strategies for those wanting to become and remain informed about policy changes that impact their work and the lives of people with disabilities. John Raffael shares insights on courageous leadership, why we need it now more than ever, and how leaders can be courageous when things look bleak. The next two articles, including a conversation with Steve Eidelman, Nancy Weiss, and Janet Butler recapped and written by our managing editor Cory Gildea and a piece by Jessica Renner, make a case for advocacy and provide concrete strategies for field leaders to get involved in leading change. Yours truly provides insights about efforts that funders are making to adapt to the times. Karen Gilchrest describes how good organizational strategy can guide leaders through significant challenges, such as those the field is facing today, and Daniel Boamah sheds light on the challenges that current federal immigration policies and priorities are and will continue to have on the wellbeing of people with disabilities. An interview with Liz Weintraub offers advocacy strategies and discusses the terrible impact that cuts to Medicaid may have. Finally, this issue closes with an overview of tools and resources useful for advocacy and lobbying.

While this isn't our lightest issue, we did strive to bring a tone of hope and collective impact for leaders working tirelessly to protect and enhance the services and communities of people with disabilities. As this issue coincides with Disability Pride Month, a moment and reminder to celebrate how people with disabilities make the world better, we hope that those reading it are inspired to keep pushing and keep demanding better.

Thanks for your leadership,

Caitlin Bailey

Caitlin Bailey is the Co-Director of the National Leadership Consortium. She holds a Ph.D. in Human Development and Family Science. Caitlin is passionate about enhancing leaders' skills and evidence-based practices in our field. Contact Caitlin at cbailey@natleadership.org.



Beyond Bugs and Windshields: Federal Policy and the Disability Service System

By Amanda Rich

This article offers a short overview of how federal policy is made, categories of federal policy, and highlights nine policy changes or proposed changes that will likely have a direct and significant impact on disability service organizations and the people we serve, should they be enacted.

Note: Federal policy is rapidly changing, and it is possible that by the time you read this, the status of the bills, executive orders, or rulings may have changed.

- Recently, there have been many federal policy changes that impact people with disabilities, their families, and service organizations.
- Understanding how federal policy is made, what recent changes have happened, and what may be coming can help us navigate and shape these changes.
- Some of the major policy changes that will impact people with disabilities and service organizations relate to potential cuts to Medicaid and changes to federal offices that support people with disabilities.
- There are many things that we can do to help us use our voice to shape the changes. Some include:
 - ◆ Find trustworthy sources of information to stay informed.
 - ◆ Take breaks to not get overwhelmed.
 - ◆ Think about what your goals for the future are and how policy changes may impact them.
 - ◆ Join with others who have similar goals.
 - ◆ Find ways to tell your story to the community in general and lawmakers specifically.



Understanding, navigating, and sometimes shaping legal, regulatory, and environmental contexts is an essential skill for effective and ethical leaders of nonprofit organizations. Lately, however, that has felt particularly challenging. Over the past several months there has been an onslaught of changes and proposed changes to federal policy and departments, many of which have the potential to significantly impact the lives of people with disabilities, their families, and the ability of disability service organizations to fulfill their missions.

There is an old saying that goes something like, “some days you are the windshield and some days you are the bug.” The saying means that some days we feel like we can shape our world and some days it feels like we are getting run over by forces beyond our control. Though it is easy to feel like we, the people we serve, our staff, and our organizations are at the mercy of those with formal political power, we are never completely without agency. That is especially true in a [constitutional democracy, one “governed by and for the people”](#) like the United States of America. Having a greater understanding of how policy is shaped and what relevant policy changes are coming down the pipeline can give us a little more power to prepare for, push back on, and/or influence those changes.

How Federal Policy Is Made

For many of us, it has been a few years since we've watched [School House Rock](#) so here is a brief review of how public policy is typically crafted at the federal level.

Legislative Branch

[Congress](#), which is made up of the House of Representatives and the Senate, is the legislative or law-making branch of the federal government. [Article I](#) of the U.S. Constitution created Congress, its two branches, and outlined its nature, roles, and responsibilities.

A proposed law or a proposed change to an existing law is known as a [bill](#). Members of the U.S. Senate or House of Representatives may introduce a bill and ideas for a bill may be initiated by individual lawmakers or a petition from a group of citizens. The House Clerk and Senate Clerk assign legislative numbers for bills introduced in their respective chambers. A bill introduced in the House will have "H.R." in front of the number (e.g., H.R. 2004) and a bill introduced in the Senate will have "S." in front of the number (e.g., S. 2004). You can track the activities of Congress and the executive branch and search the status of bills in both chambers on [GovTrack.us](#).

Once a bill is introduced, it is assigned to a committee and subcommittee in the branch of Congress in which it was introduced. In the committee, lawmakers research, discuss, hold hearings, ask for public comment, and make changes to the bill. Bills are usually assigned to specific committees and subcommittees based on the subject matter of the bill. It is often while the bill is in committee when the public will have the most influence on the bill. The committee will usually make a recommendation to pass the bill, revise the bill, and release the bill for a full vote in either the House of Representatives or the Senate. However, they may also recommend the bill not leave the committee and not be worked on further, which is known as "tabling" the bill.

If the bill is released from the committee, it may be open to the full House or Senate for debate. They may recommend further changes to the bill. Once the language of the bill is finalized, members of the House or Senate will vote on the bill. The leaders of both the House and the Senate have a lot of control over which bills are put up for a vote and when that occurs. As such, most bills, even those recommended by committees, are not brought up for a vote.

If the chamber (the House or the Senate) votes in favor of the bill, the bill gets sent to the other chamber (if it was first voted on in the House it is sent to the Senate, for instance) and the bill is sent to a committee in the other chamber for review, revisions, and recommendations. When the second branch agrees to a bill or amends a bill already passed by the first chamber, the two chambers work to resolve any differences in what is known as a conference committee. The final bill must be voted on and approved by both chambers (the House and Senate).

If a bill is approved by both chambers of Congress, it is sent to the president. The president may sign the bill, and in doing so, make it public law. The President may also refuse to sign the bill or veto the bill. If the bill is vetoed, it may be returned to Congress for further amendments or considerations. Congress may override a presidential veto by a two-thirds majority vote in the House and the Senate.

Executive Branch

The [executive branch](#) consists of the president of the United States, their advisors, and departments and agencies under its control. [Article II](#) of the Constitution outlines the nature, roles, and responsibilities of the executive branch. The departments and agencies under the control of the executive branch are established through Congress. Typically, the executive branch is responsible for implementing and "filling in details" of laws passed by Congress. The [Kaiser Family Foundation](#) provides an excellent overview of the role of Congress and the executive branch specifically as it relates to health policy.

The executive branch shapes and can establish policy in several ways. Three ways that are particularly relevant to domestic policy include: 1) The executive branch can establish policies through rules and regulations of federal agencies under their control, tasked with implementing laws passed by Congress. 2) The president may issue an executive order. The [ACLU describes](#) an executive order as “a written directive, signed by the president, that orders the government to take specific actions to ensure the laws be faithfully executed.” All presidents have issued executive orders. However, the second Trump administration has signed [more executive orders in the first 100 days](#) in office than any other president and has signed the fewest bills passed by Congress into law. Executive orders can be reversed by future administrations without the approval of Congress 3) The executive branch can set policy priorities through the budget proposal process ***Note** Congress ultimately controls the budget and a budget passed by Congress and signed by the president is law. The president may also influence public policy in other ways, such as proposing legislation and shaping public opinion on specific policies or groups that policies may impact.

Judicial Branch

[The judicial branch](#) consists of federal courts and the Supreme Court. Its makeup and responsibilities are established through [Article III](#) of the Constitution. The judicial branch shapes policy in part by deciding the constitutionality of federal laws and policies and often provides details on laws by determining how they should be applied in specific cases.

Categories of Federal Policies

Federal policies usually fall into four categories: 1) *Substantive policies* which are policies designed to address specific societal challenges. Examples of substantive policies might include criminal justice reform, education reform, immigration, and health care reform. 2) *Regulation policies* work to ensure organizations and industries operate ethically safely. Examples may include health care regulations, labor regulations, and environmental regulations. 3) *Distribution policies* shape how public services and goods are allocated without specifically taking resources from one group to give to another. Examples might include infrastructure projects and funding for public schools or universities. 4) *Redistribution policies* like distribution policies shape how goods and services are allocated but do so by shifting resources from one economic group to another. Examples might include progressive (or regressive) taxation and social welfare programs.

Key Policy Changes or Proposed Changes to Be Aware Of

People with disabilities or people who will have disabilities are part of all areas of our society. As such, all public policies are in some ways “disability policies” and can be viewed from a lens of [disability justice](#). There are some areas of public policy however that have or are likely to have a direct and disproportional impact specifically on people with disabilities, families of people with disabilities, and service providers. The chart below highlights nine policies that may be particularly significant. These were selected based on the following criteria:

- The policy directly expands or restricts health care and service funding for people with disabilities.
- The policy directly expands or restricts primary funding sources for agencies that support and or provide advocacy for people with disabilities and their families.
- The policy directly expands or constricts accessibility of public spaces, rights, utilities, and/or services such as education, housing, voting, employment, government websites, and buildings.

Policy Name & Type	Policy Overview	Potential Impact on Disability Organizations and People with IDD	Policy Status (as of June 2025)
<p>Changes To U.S. Department of Energy Direct and Final Rule</p> <p>Executive Branch/ Regulation Policy</p>	<p>The Direct and Final Rule aims to rescind regulations related to nondiscrimination for new buildings using federal funds from the agency.</p>	<p>Though it may not impact your program specifically, the policy eliminates a rule that had been in place since 1980 related to Section 504 of the Rehabilitation Act that requires new buildings receiving funding from the agency be accessible to disabled people.</p>	<p>Direct Final Rule is effective starting July 4, 2025, unless “significant adverse comments are received by June 16, 2025.”</p>
<p>Budget Bill</p> <p>Legislative Branch/ Distribution & Redistribution Policy</p>	<p>The Congressional Budget and Impound Control Act requires the president propose a budget to Congress for the upcoming fiscal year to fund the government. The budget serves as a “starting point” for Congress, however, Congress often makes significant changes. An identical resolution must be passed in both the House and Senate. This is a sweeping bill with many provisions involving lowering taxation, cutting spending on social programs, welfare reform, and increasing spending on defense, border security, and energy exploration.</p>	<p>The Budget Bill was passed by the House of Representatives (H.R.1-1 Big Beautiful Bill Act) and has the potential to have the most significant and direct impact on people with disabilities, families, and advocacy and service organizations.</p> <p>It stipulates more than 800 billion in cuts to Medicaid over the next 10 years. These cuts are anticipated to lead to a 10-20% reduction in funding for Home and Community Based Services, leading to longer wait lists, fewer services, and more limited and limiting support options. It would require a greater administrative burden to navigate increased work requirements. It increases premiums, co-pays for beneficiaries, and would lead to more frequent reverification check-ins.</p> <p>The \$300 billion in cuts to the SNAP program may impact both disability service workers and those with disabilities who use services. It may undermine the ADA and Olmstead Decision by limiting the support people need to live in the community.</p> <p>Approximately 8-16 million are expected to lose health care coverage due to Medicaid cuts.</p> <p>The final version of the budget is expected to have a detrimental impact on state councils for developmental disabilities, the lifespan respite program, and University Centers for Excellence in Developmental Disabilities.</p>	<p>The House passed their version of the budget (H.R.1-One Big Beautiful Bill) on May 22, 2025. As of June 17, 2025, the Senate Finance Committee released its version of the spending and tax bill that proposes even larger cuts to Medicaid. After significant debate and several rounds of voting, the tax bill was signed into law by President Trump on July 4th.</p> <p>Note in the time between this article was written and published the budget bill was passed by both houses of Congress and signed into law by the President.</p>

Policy Name and Type	Policy Overview	Potential Impact on Disability Organizations and People with IDD	Policy Status (as of June 2025)
<p>Improving Education by Empowering Parents, States, and Communities to Improve Educational Outcomes</p> <p>Executive Branch/ Executive Order/ Regulatory Policy</p>	<p>This executive order seeks to close the U.S. Department of Education.</p>	<p>Though the stated aim of this order is to give families and local communities greater say in how special education services are administered and some families may feel like they have more voice, the increased local control and decrease in oversight of IDEA and other federal protections could result in a loss of services, weaken protections that guarantee established rights related to education and lead to greater inequity in services across communities.</p>	<p>The executive order was signed on March 20, 2025. Though fully abolishing the Department of Education requires Congressional approval prior to the passage of the act, the Department of Education reduced its workforce by 50%. The agencies' civil rights enforcement and research offices were some of the most impacted. On May 22 2025 a federal judge ordered the administration to reinstate more than 1,300 of its fired employees and prevented moving other employees to other departments. Supreme court ruled in favor of Trump.</p> <p>"Note: In the time between this article was written and published the Supreme court ruled in favor of the Trump Administration"</p>
<p>Ending Radical and Wasteful Government DEI Programs and Preferencing & Restoring Equality of Opportunity and Meritocracy</p> <p>Executive Branch/ Executive Order/ Regulatory Policy</p>	<p>The stated aims of these orders are to end Diversity, Equity, and Inclusion and Accessibility (DEIA) programs and offices across the federal government and discourage DEIA programs in the private sector.</p>	<p>Though federal agencies are still required to follow The Rehabilitation Act and the Americans with Disabilities Act, this executive order removes staff and agencies dedicated to enforcement and technical assistance.</p> <p>This order may impact Section A in federal hiring which allows agencies to recruit individuals with disabilities through a specialized process which may reduce the number of disabled candidates for federal jobs. The order targets contracts and grants that have labels related to the term "equity." Many agencies that serve people with disabilities rely on federal grants that use language related to equity. As such, the order may reduce the availability of federal grants for disability service organizations.</p>	<p>The executive order was signed on January 20, 2025. On February 21, 2025, a Federal court in Maryland issued a nationwide injunction blocking the administration from two of the executive orders' provisions:</p> <ol style="list-style-type: none"> 1) Orders to "terminate... 'equity related' grants or contracts" and "include in every contract or grant award a certification that the contractor or grantee 'does not operate any programs promoting DEI that violate any applicable Federal anti-discrimination law.'" 2) Blocked attorney generals from taking "appropriate measures to encourage the private sector to end illegal discrimination and preferences including DEI." <p>On March 14, 2025, a panel from the U.S. Court of Appeals for the 4th Circuit granted the government's motion to stay the injunction pending appeal, meaning the provisions of the executive order can continue until the appeal.</p>

Policy Name and Type	Policy Overview	Potential Impact on Disability Organizations and People with IDD	Policy Status (as of June 2025)
<p>Protecting American Communities from Criminal Aliens</p> <p>Executive Branch/ Executive Order/ Substantive Policy</p>	<p>This executive order focuses on increasing resource allocation to identify, detain, and remove people who are in the United States without legal status. Though the executive order specifies prioritizing people who have been convicted of crimes, it is being applied to impact any person without legal status. Relatedly, the Department of Homeland Security has revoked the Temporary Protected Status for Venezuelans, Haitians, and Afghans.</p>	<p>Immigrants make up over 28% of the direct care workforce for long-term care services and 32% of the workers in home health care settings.</p> <p>Worksite immigration raids, increased visa restrictions, and the removal of Temporary Protected Status may disrupt not only the lives and safety of the workers, but also the availability of the caregiving workforce.</p>	<p>The executive order was signed on April 28, 2025.</p>
<p>Reinstating Common Sense School Discipline Policies</p> <p>Executive Branch/ Executive Order/ Regulatory Policy</p>	<p>The stated aims of the executive order are to rescind prior policies that aimed to limit suspensions of expulsions and other disciplinary actions where there were racial disparities in school discipline practices. It also encourages schools to use stronger discipline practices in order to maintain school order and gives teachers and school staff more authority to address behavioral concerns without as much federal oversight.</p>	<p>Children with disabilities who are already more likely to be suspended or expelled may now be at greater risk. There is a greater chance children will be denied access to education in a least restrictive enrollment and may have fewer resources to address discrimination.</p>	<p>The executive order was signed on April 23, 2025. The directive is in place but may be impacted by lawsuits related to challenging the Department of Education’s DEI discipline policies and staffing cuts.</p>

Policy Name and Type	Policy Overview	Potential Impact on Disability Organizations and People with IDD	Policy Status (as of June 2025)
<p>Reorganization of the Department of Health and Human Services</p> <p>Executive Branch/ Executive Order/ Regulatory Policy</p>	<p>The changes primarily involve a consolidation of several of its divisions in accordance with the executive order related to government efficiency and workforce optimization initiative. Specifically, it creates the Administration for Healthy America which will combine five different offices including the Office of the Assistant Secretary of Health (OASH) and the Substance Abuse and Mental Health Services Administration (SAMHSA) among others. It will also close five of the HHS's 10 regional offices, create the Office of Strategy that merges Assistant Secretary for Planning and Evaluation with the Agency for Health Care Research and Quality, and will effectively eliminate the Administration for \Community Living (ACL) by moving some critical programs into other HHS agencies.</p>	<p>The reorganization of DHHS is likely to change access to services by moving the offices that run critical programs. The closure of the Administration on Community Living will impact states' ability to meet the needs of their residents with disabilities, ensure critical civil rights protections, and promote systems change through the University Centers for Excellence in Developmental Disabilities and other partnerships. This will likely have a grave impact on UCEDD's, state Councils on Developmental Disabilities, and Protection and Advocacy System. States will have less support for education, healthcare, and employment for people with disabilities and without needed supports and civil rights protection more people with disabilities may be placed in restrictive, dangerous, and institutionalized settings</p>	<p>As of May 7, 2025, at least 20 attorneys general are suing to block the dismantling of the ACL and other federal health agencies. As of June 18, 2025, the lawsuits are pending.</p>
<p>A.J.T. v. Osseo Area Schools</p> <p>Legislative Branch/ Supreme Court Ruling/Regulatory Policy</p>	<p>This Supreme Court ruling found that plaintiffs did not need to meet the high standard of proving "bad faith or gross misjudgment" in suing a school district for a violation of the ADA.</p>	<p>This rule makes it easier for students with disabilities to sue should a district violate their right to accommodations.</p>	<p>The opinion was issued on June 12, 2025, with a 9-0 vote.</p>

What does this mean for me?

- **Take a breath.** There are a lot of changes happening and many of these changes may feel scary and overwhelming. Find strategies to stay well, grounded, and embodied. This may involve [self-compassion breaks, movement breaks, taking time to engage in hobbies, and connecting with those you love](#).
- **Double down on [community and community care](#).** Self-care is only possible in community. Find ways to support those around you and connect with helping resources if needed.
- **Take time to learn about the history of prior social movements and struggles.** Learning how others have navigated challenges in the past can spark ideas for paths forward and remind us of our power to impact history.
- Find trusted outlets and strategies to **stay informed without being flooded**.
- **Consider what you value** and where you stand related to potential policy changes. Learn to **put your positions into words**.
- **Use your civic power.** When you know what you want and what you don't want related to policy issues, let your lawmakers know, vote in alignment with your values, become connected with civic organizations, and take action by showing up in ways you are able (protests, demonstrations, sharing good information, donating to advocacy organizations).

What Does It Mean for My Organization and the Field?

- **Some policy changes threaten organizations in the disability field and may prompt setbacks.** Organizations like DD Councils, UCEDDs, Protection and Advocacy Organizations, offices within the Administration on Community Living, and others may lose hard-fought gains in civil rights protection and community inclusion for people with disabilities. The proposed cuts to Medicaid are potentially devastating to people with disabilities, family members of people with disabilities, and service organizations alike.
- **Continue to build and join diverse coalitions of groups with similar goals to enhance political influence.** The field as a whole and individual organizations are not without power.
- **Disability professionals should continue to learn how to effectively tell their story** about who their organization is, why their work matters, and what resources are needed to stakeholders, the general community, and lawmakers (see “Tools and Resources to Educate, Advocate, and/or Lobby” in this issue of the Bulletin) later in the issue.
- **Continue to craft a vision for the future disability field.** When times are tough, it is natural for us to focus all our time and energy on dealing with the major crises at hand. That is necessary and important; however, it is also important that professionals in the field continue to find ways to communicate a positive vision instead of focusing only on what we want to avoid.
- **Diversify funding streams where possible.** Though the pain from federal funding cuts or freezes may not be avoidable, thinking strategically about how the field can support the development of and help organizations connect with other funding streams like private foundations that may help offset some losses.

- **Advocate, educate and lobby, when possible.** Educate lawmakers about the impact of these changes on the field. Though there are some limits, [it is legal for nonprofits to lobby](#) lawmakers on matters that impact them and the people they serve. Advocacy and lobbying are somewhat different. There are some restrictions on the amount of nature of lobbying that can be done on behalf of a nonprofit organization. There are no such restrictions on advocacy.
- **Support people with disabilities and disability advocacy groups who are engaging in direct action.** Disability advocacy groups like [ADAPT](#) have been engaging in direct action (like sit-ins) to influence change which results in travel and legal costs. Groups with more financial resources who may not be able or willing to engage in direct action may choose to support those that do.
- **Think creatively and strategically about how you can effectively buffer your staff and the people you serve from potentially negative changes.** It may be sharing local food assistance, housing assistance, mental health assistance, and legal assistance programs that are not fully reliant on federal funds, for instance. It may involve sharing information about people’s rights in plain language formats.
- **Use your voice, your time, money, and energy to speak to and support human dignity.** We are not bugs and these policies aren’t windshields. We are part of systems and systems made up of people and people can create change. Some actions promote the roots of change that we cannot see right away.
- **Remember that hope is a skill.** It’s one that involves a vision for a better tomorrow, identifying possible paths to get to that vision and believing we have the agency needed to navigate the paths ahead. The history of the Disability Rights Movement is long, and though we find ourselves at a critical moment, it will continue. Like many generations before us, we find ourselves in a moment that needs us. As former U.S. Representative from Texas Beto O’Rourke recently said, [“Your country and history are calling and you have got to show up and give this every single thing you have.”](#)

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Courageous Leadership: Doing the Right Things While Under Fire and Under Threat

By John Raffaele

- People with disabilities and the disability services system are at risk because of the drastic cuts and changes to the federal government.
- We need courageous leaders to navigate and help shape federal policy changes. Courageous leadership involves people speaking up and helping people with IDD to speak clearly about why cuts to Medicaid and other important programs are dangerous.
- Courageous leaders also help advocate for fair wages, training, and support for direct support professionals.
- Courageous leaders make sure their actions come from their care for others and are in line with what they value.

Courageous leadership in intellectual and developmental disabilities service organizations — especially during times when Medicaid and other foundational supports are under threat — demands moral clarity, advocacy, and unwavering commitment to human rights and dignity. This is a time in American history that is unprecedented with threats to our federal protections of vulnerable Americans has never been so grave. As we each attempt to navigate these turbulent times, let's examine what courageous leadership looks like in action, and the kind of advice that best serves our entire service system: people with disabilities, families, direct support professionals (DSPs), and organizational administrative/ executive staff.

What Does Courageous Leadership Look Like?

It begins with anyone who is impacted by the policies, legislation, and actions of our representatives and lawmakers. We all have an obligation to advocate for our interests, both publicly and politically. In that sense, we are all leaders. [The First Amendment](#) of the United States Constitution provides all of us with the right to freedom of religion, speech, press, assembly, and the right to petition the government. Leadership in the disability field requires us to speak out clearly and consistently for the importance of Medicaid and related funding streams. We must educate policymakers about the critical role Medicaid plays in community living, access to services, and the workforce that enables those supports to exist and function. Courageous leaders will encourage nonpartisan and non-violent mobilization of staff and families to contact legislators and participate in public forums. We can do these things if we are working in an executive capacity or practicing our occupation as a direct support professional. Our official job title does not matter.

Being Person Centered

Person centered supports require us to center our focus on people with disabilities in all decision making, including public policy advocacy, especially in times that are deeply threatening the funding and policies of supports and services. Directly involving people with disabilities in organizational planning, advocacy efforts, and leadership is a cornerstone of our courageous leadership. We must treat the people we support not just as recipients of services, but as citizens, advocates, and experts on their own lives. Too often we are not driven by the time-tested self-advocacy mantra of “Nothing about me without me,” and we must never forget that without directly hearing from those that will be personally affected by any changes in policy and funding, we are not being truly person centered.

Fair Wages for DSPs

Direct support professionals are the foundation of our intellectual and developmental disability supports system. The valuation and elevation of all direct support professionals must be in the highest of priorities for all courageous leaders. Fair pay for this workforce has always been challenging. Many provider support organizations have created internal means to improve the meager standard wages of direct support workers as the national and state averages for fair wages aren't in existence. Courageous leaders will prioritize the wages as best they can and, even in the face of massive budget cuts, they will continue to advocate and rally for living and professional wage compensation in rate setting and policy actions.

Training and Support for DSPs

Direct support professionals can greatly benefit from higher and fair wages but let us not be mistaken that wages are not the only thing to consider in courageous leadership. Organizations and leadership should offer training opportunities that meet the interests and needs of the workforce. These expanded training opportunities should exceed the bare minimum requirements for training and feature topics that can enhance the professional development of the workforce. Mental health supports and trauma-informed practice training is invaluable, and we should never underestimate the impact that low wages, working multiple jobs to make ends meet, arranging for family, and child-care coverage, as well as the complexities and challenges that accompany this type of direct care work, can lead to burnout and compassion fatigue. Be proactive in training all staff about disability rights, advocacy, and systemic equity.

Career Advancement Paths

Courageous leaders will make sure that there are ways and opportunities for career advancement within the agency. Direct support professionals can specifically benefit from internal career ladders and lattices which serve to maintain retention and reduce turnover. These are key factors in making a sustainable organization. Despite the threats and impacts from negative funding and policy decisions, when organizations have mechanisms to keep staff involved, motivated, and inspired to continue on a job path within the organization, there will often be positive impacts and outcomes and positive organization cultural development.

Lead with Integrity

When anyone in leadership discusses higher-level issues (Medicaid, Medicare, health insurance, policy changes, political issues etc.), they must be empathic, honest, and transparent to those in their charge. Our courage must always be informed by empathy and self-awareness. We must always communicate clearly with our staff, the people we support, and their families about funding threats, policy changes, and our organizational responses. Effective and sustainable leadership seeks to build trust through honesty and by demonstrating moral integrity — even when current events are difficult and frightening.

Build Partnerships

We have an opportunity in these times to build coalitions and community organizational power and maintain commitment to disability rights and protections. There has never been a better time to partner with other providers, disability rights groups, and health organizations to form a strong, unified voice. Collectively, we can recognize that systemic threats require allied responses — not isolated actions. Either initiate community events that are associated with the issues and concerns of which include or seek to participate in them. Good leaders will ensure self-advocacy is highly



supported. Organizations must provide resources and tailored and specific training for individuals to speak up about their needs and rights. There must always be consideration of using and ensuring access to adaptive augmentative communication devices and technology to make sure the voices of non-speakers are protected and respected. The protection of autonomy and independence becomes critical at this time. Courageous leaders will not let budget cuts become an excuse for institutionalization or reduced community participation.

Prioritize Values in Budget Planning

Finally, be courageous in budget planning — prioritize person-centered supports and quality services and program continuity over bureaucratic expediency and pressure from our system. Look at your balance sheet with a critical and visionary eye. Where are your priorities as an organization? Are you leading with your mission, vision and values first? Make all decisions reflect your organization’s mission, not just what’s politically correct or accepted. Courageous leadership is not just about responding to a threat — it’s about rising above threats and creating opportunities for advancement and growth. It is about manufacturing and raising expectations of inclusion, justice, and equity, and refusing to let fear or funding cuts erode the essential humanity of our cherished work.

Action Steps for Courageous Leaders to Take Right Now

Here are some practical things that you can immediately do as a courageous leader directly from the National Alliance for Direct Support Professionals:

- **Call your U.S. Senator:** Call your U.S. Senator and leave a message telling them you oppose the defunding of Medicaid and tell them you expect them to protect critical human and health services for people with intellectual disabilities. Call 1-202-224-3121 and ask for your state’s U.S. Senator’s office or search [this website](#) for their phone number or email. Use [NADSP’s VoterVoice Campaign](#) to connect with senators.
- **Write a letter:** Write a letter to the Editor of your local newspaper. Tell them how you feel about Medicaid cuts potentially harming disability services and jobs.
- **Educate Others:** Work with a leader of your disability program to educate fellow employees, families, and others about the harm to Medicaid. Here is a good resource: [A Self-Advocate’s Guide to Medicaid](#)
- **Connect with Your Local Media:** Write or call your local media outlets including newspapers, local digital media outlets, radio stations, etc., and urge them to do a news story on how local people with disabilities may be impacted by cutting Medicaid.

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Staying the Course in Uncertain Times: Advocacy, Strategy, and Action for Disability Service Providers

Conversations with Steven Eidelman, Nancy Weiss, and Janet Butler, collected, recapped, and elaborated on by Cory Gilden

National Leadership Consortium founders Steven Eidelman and Nancy Weiss shared critical insights into the current threats to community-based services and the strategic actions to help service provider leaders navigate the months and years ahead. Janet Butler, CEO of Community Systems, Inc., a disability service provider in Connecticut, Delaware, Massachusetts, and Virginia, also contributed her perspective on current changes in the field. These interviews took place in mid-June, so by the time you are reading this, things may have changed.

- It's important for service providers to advocate, professionally or personally, for programs that support people with IDD.
- Service providers can strengthen their advocacy efforts by collaborating with other organizations, the people with IDD they support, and the families of people with IDD.
- Service providers can stay stable and continue to innovate during times of change by having a mix of funding sources for their programs and having plans ready for different scenarios, like what they would do if some of their program funding changes.
- As the policies continue to shift rapidly, disability service providers face heightened policy and funding uncertainty — especially people and organizations that rely on Medicaid funding.

The Policy Environment: A Backlash in Motion

After a period of expansion under the Biden administration, including increased enforcement of [Olmstead](#) and the [Civil Rights of Institutionalized Persons Act \(CRIPA\)](#), advocates brace to weather an ideological backlash. Eidelman warns, “The Trump administration isn’t likely to reverse course out of principle — it’s more about doing the opposite of what Biden did.” That could mean less federal oversight of institutional care, a weakening of protections for people with disabilities, and cuts to key programs and funding sources for people with disabilities. The field’s long-standing reliance on Medicaid leaves providers vulnerable. “Being dependent on one cow to feed our milk is coming to bite us in the backside,” Eidelman noted.

Butler agreed that relying on one funding source can be detrimental. “Going forward, the long-range look has to be — how do we stop being held hostage in this world that can sink us so quickly?”

The Need for Unified Advocacy

Weiss and Eidelman stressed that now more than ever, all stakeholders, including providers, families, and self-advocates, must recognize their role in advocacy. It can no longer be left to national organizations alone. “People can’t just say, ‘Well, ANCOR is going to do it or The Arc’s going to do it, or TASH is going to do it.’ Everybody’s got to be involved, regardless of their political leanings,” he said. “If you think these programs are important, they’re not going to get supported unless people say they have to be supported. You must to get involved in politics as if your life depends on it,” Eidelman said,

echoing the late disability rights movement advocate [Justin Dart](#). Weiss added, “You don’t need to be a Democrat or a Republican to take a stand on this issue.” They mentioned that even working for a nonprofit that may have restrictions on advocacy and lobbying efforts, professionals can use their personal email on their own time, to reach out to legislators about policy changes.

Everybody’s got to be involved, regardless of their political leanings, if you think these programs are important, they’re not going to get supported unless people say they have to be supported. You must to get involved in politics as if your life depends on it.

Strategic Actions for Service Providers

To survive and continue delivering quality services, providers must plan for instability and take proactive steps now. “This really isn’t a time of change,” Butler said. “It’s a time of chaos that we haven’t seen as a field. So, you wonder, ‘Should I panic? Should I change? Should I take a different avenue?’ And then everything halts and gets overridden by judges. So, I think it’s different than normal change. That’s gradual. Chaos means you have to be prepared in the here and now because it can go in many directions.”

Here are some strategies leaders of service provider agencies and other organizations in the field can use to prepare during times of chaos:

- **Unify across organizations**

Collaborate with advocacy and provider groups, even those you haven’t historically partnered with. Increased collaboration is already emerging, and it’s essential for collective power.

- **Use your voice legally and strategically**

Staff at nonprofits can engage in advocacy using personal time and email accounts. Know the rules and act accordingly. Check with an attorney or the Secretary of State’s office in your state with any questions about how to approach advocacy in your personal time.

- **Maximize waiver flexibility**

Every state’s Medicaid waiver is different. Advocate to:

- ◆ Add optional services like dental, transportation, or employment support and prioritize needed services.
- ◆ Preserve flexibility in your next five-year state waiver renewal.

- **Empower people with disabilities and families**

Support individuals and families in becoming visible and active advocates. Make sure they:

- ◆ Understand how funding and legislation affect their services.
- ◆ Know how to contact policymakers and testify when needed.

- **Increase Communication and Emotional Support**

- ◆ Keep the people you support and their families updated on the latest information and how it may impact them.
- ◆ Keep your staff informed and let them know how systemic changes may affect your organization.

“I think it goes to communication. One of the things we recognized in January, when the Administration changed and so much was flying around was that people were afraid.” Butler said. She spoke about the importance of open communication and taking opportunities where you can to console and calm people. “We said, ‘Let’s communicate with them. Let’s just let them know — We know you’re afraid.’ We did it with families. We did it with staff. We’ve tried really hard. It’s been in our newsletter and other things like that to just say, ‘We know it’s scary out there. We’re staying on top of this. We need you to help us to advocate. We’re paying attention to it,’ and ‘If you have questions, bring them forward.’”

- **Diversify funding streams**

Reduce over-reliance on Medicaid by tapping into:

- ♦ Behavioral health and substance use funding
- ♦ Affordable housing and homelessness services
- ♦ Children and aging services
- ♦ Property management or mission-aligned business ventures
- ♦ Community business partnerships
- ♦ Fundraising

“The reality is, if you’re in the IDD world, you can’t diversify your revenue without diversifying your services, because really the only funding tunnel is through the Medicaid waiver through those services. Medicare is not paying for IDD services and private insurance is not paying for them. So, if you want to stay in the IDD world, you have to supplement your world with other services, maybe a clinic, maybe behavioral health services that can help you to break into the private insurance pay way. You have a balance in your funding,” Butler said. “It’s not going to be that you’re going to get somebody else to pay for the IDD stuff. I’ve been doing this a really long time, and it’s not out there.”

- **Contingency planning with boards**

Prospectively develop concrete contingency plans imagining different scenarios:

- ♦ What would a 20% or 40% funding cut look like?
- ♦ What services could be protected or paused?
- ♦ How would staff and stakeholders be impacted?

“Make a plan so that no matter what happens down the road, you know what you would do,” Weiss said. Butler describes how her organization plans for change. “We have prepared budgets that look at a 10%, a 15%, a 20% cut. We have them in each of the 4 states we operate in. So that when someone comes along just with the continuity of operation plan and says, ‘We’re taking 5%,’ or ‘We’re taking 20%,’ we’re ready to go. It’s not a surprise.”

Eidelman agreed, “You’ve got to be prepared because you can’t predict it. It’s moving too fast, and the alliances are shifting too fast to understand what’s happening. By the time you get a newsletter for state or local associations, it’s two changes down the road.”

This is not just another period of transition, said Eidelman, Weiss, and Butler — it’s a potential inflection point for the disability service system in the U.S. Past policy changes often expanded services and rights. But today’s environment may bring contraction and retrenchment.

“There haven’t been other times like this,” Eidelman warned. “This is a frontal attack.”

Facing this reality requires both courage and clarity from disability leaders. The service provider field must remain grounded in its values while evolving its strategies.

*“There haven’t been other times like this,”
Eidelman warned.
“This is a frontal attack.”*

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Nancy Weiss is a founder of the National Leadership Consortium and a retired professor at the University of Delaware. Nancy has more than 40 years of experience in the disabilities field and has worked relentlessly to end the use of aversive procedures and promote supports and policies that inspire inclusive communities and the rights of people with disabilities. Contact Nancy at nancyrobinweiss@gmail.com.



Janet Butler is the President/Chief Executive Officer of Community Systems, Inc., is a committed leader, supporting persons with intellectual and developmental disabilities to find happiness in their lives for more than 40 years. She holds a BS in Nonprofit Administration from Skidmore College and an AS in Nursing. Janet is passionate about growing leaders for the future with a values focus on compassion, commitment, and integrity. Contact Janet at jbutler@communitysystems.org.



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The Importance of Medicaid Advocacy

By Jessica Renner

Jessica Renner is a self-advocate and Administrative Coordinator for Self-Advocates in Leadership (SAIL) at The Arc of Washington State. Jessica shared her perspective and experiences about the importance of Medicaid for people with co-occurring IDD and mental health support needs.

- Medicaid can be a lifeline for people with IDD.
- Talk of cutting Medicaid is a source of stress and anxiety.
- High staff turnover and a reliance on inexperienced staff is a barrier to good mental health care.
- Self-care, mental health, and physical health care are all important to wellbeing.

My name is Jessica Renner. I am a 43-year-old female who has cerebral palsy. I use a power wheelchair to get around my house and to get out in the community here in Sequim Washington where I live with my brother who is also my caregiver. I also have caregiver supports with other individual providers, or IP's. I am on Social Security income (SSI) and I also work part time for The Arc of Washington State as the administrative coordinator for Self-Advocates in Leadership (SAIL). SAIL is a coalition of 200 people across the state of Washington with intellectual and developmental disabilities (IDD) that focuses on legislative advocacy.

Cuts to Medicaid would be devastating in my life! It would also cause a great deal of mental stress and anxiety. Not only are my doctors covered under Medicaid, but so are my prescription medications, my wheelchair repairs, and my home equipment repairs such as my Hoyer lift that is used to help me transfer. Cuts to Medicaid would mean none of the things I mentioned would be covered! I don't make enough money to pay for all this out of pocket! Cuts to Medicaid would also put the caregiver services at risk! Without caregivers I would not be able to perform my activities of daily living such as dressing, transferring, toileting, and meal prep. Without these services I wouldn't have much of a life! Medicaid allows me to stay in my own home, and any change to that would cause a decline in my health both physically and mentally. I do not want this, and I know a lot of people in the IDD community don't want this either. Cuts to Medicaid would send a bunch of people to hospitals, which would be a huge step backwards!

When you talk about Medicaid cuts, they would be literally impacting folks' ability to go to bed each night in their own home and be a part of their community.

We're already working with limited resources, and without Medicaid I really don't know what I would do! I would probably end up stuck in the hospital to get the care I need. I would lose my in-home care services, meaning my current caregivers wouldn't be paid!



Healthcare is already not the best in Sequim, Washington, where I live, so a lot of the time I travel out of the county on Paratransit to have my needs met properly. Cuts would mean I would no longer have paratransit services as they are paid for by my Provider One Number with Medicaid. I'm not rich by any means and losing these services would mean I would have to go full-time with my job and doing so would add more to my plate along with more stress, but this would be my only option otherwise I wouldn't be able to do anything! Medicaid is my lifeline and everything inside me doesn't want Medicaid cut!!

I don't utilize mental health services currently, but I have in the past with Sound Mental Health Services. I was always put with young students, which on one hand was good because I could share anything on my mind and the counselors would find creative ways for me to channel my stress and anxiety into doing activities whether it be coloring pages, painting flowerpots, making care packages, or planting flowers. These activities gave me positive things to focus on. In that respect, I really enjoyed my time with Sound, but on the other hand there were such high staff turnover that as soon as I got used to someone, they would leave to go to school or for another job, meaning I would have to start services with someone new.

I know being on Medicaid, sometimes you need to take what is available, and that is not the best because your choices are limited. After four or five times switching staff, I moved to Sequim last year and discontinued services. These days, I enjoy going out for coffee, going to the movies, and getting my nails done. I still have creative outlets with coloring books, word searches, and painting kits and community outings to manage my stress and anxiety!

Mental health services look different for every person, but if I wasn't given the proper tools to turn my focus away from the negative, I wouldn't be who I am today! One of my favorite sayings is, "Mental health is self-care, both physically and mentally. Without both together, I am not complete." I'm sure I'm not the only one thinking this. With Medicaid cuts, mental health services will be cut, which will make a huge cut in people's lives and wellbeing!!!

Jessica Renner is the Administrative Coordinator of Self Advocates in Leadership SAIL, a coalition of 200 people across Washington State that focuses on legislative advocacy. Jessica holds an Associates of Applied Science Degree in Engineering Design Technology. Jessica studied at Renton Technical College. Jessica is passionate about advocacy and strives to help other self-advocates reach their full potential in their own journey through advocacy.

Contact Jessica at Sail@arcwa.org. Visit the Sail website at <http://www.selfadvocatesinleadership.com>



Crisis and Opportunities: How U.S. Funders are Adapting to Public Changes

By Caitlin Bailey

Much of the information shared in this article comes from conversations the National Leadership Consortium had with funders, as well as an investigation of websites, communications, and information from funders and philanthropy experts. The article mainly focuses on the impact of current political and economic changes on private funding (including foundations, trusts, corporations, and individual donations).

- Changes being made by the federal government will change how organizations and people give money to organizations in our field.
- People and organizations donate and provide grants differently during challenging political times. We don't know what current changes will mean, but we do know that organizations in our field are worried they will have cuts in funding.
- Leaders can get creative to try to get needed funding from private organizations and donors. Organizations can partner with other organizations when writing grants. Leaders can work on communication and telling the story of need and impact on people with disabilities and organizations.

Although funders, including foundations, trusts, and donors, have significant control over what and how they choose to fund, they also have a responsibility to use their resources in ways that are responsive to the times. For instance, in the last decade, many individual and organizational funders that traditionally put their dollars toward developing legacy services and segregated buildings (day centers, group homes, institutional facilities) that then bore their name, have updated their priorities to instead support efforts (services, technology, operations) that enhance inclusion for people with disabilities.

We are in a time when federal funding for innovation and development in our field is uncertain at best. Federal and state government and legislators and officials have both [proposed bills](#) that roll back protections for people with disabilities and publicly discussed the potential benefits of segregated supports for kids and adults with disabilities. There has also been an increased focus from the Department of Health and Human Services on [‘curing’ and preventing Autism](#), signaling a potential shift backward in government support for inclusion and disability pride. Additionally, in April 2025, [a leaked draft](#) of the proposed 2026 OMB budget revealed serious threats to funding for the DD Network (which includes state DD Councils, Protection and Advocacy Agencies, and University Centers for Excellence). In late January 2025, many recipients of DD Council grants were told to stop work on their projects for a day or two when an [executive order](#) announced and then withdrew a pause on federally funded grants. Now that policy changes have been approved to administer devastating cuts to public benefits and increased tax burdens on modest-income families, the competition for private funds will likely intensify. This is especially true for organizations seeking to advance the human rights that are being threatened by federal and state legislative decisions.

Further, in 2026, changes to individual and corporate tax structures mean that there will be a higher floor on deductions for [charitable giving](#) (you have to give more to qualify for tax deductions). [Experts predict](#) this could mean that charitable giving will either decrease or be provided in larger amounts to fewer organizations.

Philanthropic support, particularly for the nonprofit sector, has [declined](#) over the last five years. [Political](#) and [economic](#) turmoil are compounding factors, hitting organizations reliant on charitable giving and private funding harder when they may need it most. People are cautious about giving when they feel less certain about the stability of their personal or organizational funds. However, during challenging political times, many foundations, corporations, and individual donors with the capacity to do so increase their support for organizations that are working to promote the wellbeing of those most impacted. Some call it [rage giving](#). For instance, giving to organizations that provide legal aid and support for immigrants [increased substantially between 2016 and 2020](#). There was a similar trend in giving to organizations focused on promoting [racial equity](#) and addressing [climate change](#) during the 2020 presidential election and what [NPR](#) called the Summer of Racial Reckoning. Many people are motivated to fund what the government won't, particularly when their preferred political party is not in power.

Philanthropy in the Recent News

Recently, the Bill and Melinda Gates Foundation made [big news](#) when Bill Gates announced that it would close its doors and cease operations in 20 years. They are promising an 'all-in' approach to rapidly spend-down the endowment and a large portion of Gates' wealth, sharing that the future is more promising, and the investment now will help to secure that. Many are skeptical of their stated reason, given that this announcement coincides with Federal decisions that are largely cutting government funding and aid to many of the groups the Gates Foundation has backed.

Also noteworthy, a report from the [Center for Effective Philanthropy](#) evaluating the impact of [Mackenzie Scott's](#) controversial approach to giving away approximately \$19 billion in unrestricted funds has found that the approach has been transformational for the organizations and communities that received funding. Some of that funding went to disability rights organizations.

While we must wait to understand the financial impact of the current climate on our field, a preliminary analysis conducted by the National Leadership Consortium team found that foundations that fund organizations in the disabilities field are responding in different ways. Some have taken a business-as-usual approach, while others have paused new funding opportunities (for now) to determine how to maximize the impact of their support.

Other foundations have adapted their strategies to be as immediately responsive as possible to the communities they fund. For instance, some organizations have increased efforts to reach out to grantees, offering flexibility in how funds are used as unanticipated needs and challenges arise from the fallout of public priorities. Similarly, those same funders have encouraged grantees to reach out should they need additional funding. While they aren't making promises, they want to make leaders aware that they are there to help and will do what they can. Grant managers have also offered increased technical support to organizations applying for and in receipt of funds. They want to make it clear that they trust organizations to understand what communities need, and they want to update their efforts to provide effective support.

Recently, funding opportunities have also been created in direct response to legislative and policy decisions. These include opportunities to support advocacy and research efforts to protect Medicaid, as well as funds dedicated to supporting underserved and rural communities that will be most impacted. During the Pandemic, many giving organizations took similar action, allocating funds to ensure the sustainability of organizations that were helping people most impacted by COVID-19.



What Leaders Can Do

Ultimately, we don't know what the impact of the current political and economic climate will be on private giving for our field; however, historical trends may provide a call to action for leaders of organizations that rely on charitable support. Leaders can prepare by tailoring their outreach and communication with private donors and grant-giving organizations. Below are four recommendations that can inform funding strategies.

- Reach out to current and previous funders to understand how they are responding and what their immediate and future plans are for giving. You may also consider conducting a short survey or personal reach-outs to trusted individual donors to gain insight on the impact that changes in tax rules, policy decisions, and economic turbulence will have on their giving in the near future.
- Get creative, consider asking for accelerated flexible funds ahead of 2026 when the new tax structure goes into effect. Or seek alternate giving structures such as one suggested by the [Chronicle of Philanthropy](#) that uses contract agreements instead of grants to help organizations achieve their missions.
- Consider collaborative opportunities for grant seeking. If foundations and corporations do bundle their giving, they may be motivated to fund coordinated efforts that fund multiple organizations as primary and sub-contractors.
- Get clear about how you will communicate the impact of changes to funders. Avoid exploitation of people with disabilities by telling sad stories and instead put together direct and clear messages about how people with disabilities and organizations that support them will be impacted, and what funds will be used for. [Philanthropy Without Borders](#) and the [Storytelling Nonprofit](#) offer helpful suggestions.

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Navigating Change — One Nonprofit’s Perspective

By Karen Adams-Gilchrist

- A strategic plan is a road map for an organization to achieve its goals.
- Service providers should use their strategic plan to guide them through uncertain times.
- Using a strategic plan to guide decisions during times of change helps organizations stay true to their vision, mission, and values.

[Providence of Maryland Inc.](#) (“Providence”) has been part of its local community since its founding in 1961 and currently supports more than 300 people with intellectual and developmental disabilities to live their best lives. We believe that everyone can contribute and engage in their communities, and we work alongside each person to make this possible for themselves through real connections, real opportunities, and real experiences.

So how do we meet this mission through times of extreme change? At Providence, whether it was the pandemic, the current economic and political environment, or just the everyday situations that come with running a business, the answer is found in our strategic planning and our commitment to what makes us Providence.

Providence prepares for change in the same way that we plan for everything – with our strategic plan as a guiding force. Our strategic plan provides a roadmap to keep us on course, and with “real time strategy” work using a strategy screen, we can test and ensure that every business decision, whether taking advantage of an opportunity or meeting a challenge, is not only the best strategic decision for our organization but also aligns with our mission, vision, and values.

This work includes understanding the business landscape in which we operate and the potential impact that landscape will have on us and how we will respond. It’s obviously difficult to have definitive plans in place given the level of uncertainty and the evolving environment we are operating in today, but our real time strategy work helps us to adapt. It is a process that supports us to be agile in these uncertain times and to make quick, effective, and strategic decisions that support and align with our mission. We believe our real-time strategy approach has positioned us to do just that.

Given the array of the current proposed changes facing providers and the people we support, and the uncertainty of what these changes will really mean, our strategy is to continue to remain steady, aligning our efforts with our mission and our beliefs for people and our community. We will continue to:

- Live true to our values
- Invest in the staff who are the foundation of our organization
- Be transparent in what we know and what we don’t
- Listen and respond with authenticity
- Build a foundation of strength that positions us to respond to changes without giving up on our promise to people



Could some of the changes require us to think about adapting our business model, or instituting more agility in how we work, or even impact our staffing models? Absolutely, but it will not change our archetype to mentor and advocate for the empowerment of people with IDD, it will not change our dedication to action, and it will not change our intrinsic motivation to embolden the people we support, our families, our volunteers, our staff, our board, and our communities.

We have learned to embrace that “uncertainty is the only certainty,” and we operate from a place of growth, learning, and innovation focused on turning uncertainty into something manageable. The fact is: we have weathered storms before. The Providence family saw our organization come out of the recent pandemic stronger than ever. This was a result of our ability to be agile and adapt quickly, our financial strength, and our work as a learning organization to be in constant growth and improvement mode. It was also because we operate with an empowered team of leaders who *believe* in people and the meaningful and authentic connections where each person is heard, seen, known, and valued.

We as an organization will continue to lead through changes as we have in so many past instances with a level of steadiness, our mission, beliefs and values as our compass, and our real time strategy approach as our guide. It works for us.

Karen Adams-Gilchrist is President and CEO of Providence of Maryland. Karen received her bachelor's degree in Psychology from Bowie State University. Karen is passionate about people and has spent her entire career supporting people with intellectual and developmental disabilities to live their best lives in their communities. Contact Karen at kadams-gilchrist@providenceofmaryland.org



The Role of Immigrants and the Current Immigration Policy in Disability Services

By Daniel Boamah

- The Trump administration immigration policies' goals are to have less people from other countries come to live in the U.S., which could decrease the amount of people who can support people with disabilities.
- Immigrants, or people who move from one country to live in another, make up a large and growing part of the employees who work supporting people with disabilities, including 28% of all long-term care workers and 32% of in-home care providers — making them essential to keeping these services running.
- If many people are forced to leave the country or if rules make it harder for them to come here, it could cause big problems. Some programs that help people with disabilities might have to close. People may have to wait longer to get help, and the help they get might not be as good.
- Leaders should speak up for fair immigration rules. The rules should keep the country safe, but also treat people with respect. We also need more support and money for the people who give care, including better jobs and protection for immigrant workers.

The Trump administration's immigration policy agenda, characterized by aggressive enforcement, expansion of deportation priorities, and significant curtailment of both legal and undocumented immigration pathways, poses substantial implications for the United States labor market, particularly for sectors that are heavily reliant on immigrant labor. One such sector is the Direct Support Workforce which delivers critical care services to people with disabilities and other vulnerable populations. This analysis outlines the key components of these immigration policies, assesses their implications for the industry leaders, and provides a forward-looking view of the challenges these policies introduce to service provision, workforce sustainability, and quality of care. The paper provides recommendations to industry stakeholders for advocacy.

Overview of Trump Administration Immigration Directives

Framed under a national security narrative, "[Protecting the American People Against Invasion](#)," the Trump administration's immigration agenda aimed to drastically reduce unauthorized immigration, limit legal immigration, and expand enforcement capacity. A January 2025 [Executive Order](#) mandated:

- Maximum enforcement of existing immigration laws, including expedited removals and expanded detention.
- Revocation of previous guidance was deemed lenient, and federal agency directives were restructured.
- Mobilization of federal, state, and local law enforcement partnerships to assist immigration enforcement.
- Public legal notices to compel compliance by previously undocumented populations.
- Review and potential termination of funding to Non-Governmental Organizations supporting undocumented immigrants.

- Sanctions on foreign governments that obstruct repatriation efforts.
- Reassessment of protections such as Temporary Protected Status (TPS) and Parole Authority.
- Ordered Civil and criminal penalties against jurisdictions with “sanctuary” policies.

These actions reinforced a broader anti-immigration stance, including heightened visa restrictions, reduced refugee resettlements, and reinterpreted long-standing legal protections for immigrants, and dramatically shift from contemporary administrations’ approach with immigration in terms of tone, scale, strategy, and scope.

Comparative Policy Context

While immigration enforcement is [not unique to the Trump administration](#), President Obama oversaw over 3 million deportations, and President Biden approximately 682,000; President Trump’s approach is distinct in its explicit prioritization of mass removal, public deterrence strategies, and dismantling of humanitarian immigration channels. The administration pledged to remove over 10 million undocumented immigrants, a figure unprecedented in modern U.S. history.

Contributions of Undocumented Immigrants

This level of enforcement poses a direct threat to sectors employing large shares of immigrant workers, including undocumented immigrants. According to the [Immigration Research Initiative \(2024\)](#), undocumented immigrants are concentrated in:

- Service industry (29%)
- Construction (24%)
- Transportation (19%)
- Supervisory/management (17%)

These undocumented immigrant workers fill gaps in these labor-intensive industries and provide their needed human resources at relatively cheaper costs. Notably, these industries rely on a similar labor force that Home and Community-Based Waiver Services (HCBS) providers would need to support individuals and families. Hence, mass deportations would likely result in widespread labor shortages and increased labor costs, triggering structural instability in these sectors.

Additionally, regardless of status, immigrants significantly contribute to the U.S. economy. In 2022, undocumented immigrants paid an [estimated \\$96.7 billion in combined federal, state, and local taxes](#), including (many of the programs they are barred from receiving):

- \$25.7 billion in Social Security contributions
- \$6.4 billion in Medicare taxes
- \$1.8 billion in unemployment insurance taxes

Many of these tax-funded programs are under strain due to policy priority shifts at the federal and state levels of government. The loss of such contributions would intensify fiscal pressures, particularly in public health and social service funding mechanisms such as Medicaid.

Workforce Supply and Demographic Realities

In addition to removing immigrants from the U.S., the administration has taken measures to [restrict some aspects of legal migration](#). There has been a halt of almost all refugee resettlement, rolled back of parole and temporary protection status of some groups of asylum seekers (for example, the temporary status of people from Cuba, Haiti, Nicaragua, and Venezuela has been revoked), heightened visa restrictions, and travel ban of immigrants from specific countries from entering the United States. The net effect would be a significant disruption of the labor market, especially in labor-intensive industries such as the health and human services sector, where immigrants (both documented and undocumented) make up a significant share of the workforce.

The U.S. labor force outlook depicts a continuous significant decline in the labor force participation rate among the prime working-age population (25–64 years old) since the mid-1990s. According to the [Employee Benefit Research Institute \(EBRI\)](#), labor force participation among prime working-age adults (25–64) has been in long-term decline, with older workers filling growing gaps. This is not due to a reduction in the labor participation rate of the age group but relatively fewer members of them available to replace the aging workforce, indicating that the problem is structural and more likely to continue at least in the next few decades. Therefore, efforts to address the deficit, especially in sectors where technology cannot easily replace humans, should be of priority.

The data shows that the immigrant workforce has been a viable solution to the challenges in the labor market, and efforts should be scaled up to attract the needed employees for the future. [Immigrants represent 14.3% of the U.S. population and 17.7% of the working-age population](#). The participation rate of immigrants in the labor force in the U.S. is 19%, a rate higher than native-born workers.

In the service sector, [immigrant representation is disproportionately high](#). For instance, of the 171.9 million people in the U.S. civilian labor force in 2023, the percentage of immigrant participation in the service sector was high (21%) compared to U.S.-born workers (15%). They work in diverse areas in the service sector, such as disability care, home health aides, personal care assistants, eldercare providers, childcare, and domestic workers.



Implications for IDD Service Providers

The current status of immigrants in the direct support workforce is [high and increasing](#). Direct care workers providing long-term (LTC) services who are immigrants increased from 24% in 2018 to 28% in 2023. Immigrants (naturalized citizens and noncitizens) in the direct support field for Long-Term Care services constitute about 28% of the overall direct care workforce. However, they comprise about 17% of the adult workforce in the United States. The percentage of those who work in home care settings is notably higher, constituting about one in three workers (32%). In contrast, those in residential care represent about 24%. Also, [immigrants are more likely to stay in their jobs longer](#) than U.S.-born citizens, hence providing employment stability that benefits the organization and the people they support.

Therefore, the migration policies, which are aimed at reducing the number of immigrants in the country through deportation and restriction of immigration into the country, would have a profound impact on disrupting the direct support workforce in the U.S. by reducing the availability of the immigrant direct support workforce.

Case in point are direct support workers who work with people with individuals with intellectual and developmental disabilities (IDD). They provide critical services to people with IDD to live and engage in the communities of their choice. However, many providers are already experiencing critical labor shortages

of this essential workforce nationwide. A 2024 survey of 496 providers from 47 states and the District of Columbia by the [American Network of Community Options and Resources \(ANCOR\)](#) indicated that:

- 90% of providers face moderate or severe staffing challenges
- 69% have turned away new referrals due to staff shortages.
- 39% discontinued programs or services in the past year.
- 57% of case management services reported having difficulty connecting people with services.

Immigrants represent a growing share of this workforce, constituting 28% of the overall long-term care direct care workforce and 32% of the in-home care providers. They are shown to [have a greater retention rate](#) than their U.S.-born counterparts. Restrictive immigration policies targeting both undocumented and documented immigrants threaten to further destabilize this already fragile workforce. This would seriously affect access to services and quality of care for people needing support.

Key Impacts of Restrictive Immigration Policies on Disability Services

Labor Supply Disruptions

Mass deportations and entry restrictions would reduce the availability of trained caregivers in the short- and long-term, amplifying workforce shortages across the sector. The potential short-term disruption or long-term deficit in entry-level caregivers would disproportionately affect agencies that rely on public funds such as Medicaid. This is because the reimbursement rate adjustment to meet the increasing cost of labor due to the economic dynamics of labor shortages may lag behind the speed of the rising price of labor. Hence, this is exacerbating the dire labor situation faced by providers.

Wage Pressures Without Reimbursement Adjustments

While reduced labor supply may push wages up, public reimbursement systems (primarily Medicaid) do not automatically adjust, leaving employers unable to match demand with compensation. This will further fuel burnout and exodus from the profession.

Increased Psychological Distress Among Workers

Heightened immigration enforcement activity (by federal, state, and local law enforcement groups) and enforcement in sensitive locations (e.g., schools, churches, community events, and workplaces) generate anxiety, erode trust in “agency,” and withdrawal from public life, particularly in mixed-status households. This results in workforce attrition and reluctance to engage in formal employment channels.

Quality of Care Erosion

High turnover and inadequate staffing would lead to disruptions in care for people with disabilities. Also, staff shortages would lead to more closing of agencies, cancellation of specific programs and services, and increasing demand on existing staff. These would result in denial or reduction in accessibility and quality of care of services to service recipients.



Policy Recommendations

Should the Trump administration's immigration policies continue as intended, they pose a structural threat to the viability of the Direct Support Workforce. Removing or restricting the immigrant labor force without viable domestic replacements would exacerbate shortages, increase care gaps, reduce the quality of care, and impose significant costs on public and private systems. It is the people with IDD and their families that will pay the ultimate price, especially those who live in areas where services may not be available due to the limited availability of service providers and/or cannot afford to pay for higher costs of private caregivers.

Call to Action: Strategies for Disability Field Leaders, Policymakers, and Advocates

- Recognize the critical role of immigrants in caregiving and disability services.
- Advocate for balanced immigration reform that supports both national security and workforce sustainability.
- Ensure that funding mechanisms (e.g., Medicaid reimbursements) are responsive to labor market realities.
- Support legal pathways for direct care immigrants, including work-based visas and permanent residency options tied to service roles.

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Only You Can Tell Your Story. Speak Up, Even If You Are Scared

An Interview with Liz Weintraub by Amanda Rich

Liz Weintraub is a Senior Advocacy Specialist at AUCD who has a long history of leadership in self-advocacy. In this interview, Liz shares her experience testifying (speaking) in front of Congress about issues that impact people with disabilities.

- It is important for everyone to speak up about what matters to them, even when it is scary to do so.
- Cuts or caps to Medicaid and the Transformation to Competitive Integrated Employment Act are current policy changes that disability advocates should research and pay attention to.
- Less Medicaid funding could lead to fewer programs that help support people with IDD to work and live in the community.

How did you get into political advocacy and what do you do in your current role?

I work for the [Association of University Centers on Disability](#). I'm the Senior Advocacy Specialist. Some of what I do includes going up on Capitol Hill or doing other kinds of advocacy and helping others when they go up on Capitol Hill. I try to advocate for my friends. One major thing that is coming to mind is Medicaid. There is a huge fight against Medicaid now, and we are trying to fight against cuts. Right now, it doesn't look like we are winning, unfortunately, and it breaks my heart. When I go up there, I make sure lawmakers know the impact from a person with a disability's point of view. I tell my story, or I tell other people's stories on why Medicaid is so important, for example.

I have advocated for [The Transformation to Competitive Integrated Employment Act \(TCIA\)](#) which would allow people to be paid a competitive wage and not sub-minimum wage. People should be paid fairly for their work.

Some of my work has grown into Instagram Stories or Posts. In the past I had the [Tuesdays with Liz](#) podcast to have policy discussions in plain language so everyone can understand.

I really believe it began from my own experiences. When I was probably 9 or 10 and sat around the dinner table, I was always included in family life, but sometimes left out of family discussions. My family likes and always liked to talking about policy and politics. Sometimes I did not understand what they were taking about when it came to things like amendments or specific legislation. When I would ask my Mom or Dad they kept saying, "Look it up. Look it up."

Well, that didn't and doesn't work for me and I know there were others it wouldn't work for. So, when I had a chance to do videos with AUCD, I did them. I wanted to make sure that my friends could go up on Capitol Hill, Dover in Delaware, Annapolis in Maryland, or wherever and they would know what they needed to advocate too. I wanted to know that they knew what to talk about and understood what others were saying about policy.

I wanted to understand these things myself too, so it helped me, and I then could help other people. Another way is to make Easy Read materials so the language is something more people can understand.

What are the policy changes you are most concerned about right now?

There are so many with the current administration. I am really worried about my friends and their families. I think the biggest is cutting or capping Medicaid in the current budget plan. People need their Medicaid to survive in the community. For me, I have someone who comes in to help me once a week. They help with several different things. They help me with cooking and other things. She's a very nice person but when she comes to help me, she's working, and she wants to get paid. If a person or family can't pay for that out of pocket, the only way to do that is through Medicaid.

Another piece of legislation that is important right now is The Transformation to Competitive Integrated Employment Act which says that people with disabilities can get a regular paycheck. When I used to work in a workshop many years ago, probably over 20 or so since it was before I was married and I've been married for 20 years, I didn't even know how much money I was getting paid. And even now, some people only get 2 cents an hour. That's not fair. Now I get a regular paycheck just like you do and everyone else should as well.

I'm also worried about the possible closure at the Department of Education, though it would have to be an Act of Congress. I worry about that too though. People with disabilities have the right to go to college just like anyone else. I have a lot of friends who graduated from inclusive post-secondary education programs, and those programs need more funding not less.

What is giving you hope right now?

The future advocates. AUCD partners with Think College in Massachusetts and for the last six years we have brought in 10 teams of students and staff for students to learn how to advocate for themselves. We will see if it continues, but it gives me so much hope to see students advocating for themselves. I went to a meeting with a student. It was her first meeting. She was nervous and she read from a paper, which is normal. I do it sometimes. In the second meeting, she talked from her brain and her heart. It gave me hope.

Another thing that's giving me hope is that there are so many advocates out there willing to say, "No." It is not even just about disability issues. There have been so many rallies against harmful things happening with thousands and thousands of people there, standing up. People are not going to take no for an answer.

What advice would you give to people who work for and lead disability organizations who may feel uncomfortable, nervous, or maybe a little scared about doing more political advocacy?

Well, I'll go back to how I started in self-advocacy because that might tell you something important. When I first got involved with Self-Advocates Becoming Empowered (SABE), I thought it was a political group. I thought it would be mostly about how you stand up to governmental administrations. I learned it wasn't that, or it wasn't just that. I learned it was about how to say "no" to your mom and dad. I learned that it was saying, "I need Medicaid to help me live in the community."

What I'm saying is that you need to start with you. You get braver as you take a stand in your day-to-day life and then you can grow into being political. Yes, right now, we need to be political, and we need to talk. But if you don't know the basics about what you need and want in your life? How can you fight for others? It helps to see how policy connects to your life.



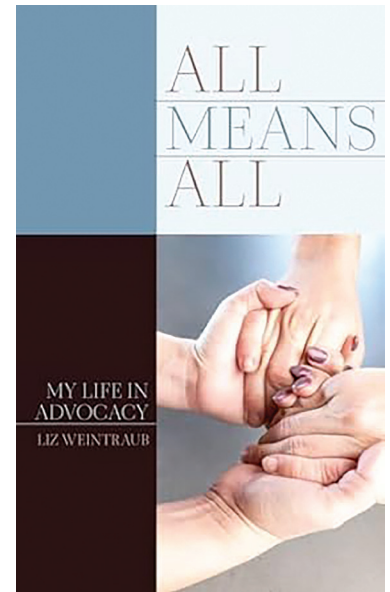
How do you respond to people who say, ‘You’re making too big a deal out of Medicaid cuts, we’re just talking about work requirements. It won’t impact people who really need it’?

That has happened. I tell them about my friends who don’t walk the way I talk, who use communication devices. He does work. He owns an ice cream shop. Medicaid doesn’t prevent people from working. For many, it helps them work. There are many possibilities. People want to work but that’s not possible for many without Medicaid.

You recently wrote a book, *All Means All: My Life in Advocacy*. How did your book come to be and what is it about?

I wrote this book because I wanted people to see what people with disabilities can do. People have often said to me, “Why don’t you write a book?” I have always loved to write. I love to write poems. I love to write stories but when people asked me that, I had always said, “No, no, that’s not for me. It’s too much work.” I learned, though, that no one else can write your story. You need to tell your own.

I didn’t want to write a book to seem like I was bragging. I wanted to write a book to help people understand that those with disabilities can do anything that they put their mind to. My friend suggested that I write about the lessons that I have learned throughout my life so far. This book is about those lessons.



You have testified in front of Congress. Please tell us a little bit about that experience and the advice you would give others who may be scared of speaking up.

I think you just need to be brave! Take a deep breath and say “This is my life. I need to speak up!” It’s okay to be scared. Do it anyways. That’s what it means to be brave. I’ll tell you a story because it relates to this. Over 20 or 30 years ago, my parents called a family business meeting and I was not invited to the meeting. It doesn’t really matter what it was about. To make it even worse, my cousin was asked to come over and “babysit me” or take me out during that meeting. I was an adult at the time, and I was very upset. That night we were out to dinner with everyone, and I asked my sisters what the meeting was about. They didn’t tell me because mom and dad told them not to say anything. That experience stuck with me.

When we found out at AUCD, about Judge Kavanaugh’s case, I knew about this important case that reminded me of that feeling with my family. Many did not know about this case. It seemed hidden away from media coverage. But like any good advocacy organization, we dug into his background as it related to people with disabilities and their families and this case was very important. This case was like that day being excluded from the family business meeting. The case is about two or three women. I talked about this in my book in some detail. They were living in Forest Haven which was an institution in DC that has since closed. The staff wanted them to have an abortion or other surgeries, some of which they didn’t want. Kavanaugh ruled that women with disabilities were not allowed to make the decisions about their own bodies. Kavanaugh said you do not need to listen to these women. Of course you need to listen to these women! Oh my gosh, this is my case.

To get ready, I had to be interviewed by the Democratic side because that was the side I was testifying

for. I was interviewed by staff, by the congress person and I practiced with my boss. We practiced and practiced and created a written statement and an oral statement. He was sitting right behind me. I said that I don't support Kavenagh.

So, yes, I was nervous. But sometimes you need to do what you need to do, even if you are scared, if it's the right thing to do.

How else can people meet this moment in time and be part of fighting for positive change?

I won't deny that speaking up can be very scary. It is very scary to go up on Capitol Hill and talk about things. But whose life is it? It's your life. You need to speak up because no one else will. No one else can tell your story. There is a wonderful woman who just graduated from the IPSC program at Georgia Tech a few years ago. She just spoke in front of The Arc rally in Washington, D.C. about why Medicaid is so important.

People see that when some people can do it, I can do it too. Keep helping future advocates. Someday I would like to retire. Maybe not too soon, but eventually. If I can help others learn to speak for themselves and help other people, that is what I am going to do. It makes me happy to teach other people how to use their voices. It's up to us to keep fighting and help those behind us have what they need to speak up, too.

I won't deny that speaking up can be very scary. It is very scary to go up on Capitol Hill and talk about things. But whose life is it? It's your life. You need to speak up because no one else will. No one else can tell your story.

Liz Weintraub is a Senior Advocacy Specialist with the Association of University Centers on Disabilities (AUCD) and host of the YouTube show *Tuesdays with Liz: Disability Policy for All*. Liz has worked for the Council on Quality & Leadership, completed a fellowship with Senator Casey of Pennsylvania, and has served on President Obama's President's Committee for People with Intellectual Disabilities and continues to serve on President Biden's President's Committee for People with Intellectual Disabilities to advance policy on issues affecting the disability community. Contact Liz at lweintraub@aucd.org.



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Tools and Resources to Educate, Advocate, and/or Lobby

By Amanda Rich

- It is important for leaders of organizations that serve people with disabilities to use their voice to shape political action that may help or harm the people they serve.
- Keeping track of and understanding policy changes can be hard, as there are many and they can change quickly.
- Many advocacy organizations provide resources to help people understand important policies, learn how to advocate, and provide tools for people to effectively communicate with lawmakers.
- This chart describes 8 organizations with tools and resources for leaders to help advocate.

Resource	Resource Type			Description
	Resources to Understand and Track Relevant Policies & Policy Proposals	Tools & Resources to Learn to Advocate & Educate Others	Tools & Resources to Act (Spaces to Share Your Stories & Contact Lawmakers)	
The Arc Policy & Advocacy Action Center	X		X	The Arc's Policy & Advocacy Action Center provides state fact sheets on Medicaid, information on relevant policy topics and why each matter, tools to contact law makers, and tools to share your story about Medicaid, SSI asset limits, and why inclusive education matters. Additionally, they have email updates about relevant policy changes and how you can act.
AUCD Policy & Advocacy Issues & Resources	X	X		The AUCD Policy & Advocacy Issues and Resources Page has briefs on relevant policies and processes such as the Budget and Appropriations Process. They provide resources to understand how Congress works, with fact sheets and talking points on policies and the difference between educating and lobbying law makers. The page also provides tools to educate on how you set up meeting times with, call, or contact law makers.
Autistic Self Advocacy Action Center	X	X	X	ASAN's Action Center provides a policy library with plain language information about relevant policies, tools to track progress and policies on relevant issues, action alerts for specific pressing policy issues, tools to find your lawmakers, learn how to effectively advocate, share your story, find town halls in your community, and a proxy calling tool for people who may not be able to make phone calls.
Govtrack.us	X			GovTrack allows you to search and review activities of the United States White House and Congress. It allows you to track the process of bills as they work through the legislative process.

Resource	Resource Type			Description
	Resources to Understand and Track Relevant Policies & Policy Proposals	Tools & Resources to Learn to Advocate & Educate Others	Tools & Resources to Act (Spaces to Share Your Stories & Contact Lawmakers)	
Nonprofit VOTE		X	X	Nonprofit VOTE provides resources and webinars to help nonprofits of all missions engage their stakeholders in voting and elections.
National Disability Rights Network	X		X	The Disability Rights Network provides updates on relevant court rulings, a legislative tracker, and tools to contact your law makers on important issues such as opposing cuts to Medicaid, the dismantling of the Department of Education, and cuts to disability and aging programs.
DREDF	X	X	X	The Disability Rights Education and Defense Fund (DREDF) provides education and training for people with disabilities and families to understand their rights, education for lawyers, government officials and service providers about disability rights laws and policies, prepares and files amicus curiae (friend of the court) briefs related to disability rights issues, and tools to help understand and communicate with law makers about issue impacting disability rights. It provides a site to tell your story, scripts for phone calls and examples of letters to help prepare for communication with lawmakers.
Alliance For Justice Being A Player: A Guide to the IRS Lobbying Regulations for Advocacy Charities		X		This report provides detailed information about the IRS rules and regulations for nonprofits in lobbying.

Amanda J. Rich is the owner and CEO of [Open Road Inclusive Community Consulting](#) and the managing editor of the *National Leadership Consortium Bulletin*. Amanda holds a Ph.D. in Human Development and Family Sciences and is interested in the health and well-being of the human service workforce, trauma-informed and healing-centered practices, and disability justice. Contact Amanda at openroadicc@gmail.com.



What We're Reading, Viewing, and Listening To

Title: [All Means All: My Life in Advocacy](#)

Author/Editor: *Liz Weintraub (2025)*

Description: In this book, Liz Weintraub describes the lessons she learned throughout her life as a disability advocate. Her experiences and wisdom can serve as a guide to others as they navigate self, local, state, and federal advocacy.

Title: [Courage, The Most Important Virtue](#)

Author/Editor: *Bari Weiss/ TedTalks (2024)*

Description: In this talk, journalist Bari Weiss highlights why courage is a particularly important virtue in today's political climate. She highlights examples of people who have exemplified the courage of speaking-up in the face of injustice over time.

Title: [Leadership in the Eye of the Storm: Putting Your People First in A Crisis](#)

Author/Editor: *Bill Tibbo*

Description: This book serves as a practical guide and uses compelling examples to help leaders create opportunities from crisis. Tibbo draws upon successful corporate and nonprofit leaders who successfully navigate potentially devastating circumstances.

Title: [Family and Disability Activism: Beyond Allies and Obstacles](#)

Author/Editor: *Pamala Block, Allison C. Carey, and Richard K. Scotch (2025)*

Description: This book describes the experience of Disability activists from a wide range of intersectional backgrounds in that fought injustice. In doing so it provides inspiration for new paths as activists determine how to meet the challenges and opportunities of the current moment.

Title: [The Upstander's Podcast with Dr. Omekongo](#)

Author/Editor: *Dr. Omekongo (2018)*

Description: This podcast interviews and explores people who have taken a stand against injustice. It is compelling and weaves together art and activism.

Title: [Poor People's Medicine: Medicaid and American Charity Care since 1965](#)

Author/Editor: *Jonathan Engel (2006)*

Description: This book provides a competitive history of Medicaid since its inception in 1965. It helps provide context as leaders determine how to fight and or navigate potential cuts.

Title: [Beautiful Trouble](#)

Author/Editor: *Andrew Boyed & Dave Mitchel (2019)*

Description: This podcast interviews people from across the globe and from a wide range of backgrounds on how to create change.

Title: Be the Change: A Toolkit for the Activist in You

Author/Editor: *Gina Martin (2019)*

Description: This book draws upon Martin’s experience with changing the law to provide a road map of how ordinary people can create social change.

Title: Are You Leading Through the Crisis...Or Managing the Response?

Author/Editor: *Eric J. McNulty & Leonard Macros (2020)*

Description: This article in the Harvard Business Review provides a description to leaders about pitfalls to avoid when navigating times of crisis. It is concise and constructive.

Title: The Invaluable: The Unrecognized Profession of Direct Support

Author/Editor: *Jerry W. Smith (2019)*

Description: This documentary by the University of Minnesota’s Institute on Community Integration and University Center for Excellence in Developmental Disabilities explores the vital and underappreciated work of direct support professionals.

Upcoming Events

Applications/Registration is open for the following Programs:

August 2025

The Keys to Leadership: A Five Part, Virtual Workshop Series

We know that there are leaders at every level of organizations and systems, and at each level there are unique challenges and opportunities that exist for leaders in the positions. Throughout this series, we explored key areas of leadership success. Our last installment of this series will be The Relational Side of Leadership, held August 14, 21, and 28. **Register Today!** [<https://form.jotform.com/TheCQL/nlc-2025-keys-leadership>]

The Fall Leadership Institute in San Diego, CA

November 9-14, 2025

The Fall Leadership Institute will be held November 9-14, 2025 in-person in San Diego, California, at the San Diego Regional Center. Applications are open now, **click here** [<https://natleadership.org/week-long-institute3.html>] for more information or to apply. This Institute is open to all disability sector leaders. If you are a leader with a disability or a Direct Support Professional you can apply for scholarship support to cover tuition and some travel and hotel costs!

July 12-17, 2026

The Wisconsin Leadership Institute will be held July 12-17, 2026 in-person in Wisconsin Dells, Wisconsin, at the Kalahari Resort. Applications are open now, **click here** [<https://natleadership.org/wisconsin.html>] for more information or to apply. This Institute is open to Wisconsin-based disability sector leaders. Due to generous funding through the **Inclusa Foundation**, participation in the program is \$100 per person.

Application will be opening soon for the following Programs:

The Workforce Innovations Leadership Institute in partnership with NADSP (November 2025)

The Winter 2026 Leadership Institute (February 2026)

If you'd like to be notified when we open registration or applications for future trainings including the Institutes listed above, please add your name to the **list here** [https://natleadership.qualtrics.com/jfe/form/SV_9z9rSudkRwkIVPg].



Contact Us: <https://natleadership.org/bulletin> • bulletin@natleadership.org

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